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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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# **A Qualitative Study of Families of Children with Autism in the Somali Community: Comparing the Experiences of Immigrant Groups**

Report to the  
Minnesota Department of Health

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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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.

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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.

# Background

In 2012 the Minnesota (MN) Legislature authorized a study of autism in the Somali community. The authorization for a study was in response to increasing concerns that there was insufficient attention to, or understanding of, autism in the Somali community. The study was not intended to assess the prevalence or incidence of autism spectrum disorders<sup>1</sup> or the causes of these disorders. Instead, the study commissioned by the MN Legislature focused on the experiences of families and their children with autism. The intent of the study is to understand “cultural- and resource-based aspects of autism spectrum disorders (ASD) that are unique to the Somali community.”

In response to the legislature’s request for more information about the experiences of barriers to care among the Somali community, a community-academic research partnership was developed between researchers at the University of Minnesota, School of Public Health, the Somali, Latino and Hmong Partnership for Health and Wellness (SoLaHmo) and the Confederation of Somali Community in Minnesota (CSCM). The goal of the partnership was to develop and implement a research project that could be used to understand the unique experiences of families in the Somali community. However, the team felt that in order to understand the ‘*unique*’ experiences of families in the Somali community, it was necessary to compare their experiences with families from other communities in Minnesota. Thus, the study was developed to focus on three major cultural groups in Minnesota: the Somali, Latino, and Hmong communities. Although these populations have diverse immigration histories; they share the experience of being relatively new to the United States, and face many similar structural disadvantages that are not faced by the majority of the European-American community.

With the agreement of the Minnesota Department of Health (MDH), the agency overseeing the project, the study was designed to include the experiences of families in the Somali, Hmong and Latino communities. The specific objectives, developed by the community and academic researchers involved in the partnership, included:

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

Throughout the research, we were concerned with similarities and differences in the role of culture for understanding the experiences of families and the challenges they faced. We also

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<sup>1</sup> The term autism is used in this report to refer to disorders that fall on the spectrum

emphasized the importance of ensuring that recommendations were culturally relevant. That is, the goal of research was not only to generate knowledge, but also to use that knowledge to develop recommended solutions.

## The Hmong, Somali and Latino communities in Minnesota

As shown on Table 1, the Hmong, Somali and Latino populations are younger than the general MN population and have larger families. In addition, compared to the total population, individuals from these immigrant groups have lower educational attainment, and in the cases of the Somali and Hmong population, they are less likely to be in the labor force. The Hmong, Somali and Latino populations have substantially lower household incomes than the total MN population. As well, many are not proficient in English.

**Table 1: Demographic Characteristics of the Population**

| <b>Characteristics</b>  | <b>Hmong</b> | <b>Somali</b> | <b>Latino</b> | <b>Total Minnesota</b> |
|---|--------------|---------------|---------------|------------------------|
| Total Population  | 65,637       | 32,449        | 257,186       | 5,344,861              |
| <b>Age</b>  |              |               |               |                        |
| Under 5 Years of Age  | 11.1%        | 18.5%         | 13.2%         | 6.6%                   |
| 5-17 Years of Age   | 30.1%        | 29.2%         | 27.2%         | 17.3%                  |
| Average Family Size   | 5.4          | 4.3           | 3.8           | 3.1                    |
| <b>Educational Attainment (Population 25 Years and Older)</b> |              |               |               |                        |
| Less than High School   | 36.7%        | 44.5%         | 36.2%         | 8.0%                   |
| In Labor Force (Population 16 years and Older)                | 64.3%        | 60.4%         | 73.1%         | 70.2%                  |
| Median Household Income                                       | \$43,128     | \$15,902      | \$37,795      | \$56,954               |
| <b>Language Spoken at Home (Population 5 Years and Older)</b> |              |               |               |                        |
| English Only  | 5.0%         | 3.8%          | 32.2%         | 89.2%                  |
| Speaks English Less than Very Well                            | 42.4%        | 51.1%         | 34.2%         | 4.3%                   |

Estimates from U.S. Census Bureau, American Community Survey (Somali estimates based on 5-year data; Hmong estimates based on respondents who reported that they were Hmong ethnicity only using 3-year data; Hispanic and total population estimates based on 1-year data).

The Hmong, Somali and Latino populations share structural socio-economic disadvantages that may make it more difficult to access services or navigate systems of care. However, they also have many differences in terms of cultural history, beliefs and values allowing us to examine both similarities and differences across groups.

## **Families with children with autism**

Autism is one of the most disabling conditions of childhood. Children with the disorder struggle with communication, behavior and social interaction. Autism also affects the entire family. Parents whose children have autism, especially mothers, are at risk for caregiver stress and psychological distress (Boyd, 2002; Hayes and Watson, 2012). Early detection and access to timely, quality services are critical for positive child and family outcomes (Eldevik et al., 2009; Rogers and Vismara, 2008; Vismara and Rogers, 2010).

Almost all of the existing research describing the experiences of families who have a child with autism has been conducted with the majority European-community. Previous research may not represent the experiences of families from diverse cultural backgrounds or who speak languages other than English. For example, among new immigrants, we expect different types of challenges in getting services for a child with autism than are experienced in the majority US born population. English language difficulties, isolation from extended families, discrimination, stigmatization, mistrust of providers, lack of health insurance, unfamiliarity with the US school and medical systems etc., all might make the process from diagnosis through seeking treatment for a child with autism extraordinarily difficult. At the same time, strong cultural ties, social support and connectedness, as well as religiosity might help families access effective services and may foster positive coping with the challenges faced by families of children with autism.

Research done in Minneapolis, Minnesota has focused on the perceptions of providers of services for children with autism in the Somali community. Kuenzli (2012) interviewed a small sample of professionals who work with Somali families living with autism including interpreters, Special Education staff, a psychologist and a school principal. While providers did recognize problems in the system such as lack of coordination between county, school and medical services, one of the most striking findings is the degree that providers attributed many of the problems experienced to Somali families. For example, some felt that Somali families did not understand the diagnosis, were in denial, and had different views of the socialization of children that overlooked behavior that might cause other families to seek services early. That is, many professional perceived that the problems experienced by Somali families were caused by ignorance and lack of education, implying that 'education' campaigns are needed to improve services. These conclusions, however, are premature. We know little about whether the views of providers (the majority of whom are not Somali) comport with the views of their clients. Moreover, less is known about the experiences of families from the Hmong and Latino communities in Minnesota. Only by incorporating the voices of parents in our research can we begin to understand and then remedy the problems faced by families of children with autism. The purpose of this study is to begin to provide such a voice for parents and identify specific recommendations that, if followed, would alleviate the challenges faced by their families.

# Methods

The research was conducted through a community-based participatory research (CBPR) model. The central components of CBPR are listed on Table 2, but the essence of the method is the principle that those most affected by disparities must fully participate in the development of the research and resulting interventions (Gaveenta, 1991; Horowitz, Robinson, and Seifer, 2009; Israel et al., 1998)

**Table 2: Participatory Research Components**

|   |
|---|
| 1. Recognize communities as units of identify.  |
| 2. Build on strengths and assets with the community   |
| 3. Facilitate collaborative, equitable involvement of all partners in all phases of research. |
| 4. Integrate knowledge and inform action for mutual benefit of all partners.                  |
| 5. Promote a co-learning and empowering process that attends to social inequalities.          |
| 6. Utilize a cyclical and iterative process.  |
| 7. Address health from positive and ecological perspectives.                                  |
| 8. Recognize communities as units of identify.  |

Source: Adapted from Israel et al., 1998

Models of participatory research vary, but often bring community members together with members of academic institutions and/or state agencies. The goal is to build a team that draws on the unique skills, resources, and perspectives of its varied members. Community members' participation in the definition of the research questions and search for answers helps ensure the relevancy and usefulness of study results. Active involvement by community researchers in all stages of the study fosters trust in the process and research results and may better activate members of the broader community to work toward solutions (Schultz et al. 2001). Members from academic and government agencies benefit by gaining an understanding of the local context, and the strengths and constraints community members face in pursuing good health and health care. Change is more likely to occur through a process that engages community partners to stimulate discussion of issues from an insider's context; help frame problems and questions; and interpret findings grounded in a specific cultural, linguistic, or environmental context.

At the same time, there is a need for scientific rigor throughout the research process. Participatory research sometimes risks sacrificing such rigor in order to attain the support of community members. However, traditional models of research sometimes place the needs of researchers ahead of the needs of those affected by disparities. Often such research is viewed negatively, and the communities that are the 'subjects' of this research rarely use or benefit from the results (Green and Mercer, 2001).

Through using community-based participatory research (CBPR) methodology in the design and implementation of this study, we were able to draw on the expertise and experience of community researchers. We were able to incorporate the needs and perspectives of the community into decisions about research design, while maintaining scientific standards of validity. The research team included researchers from each of the three cultural communities who were bilingual in the Hmong, Spanish, or Somali and English.

The research was conducted in two stages. During the first stage, we conducted interviews with key informants in the community who had knowledge of the experiences of families with a child with autism in the Hmong, Somali and Latino communities. We then used the information gathered from these interviews to help design the recruitment methods and survey questions for the parent interviews.

## **Key informant interviews**

Key informants chosen were knowledgeable about autism and had experience working with families from the Hmong, Latino or Somali communities. A total of 33 key informants participated in individual interviews (interview questions are provided in Appendix A), that lasted between 18 to 96 minutes (average 42 minutes). Key informants included parent and autism advocates (N=5); researchers (N=1); spiritual leaders or healers (N=4); direct providers of services for children with autism including doctors, psychologists, and other therapists (N=5); county workers (N=5); staff from disability or autism centers (N=6); and persons who worked mainly within the school system (N=7). Some key informants had experience working across multiple sectors. Fifteen of the key informants had experience working with children with autism in the Somali community, 7 with the Hmong community and 6 with the Latino community, while the remainder had experience working with families and children from multiple communities.

The primary goals of the key informant interviews were to define the research questions and gather the information necessary to structure the interview guides for the parent interviews. A secondary goal was to receive guidance about how best to recruit parents to participate in the interviews. Interviews were audiotaped and research team members compiled notes from the audio recordings reflecting each section of the interview. All members of the research team independently coded the notes, and the team met to reconcile any differences. Major themes were identified which were then used to construct the questionnaires for the parent interviews.

## Interviews with parents

Following the advice of the key informants, parents were primarily recruited through canvassing places where members of each community were likely to be such as places of worship, libraries, health fairs, and meeting with parents, local businesses, and autism providers. Flyers were distributed in Hmong, Somali, Spanish and English and potential participants contacted the researchers. The purpose of the study was explained and respondents who agreed to participate scheduled an interview. An incentive of \$30 dollars was provided as a thank-you for participation, in addition to \$20 dollars per hour for a maximum of two hours for individuals who needed childcare.

Parents were asked to fill out a basic demographic survey (Appendix A). The main interview questions were based on data from the key informant interviews and gaps they identified in our understanding of the experiences of families who have children with autism. The full interview guide is included in Appendix A). The questions focused on perceptions of autism, the process through which their child was identified as having autism and experiences and challenges getting needed services. We also asked parents to describe their main recommendations to improve services for families with a child with autism.

Table 3 describes the characteristics of the 70 interviews that were conducted with parents. Originally, the research was designed to be exclusively conducted through focus groups. However, we found that some respondents preferred individual interviews. This was particularly true in the Hmong community. Early in the research process we realized that Hmong respondents preferred individual interviews, so all fifteen of the interviews held in that community were individual interviews. In contrast, over 90% of the interviews with Somali parents and 75% of the interviews with Latino parents were conducted in focus groups. The majority of Latino and Somali interviews and about one-half of Hmong interviews were conducted with participants in their native language.

Interviews were audiotaped and then transcribed into English. A research team member from each cultural community was responsible for the transcription that was then checked by a second community research team member for accuracy. Two members of the research team independently coded the transcripts based on pre-existing themes. The team members met to reconcile any discrepancies in coding. A final code tree that incorporated codes from all three teams was updated and utilized by the full team for all transcripts. The results are organized according to the most common themes that emerged.

**Table 3: Characteristics of Interviews with Parents**

|  | <b>Hmong</b>                                   | <b>Somali</b>                        | <b>Latino</b>              | <b>Total</b> |
|--|--|--------------------------------------|----------------------------|--------------|
| No. Focus Groups                       | 0  | 4                                    | 3                          | 7            |
| Average Focus Groups Size              | NA   | 8.8                                  | 4.3                        | 6.9          |
| Language of Focus Groups               | NA   | 75% Somali<br>25% Somali/<br>English | 67% Spanish<br>33% English |              |
| Average Length of Focus Group, Minutes | NA   | 81.3                                 | 56.3                       | 70.1         |
| No. Individual Interviews              | 15   | 3                                    | 4                          | 22           |
| Language of Individual Interviews      | 33% Hmong<br>53% English<br>13% Hmong/ English | 100% English                         | 100% English               |              |
| Average Length of Interviews, Minutes  | 42.7   | 41.1                                 | 25.5                       | 35.2         |
| Total Number of Participants           | 15   | 38                                   | 17                         | 70           |

## Results

### Key informant interviews

The key informant interviews were designed to help narrow the research questions and construct the survey questions for the interviews with parents. Informants were asked to answer questions only about the communities that they had experience working with. Here, we review the main themes that emerged from the key informant interviews; but we focus much of the results section on information gathered directly from parents.

### Perceptions of autism:

Key informants were asked how they thought people in the Hmong, Latino and Somali communities’ perceived autism. The majority of respondents indicated that they thought members of these communities were confused about what autism was and that further education was necessary. The most common belief of informants was that the Somali community saw autism as having spiritual causes. While less frequently mentioned by informants in discussions of the Hmong and Latino community, still one-third of informants for the former group and one-

quarter in the latter group believed that members of that community perceived autism as a spiritual issue.

Informants (42%) also frequently believed that members of all three communities were likely to be in denial about their child having autism or perceived early symptoms as just part of normal child development. However, key informants also commonly (25%) remarked that it was difficult or impossible to generalize, as individuals within communities hold many different beliefs about autism.

### **Early identification:**

Almost all key informants felt that children from minority cultural communities are identified with autism at later ages than children from the dominant cultural community; with many believing that children in the Hmong, Somali and Latino community are typically not identified as having autism until they are school-aged. The perceived reasons for late identification were varied, but the most common cited were that parents lack knowledge of the developmental milestones or symptoms of autism and that they normalize early behaviors and do not take their children into providers to be assessed or diagnosed. The second most common was stigma or shame that would prevent parents from acknowledge their child may have a developmental problem. Other causes of delayed identification of autism such as linguistic and cultural differences between providers and parents, or culturally inappropriate screening instruments were mentioned less frequently.

### **Barriers to services:**

Informants were asked their perceptions of the factors that made it difficult for families in the Hmong, Somali and Latino communities to get the services they needed, and what could be done to overcome barriers. The most common barrier cited was parents' lack of knowledge of the condition and the services that are available. Informants emphasized the need for outreach to the community to provide education about the signs of autism and available services. However, informants also acknowledged a range of cultural and linguistic barriers that make connecting to services difficult such as the lack of providers who understand the various cultures or speak the same language as their clients, and problems with quality of interpreter services. The key informants also suggested that it was important to know the types of services that parents wanted but were not getting.

### **Parent interviews**

Table 4 describes the demographic characteristics of the parents who were interviewed. Most parents were between the ages of 31 and 50 years, and over two-thirds in each group were mothers. Fathers were more likely to participate in the Somali community than in the other two

communities. Hmong and Somali families had larger families (on average over 4 children) than Latino families (an average of almost 3 children). Approximately three-quarters of parents were married, but single-parent families were also common in each community: Hmong (31%), Latino (29%), and Somali (19%). The majority of parents in all three communities were born outside the US, but this was particularly high in the Somali community where 97% of respondents were not born in the US. Among parents not born in the US, the average time in the country ranged from about 13 years (Somali) to 24 years (Hmong). About one-half of respondents had less than a high school education, although a larger share of Hmong respondents reported they had higher than a high school education (64%) than Somali or Latino respondents (32% and 36% respectively).

Most families had one child with autism, but almost one-fifth of Somali families had two or more children with the disorder. The age of the oldest child with autism in these families ranged from 2 to 30 years, with the average age across communities ranging between 9 to 10 years. Thus, we were able to capture the experiences of families with young children and those whose child with autism is now an adult. About 90% of the oldest child who had autism in each community was born in the US.

**Table 4: Demographic Characteristics of Parents and Children**

| <b>Parent Characteristics</b>            | <b>Hmong</b> | <b>Somali</b> | <b>Latino</b> | <b>Total</b> |
|--|--------------|---------------|---------------|--------------|
| <b>Age:</b>                              |              |               |               |              |
| 18-30                                    | 15.4%        | 7.9%          | 11.8%         | 10.3%        |
| 31-50                                    | 84.6%        | 78.9%         | 82.4%         | 80.9%        |
| 51+                                      | 0.00%        | 13.2%         | 5.8%          | 8.8%         |
| % Female                                 | 78.6%        | 68.4%         | 82.3%         | 73.9%        |
| Average No. of Children (Range)          | 4.2(2-8)     | 4.7(1-10)     | 2.8(1-7)      | 4.1(1-10)    |
| <b>Marital Status:</b>                   |              |               |               |              |
| Married                                  | 69.2%        | 81.8%         | 71.4%         | 76.5%        |
| Separated/Divorced/<br>Widowed           | 30.8%        | 18.9%         | 28.6%         | 23.4%        |
| % Born in US                             | 41.6%        | 2.60%         | 37.5%         | 18.1%        |
| Average Years in US (Range) <sup>a</sup> | 23.8(9-35)   | 13.4(1-21)    | 18.2(10-32)   | 16.6 (1-35)  |
| <b>Education:</b>                        |              |               |               |              |
| Less than High School                    | 36.3%        | 56.8%         | 57.1%         | 53.2%        |
| High School Grad                         | 0.0%         | 10.8%         | 7.1%          | 8.1%         |
| Greater than High School                 | 63.6%        | 32.4%         | 35.7%         | 38.7%        |

**Table 4: continued**

| <b>Child Characteristics:</b>                   | <b>Hmong</b> | <b>Somali</b> | <b>Latino</b> |            |
|---|--------------|---------------|---------------|------------|
| % with More than One Child with Autism          | 6.7%         | 21.6%         | 11.8%         | 15.7%      |
| Average Age of Oldest Child with Autism (Range) | 10.7(3-23)   | 9.1(3-22)     | 10.1(2-30)    | 10.2(2-30) |
| % Oldest Child with Autism Born in US           | 91.7%        | 89.4%         | 87.5%         | 87.9%      |
| <b>Total Number</b>                             | <b>15</b>    | <b>38</b>     | <b>17</b>     | <b>70</b>  |

<sup>a</sup>Among parents not born in the US

### **Community perceptions of autism:**

The interviews began with a discussion of how parents defined or thought about autism. Often parents discussed what they thought had caused autism, although the survey was not focused on this area.

Table 5 describes the most common themes that emerged from parents' discussion of the nature of autism. Across all communities, many parents talked about how the condition was unclear and how they were confused about what caused it:

*"According to me, I, I...don't know. That is something I, every day, still question what is Autism caused by. I don't quite understand it, so I don't know."* (Hmong Parent)

*"...autism is, also, I don't know, I...I guess I don't have much knowledge on what it really, really is."* (Latino Parent)

In the Hmong community, many parents reported having never heard of autism before. Not having a word for 'autism' in the Hmong language also made understanding the disorder perplexing. As mentioned by a Hmong parent,

*"...we don't, heck, we don't have a term for autism in Hmong. That's how gray it is and I bet that's the same thing for many cultures. And how are you gonna...expect...to raise awareness in those cultures if you don't even have that?"* (Hmong Parent)

Somali parents, who likewise did not have a word for autism in the Somali language, commonly

expressed confusion about autism, but were also more likely to link it to being in the United States:

*“May peace be upon you all. I think autism is, I have never seen it or heard about before my son. I don’t know whatever it is. It is something I heard in this country.”* (Somali Parent)

**Table 5: Most Common Perceptions of Autism**

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

However, as shown on Table 5, important differences also emerged across communities. Parents in the Somali community were especially likely to discuss their belief that vaccinations caused autism. Many recalled specific symptoms such as crying, vomiting and stomachaches that immediately followed when the child was vaccinated. For example, one respondent stated:

*“My son was so fine. He was saying, ‘dad, mom.’ When he got the 2 year shot, my son stopped talking, zip. The day he got that shot, he started crying and vomiting. I did not take it serious because I did not know. Afterwards when I couldn’t get any speech from the boy, mom...dad, and I saw that his eyes were spaced out and he was just running, that is when I took him to the hospital. They checked his ears. After that, I was told that it is autism. I didn’t know autism.”* (Somali Parent)

Although vaccines were also discussed in the Latino community, they did not emerge as a central concern in the Hmong community. In the Latino community, the parent who thought vaccines might cause autism was not completely convinced:

*“I was reading in the internet that some people get autism because of the vaccines.... that they received or.... because it is hereditary but I do not understand...”* (Latino Parent)

Hmong and Somali parents were also more likely than Latino parents to explicitly link autism to spiritual concerns. As one Somali parent succinctly states:

*“I believe that it is God’s will and doing and that you have to accept what God brought onto you. It is up to you how you will deal with it.”* (Somali Parent)

For some parents in the Hmong community, their perception of autism revolves around the child’s soul or spirit. When a child is frightened, their soul or spirit may become displaced from the body resulting in physical and mental manifestations:

*“...from a cultural...spiritual ...view, it was more of the spirit/soul, or you know, the missing of the spirit or you know, displacement of the spirit...but when my son was displaying developmental delays, ...my parents started pointing that it was because his name, so they wanted us to ‘hu plig’ (a soul calling ceremony) and change his/her name.”* (Hmong Parent)

While spiritual concerns and beliefs about vaccines were common, it is also important to note that parents across all communities also commonly adopted standard perceptions of autism as a ‘mental illness’, ‘medical’ or ‘developmental’ issue:

*“Medically autism is a cognitive neurological disorder that has a couple of components ... the big components are ... social ...[and] that goes with communication and then there is a tendency to be very very repetitive on certain things...”* (Hmong Parent)

*“I think autism is a neurological disorder that a cure has yet to be found. I mean, that’s about it. You just have to manage the symptoms of autism at this point. That’s what I do with my son.”* (Somali Parent)

*“I think that autism is a mental disorder and, to be frank, I do not understand... what autism is...”* (Latino Parent)

Sometimes, while parents’ perceived autism as a medical condition or mental illness, it was clear that their perceptions were shaped by their culture. For example, a Hmong parent, while believing autism was a medical/genetic condition, also emphasized that it could not be traced to her side of the family:

*“Maybe it is the genetic from his father because we don’t have anything like that... for me, I don’t know how autism looks like, but myself, I think how come my child is like a kid who doesn’t understand words. And, when I talked to him, I said something else and he responded with a different answer. So, then it makes me think that how come, well, I think that maybe, he is probably one of those children with a slow brain or maybe it is the genetic from his father, or whatever because my family, we don’t have anything like that. My family, the children, we don’t have any one that are like that...”* (Hmong Parent)

Similarly, when parents from the Somali community attributed autism to a mental condition, it had clear cultural meaning of being ‘insane’. As one parent said:

*“I think autism is someone insane, an insane person with no mental capacity and staying in your home. You are his doctor and you are everything for him. It is just like someone insane, just running, not getting good sleep, running, escaping not aware of the dangers with cars, trains, risks and no matter what age, still needs help. That needs assistance with dressing, bathing, like someone with no brain. Autism is someone insane with no cure and left alone solely with his parent.”* (Somali Parent)

### **Early identification of autism:**

Key informants had described parents waiting too long to seek help and late identification as major challenges in the Hmong, Latino and Somali communities. To better understand how children were identified, we asked parents to describe the process through which they or someone else began to notice something different about the child and then to describe what they did next.

Overwhelmingly, parents indicated that they were the one who first noticed something was different about their child. Often they noticed delays in speech or behavioral differences in the child. Many told stories of trying to seek help quite early, but feeling frustrated at the response of professionals. The experience of going to see a doctor but being told nothing was wrong was not uncommon:

*“We took him to the doctor and told her that we have observed these behaviors. The child will run away. The doctor will say, ‘[Name of Child] say hello’ ‘He is OK’. ‘This child has nothing wrong with him.’ I even called his grandmother in Africa and she told us that his uncle was just like that and had a delayed speech. ‘His father stutters also. Is it possible that he has stuttering?’ We just got confused with the child and he completely shut down, zip. He was close to 3 years at that time. We were constantly taking him back to the doctor. Numerous times he run away, either the police found him or we found him and police continued strictly monitoring us for child neglect. Then finally, he threw himself from the second floor.”* (Somali Parent)

*“I was told earlier that my child did not need any therapy and that he will just get better ...and that any early therapy is just a waste of money...is like throwing money down the toilet.”* (Latino Parent)

We also asked parents about why they thought some parents tended to wait to seek help after they noticed a difference with their child. We categorized reasons for waiting to get help as family or individual issues, provider-related issues or system-related issues. These issues were

often intertwined and together resulted in a delay getting the child early intervention. Working through these issues also proved to be a frustrating challenge for parents who only wanted the best for their child.

**Family / individual challenges associated with late identification**

Table 6 describes the most common individual/family-related challenges that parents believed interfered with early identification. Lack of knowledge about the availability of resources or about autism emerged as common reasons for delayed identification, and were a common cause of frustration:

*“Maybe some parents just don’t know how to work the system and know their rights and what they can or cannot do.” (Hmong Parent)*

*“I have no knowledge of all the services. I do not know where to go in order to get. I do not know what I am entitled to, I have not been told any of these. They say there are services, but what they are, I wish somebody would explain them to me.” (Somali Parent)*

*“I think that the most important thing is lack of information ... we do not know what to ask for... it is like ...if you do not know what is out there...that there are resources...but we do not know and we do not know how to ask for.” (Latino Parent)*

*“First, they don’t know the services and where to get information, Somalis that is. They also lack knowledge. The disease is a disease that we never saw before. We only saw it when we came here.” (Somali Parent)*

**Table 6: Most Common Family/Individual Challenges Associated with Late Identification**

| <b>Rank</b> | <b>Hmong</b>                      | <b>Somali</b>                     | <b>Latino</b>                  |
|-------------|-----------------------------------|-----------------------------------|--------------------------------|
| 1           | Lack of knowledge about resources | Lack of knowledge about autism    | Lack of knowledge about autism |
| 2           | Normalize behavior/denial         | Lack of knowledge about resources | Normalize behavior/denial      |
| 3           | Lack of knowledge about autism    | Stigma/cultural differences       | Stigma/cultural differences    |
| 4           | Competing demands                 | Normalize behavior/denial         |                                |
| 5           | Stigma/cultural differences       | Lack of trust                     |                                |

In each community, respondents often talked about the tendency of parents to normalize their child’s behaviors when they were first noticed. Parents often described that with the onset of what appeared to be subtle developmental concerns or peculiar behaviors it was easy to feel the

behaviors to be part of “normal” children’s development and hold onto the notion that the child would “grow out” of the behaviors:

*“I think that sometimes we tend to ignore what is happening and that it will go away when the child gets older.” (Latino Parent)*

*“There’s no way to turn and say that my son is sick. And you think, oh my son is like, maybe he’s gonna talk. Maybe you know, you think he’s gonna talk tomorrow or after tomorrow.... It’s difficult to even know yourself besides telling the doctor.” (Somali Parent)*

*“... believe that many people wait to go to see a specialist or a neurologist...well...we as parents tend to resist to acknowledge and to accept ...because we see them as normal...we see them with paternal love ...we do not see them as children with disabilities.” (Latino Parent)*

The period of waiting was often connected to feelings of stigma or not wanting their child to have a diagnosis of autism:

*“They [parents who wait to get their child identified] probably think that ‘Well, you know, he’s too young. You know, we’ll wait couple more... months or years. Maybe he’ll improve’ or...or for some, they’ll probably ‘Oh you know, he was just being a baby.’ ...and some doesn’t want their child to be labeled-having a disability. ....Most mostly, I...I notice that...that in our culture. I don’t know about other culture but mostly in our culture, we don’t want to have that label that our child have a disability.” (Hmong Parent)*

Indeed, across all communities, parents discussed the impact of shame or stigma on decisions of parents to wait to get their child help. Within the Somali community, one respondent explained:

*“You either crazy or you’re sane. There’s no gray area. So, you’re schizophrenic and that’s it, and people always shun you. Well, you’re an embarrassment to the family, so they, they hide you away. So they’re afraid of that stigma, they don’t want people to look at them different. Oh, especially women in our culture, most people would say, ‘oh, it’s because of the mother’.” (Somali Parent)*

Fear that their child might be perceived as ‘crazy’ was also expressed in the Latino community:

*“They don’t want to accept that their child has autism. Or they look at them on the street and say. ‘Oh there goes a crazy child’ ... What they don’t want is to accept or they are ashamed.” (Latino Parent)*

In the Hmong community, the stigma or shame is more associated with a cultural belief that families may be genetically flawed or cursed for having a child with a disability. Parents reported that many people in their community might feel ashamed, embarrassed, or afraid of the stigma of having a child with a disability of any kind and then would be less likely to seek early intervention services for their child:

*“...culturally. I think there’s a stigma. I mean...if your child is not normal then you know the community tends to frown on your family and like ‘what ...oh what did that mom do wrong?’ or ‘what is wrong with that family?’”* (Hmong Parent)

The distinction between normalizing and denial was very fine for many parents and often overlapped. Denial became more apparent in parents when their child received a diagnosis of autism. Parents either grew to accept the diagnosis or initially denied that there was anything wrong with their child, not wanting to believe they had a child with a disability, and so continued to normalize their child’s behaviors.

*“I wanted to wait it out to see my child progress because I don’t want to believe the fact that he was, he had a condition... And I waited, you know, I was in denial. I didn’t want to accept, uh, that fact that my child was different.”* (Hmong Parent)

Hmong parents also commonly indicated that competing demands such as work, lack of time, and having multiple children to care for contributed to parents not getting their child identified earlier. Parents described working hard to provide for their families and with having more than one child, parents’ time was split. As one parent shared, she worked a lot and had many children to care for so she did not have the time to observe her child’s behavior in detail until the childcare provider raised concerns.

Finally, trust was more likely to be explicitly discussed as an issue in the Somali community. As one parent expressed it:

*“I would say that the system has failed us as a Somali community.”* (Somali Parent)

Parents were more likely to trust providers or institutions that knew their culture:

*“He goes to [Name of School] that is a Somali Charter School. I took him there because I trust them and I know that they will not drug him. I heard that other schools they drug them with something that shuts them up. I trusted this school because of the culture.”*  
(Somali Parent)

### **Provider-related challenges associated with late identification**

As shown on Table 7, many parents described the attitudes and behaviors of doctors as reasons that identification of autism is often delayed. Challenges ranged from doctors normalizing the behavior and dismissing the concerns of the parents, though not screening for the disorder and discrimination (Latino and Somali communities).

In all communities, parents felt that doctors did not sufficiently screen for autism or focus on developmental issues, lacked knowledge about autism or normalized the child’s behaviors as main obstacles to early identification of autism. Parents described a lack of agreement between primary care doctors and specialists resulting in delayed diagnosis, doctors diminishing parent concerns until behaviors become extreme enough to result in injury, or not providing assistance in finding resources, and in general being unable to recognize the signs of autism. As one Somali parent described:

*“We took him back to the pediatrician, and the pediatrician said ‘there is nothing wrong with the child.’ Check him from here, check him from there, his growth was very normal. When he was 3.5 years and you can see that the child is not normal, not normal I mean, crying a lot, complaining about something, and not his normal usual self. That is when he referred us to a neurologist err a psychiatrist. Then the psychiatrist sent me to a neurologist. The neurologist was the first one who diagnosed him, and told me that he is autistic....His pediatrician couldn’t accept, he said ‘that is not logical.’ ‘This child is normal and I think they are making a mistake.’ Anyways while going through this period of doctor conflicts, he turned 4 years.” (Somali Parent)*

**Table 7: Most Common Provider-Related Challenges Associated With Late Identification**

| <b>Rank</b> | <b>Hmong</b>                               | <b>Somali</b>                                    | <b>Latino</b>                                    |
|-------------|--|--|--|
| 1           | Doctors normalize behaviors/lack knowledge | Doctors normalize behaviors/lack knowledge       | Discrimination                                   |
| 2           |  | Shifted around between providers                 | Doctors normalize behaviors/lack knowledge       |
| 3           |  | Discrimination                                   | Cultural disconnect between provider and parents |
| 4           |  | Lack of providers who speak the language         |  |
| 5           |  | Cultural disconnect between provider and parents |  |

Similarly, a Latino and a Hmong parent recount their stories of when they first went to the doctor with concerns about their child:

*“...always went to the doctor and they always told me that he was just fine...they did some tests and they told me that he was just fine. Then later, a doctor who was a specialist told us that he had to speak because he was going to be three years old and he had to speak and he needed to know more than 15 words...then it was when we started to look for more help.”* (Latino Parent)

*“...when I started it, there was nobody. The doctor, our doctors didn’t talk to us about autism. You know, and I don’t blame her because you know, you just don’t think that ‘Hey, this child is going to be born with autism’...”* (Hmong Parent)

While frustration with providers was common across communities, Somali and Latino parents were more likely than Hmong parents to mention discrimination as a source of the problems:

*“The doctors should listen. I experienced that a lot of doctors just ignore you because of the way you talk, or who you are. You know this country you can tell that some doctors they are not as friendly as others.”* (Somali Parent)

*“We then went to the school and the school pressured us with one and another thing ...the doctor said something different and I was feeling that I was discriminated against by the school because I believe that they did not want to help my child.”* (Latino Parent)

*“I heard a lot about interventions and early interventions. Those same words I have heard at school when my son started school. But I asked myself, what is an early intervention? What do I have to do? How to do it? It is like early interventions are just for a selected few, a selected group of families. But I honestly have been very discriminated against...for me the early intervention never arrived.”* (Latino Parent)

Perceptions of being ignored by providers due to race, ethnicity or language; providers being unfriendly or withholding information about resources; and being treated disrespectfully in provider offices were common. Many instances were described in which providers did not return phone calls, social workers did not reach out to families to identify themselves and make themselves available, and providers were not forthcoming with helpful information or resources. One participant described overtly being spoken to rudely:

*“I am not good with the language and navigating the system and every door I knock is slammed in my face with harsh language and false remarks, ‘How can I help you?’ ‘Sit over there.’”* (Somali Parent)

Discrimination may be linked to frustration at not having providers who speak the language:

*“[there are many temporary agencies that open] ...they hire someone who doesn’t know anything and have very little language capability and know nothing about your problems and don’t feel your pain and have no knowledge about it.” (Somali Parent)*

*“I have felt so much discrimination...because of my color. Because of my color or because I don’t speak the language.” (Latino Parent)*

### **System-related challenges associated with late identification**

Table 8 identifies the most common system barriers to early identification that were discussed by parents. Across all communities, despite trying to be proactive in their child’s care, many parents experienced long wait lists with providers and a long wait before services started. Especially when working with more than one provider, many parents encountered multiple long wait periods before services actually began. One parent’s story of going from specialist to specialist illustrates the frustration of the process:

*“And so...I was able to get in...an appointment with the specialist, you know...cause you- I just went directly to our-my older son’s specialist and said ‘You know, You know I think my son has ASD and the school...this is...evidence that the school has provided with’ and so...and they gave us some paperwork to fill out but that was during the summer and the teacher has to fill out paperwork too as well and so they weren’t...in session so...the teacher still has to you know, complete the paperwork, submit it in and then do another schedule, another appointment and according to the specialist you know, we’re on the waitlist to be seen because they’re all booked...And so we’re just...we just have to wait until the teacher completes the paperwork and when I last spoke with the specialist you know, she said that it’s ...it’s going to be a couple months because she’s all booked up.” (Hmong Parent)*

**Table 8: Most Common System Related Challenges Associated With Late Identification**

| <b>Rank</b> | <b>Hmong</b>                               | <b>Somali</b>                              | <b>Latino</b>                              |
|-------------|--|--|--|
| 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                          |

The struggle to get an early diagnosis was also connected to access to services. As an example, parents need to first get their child evaluated and diagnosed with an official autism diagnosis

before other autism-related services may be obtained. For some parents, trying to obtain a diagnosis took several months up to almost a year. For Somali families the time from noticing to diagnosis took up to 3 years. Afterwards, parents tried navigating the system to figure out what type of services their child needed. Once a service provider was identified and contacted, families were often informed that there was a waitlist and, for those who had not obtained a formal referral from their doctor, they were required to have one in order for their insurance plan to authorize coverage of services. In addition, some parents encountered long waits for their primary care provider to make a referral due to the need for supporting documentation from the provider who made the autism diagnosis. Once the referral could finally be made, the parents were placed on the waitlist or an appointment was made many months out:

*“...so...maybe...for insurance companies to...some of the allowable would be more flexible because even with our private insurance, you know, he had to be referred by the specialist to another agency in order for the insurance to pay out the agency because you know, he need occupational therapy, speech, language, and physical therapy and which...if it’s not referred by the specialist, then the insurance company won’t pay out to the other agency who would be providing that service for...And ...you know, and...throughout that whole time process, it’s very time consuming because you know you have to get the referral out to the other agency. Then you have to do the intake. Then after your intake, you’d have to set up your appointments, do your therapies and you know, by that time, from that time period to another, it’s already couple months to even get started. And everything is time consuming.” (Hmong Parent)*

Parents identified a lack of cultural competency as a system-related barrier to early identification. They cited a lack of culturally competent service staff, a lack of cultural diversity among staff, and a general lack of culturally appropriate resources available to the Somali community. Parents expressed feeling marginalized when interfacing with services that were designed for a population of English speakers with access to information and resources (i.e. transportation). One parent, for example, noted that the difficulties of parenting a child with autism are compounded for immigrant and refugee groups who endured trauma in their home countries or in refugee camps, and that this trauma often continues to go untreated. As such, participants pointed to the need for culturally competent services that pay attention to the complexity of mental health issues a family might be dealing with as they navigate parenting and seeking services for a child with autism. In addition they asserted that the system should be attuned to providing education and outreach in ways that address the role of stigma in how a parent goes about seeking a diagnosis, treatment and services for their child:

*“...yeah, the services are out there. They are available for everybody who you know, has car, can speak English, who can seek, who has knowledge of them. But here’s the dilemma, we’re dealing with a community that is immigrant, you know, refugee, who*

*went through mental trauma who themselves, you know, haven't been treated for that. The parents themselves, of the trauma that they went through.” (Somali Parent)*

*“We have a culture issue. It, we cannot express and tell people, oh, I need this and this. It, we get shy about that. We don't talk about it. Things, uh, hurt.” (Somali Parent)*

Parents across all communities also talked about the complexity of the system as a barrier to early identification. Parents talked about the difficulty of knowing where to go or what they had a right to access:

*“...some of the parents just don't know how to work they system and don't know their rights and what they can or cannot do.” (Hmong Parent)*

One Somali participant recognized that the prior untreated trauma suffered by many Somalis makes navigating an already complex system all the more challenging:

*“...yeah, the services are out there. They are available for everybody who you know, has car, can speak English, who can seek, who has knowledge of them. But here's the dilemma, we're dealing with a community that is immigrant, you know, refugee, who went through mental trauma who themselves, you know, haven't been treated for that. The parents themselves, of the trauma that they went through.” (Somali Parent)*

Language barriers are associated with difficulty navigating the system. Parents, especially in the Somali community, talked about low quality interpreter services, poor interpreter qualifications, an inadequate supply of interpreter services, and a lack of providers who speak Somali. The various language barriers leave parents uncertain of how to go about seeking help, lacking in understanding of where to go or what to do, and untrusting of the very interpreters who are counted upon by providers to help bridge the language gap:

*“I am not good with the language and navigating the system.” (Somali Parent)*

*“I think lack of language. I don't know where to seek help. Schools trying their best, yet me not understanding their efforts. That I need Somali speaking professionals to work with me and help me with their assignments and what the teachers requested and all.” (Somali Parent)*

Insurance and cost issues were also common in the Latino and Hmong communities. Parents talked about the difficulty affording copayments or not having any insurance and the difficulties getting enrolled in Medical Assistance:

*“You know, when we had my child, uh, we didn’t add him onto [insurance], so my husband was working at that time and I...by that time I was pregnant with my third child, and I was home, and, because my husband was working, and there is only two child, so there is four of us, we didn’t qualify for medical assistance,...at that time, so my husband didn’t put my son into his, he didn’t put him into his plan, so we had to pay separately, so that was another reason why we also waited in order to seek the help that we needed. So yes, medical was...a huge factor in the decision making” (Hmong Parent)*

While parents in each of the communities shared many of the same frustrations with system-level barriers to early identification, parents in the Latino community cited a challenge unique to their community: immigrant status. Many expressed concerns that they would be investigated about their status when seeking help for their child:

*“For me it would be very helpful that the state do not investigate the social security status of the parents...we are asking for assistance for our children...also... that the renovation for the medical insurance should be more than six months as it is now...” (Latino Parent)*

*“The problem is that we do not have documents or the social security... to apply for services. We would like to get a social security so we could ask for services.” (Latino Parent)*

## **Challenges accessing services:**

Parents were asked about times they may have had difficulty accessing services that they felt were important for their child. They were asked to describe these difficulties, which were then categorized based on whether they were related to family or individual problems, providers or system level problems.

### ***Family / individual challenges associated with accessing services***

Table 9 describes the most common family or individual level challenges parents experienced when trying to access services. Across all communities, but especially in the Somali community, parents talked about the enormous amount of stress and trauma associated with having a child with autism. Parents discussed how autism had affected their own physical and mental health. They recounted how the stress of caring for a child with autism impacts siblings, affecting their academic and behavioral performance in school. For many parents in the Somali community, autism had touched every aspect of their lives and rendered them incapacitated:

*“Autism is like you have been run over by a car. Like you are walking in the street and you are run over by a car. There will be changes in your life. There will changes in you*

*spiritually. There will changes in your family's life and your lifestyle. There will be a lot of changes in your life. Autism is like you had an accident and was run over by a truck.*" (Somali Parent)

*"We were affected financially, physically, psychologically in every way, once you have that diagnosis. It is like a death sentence."* (Somali Parent)

As one parent mentioned, families from Somalia have already experienced considerable trauma as refugees from a prolonged civil war, having witnessed their loved ones killed, losing all their belongings, and relocating to a new and extremely different environment. Autism exacerbated an already difficult situation. Parents described never-ending stress associated with always being on the lookout for the child not to hurt oneself, damage or set a fire on the property, run away in the middle of the night, or disturb the neighbors. They mentioned the stress of getting rejected for services, enduring long waiting lists to get services, and other related issues and how the stress takes a toll on their own physical and mental health:

*"The young child was up all night long. Never slept in his life. When he could not sleep, my husband quit one of the two jobs, initially I was looking after the child all night long, and then my husband switched was looking after the child all night long. Then, my husband had a stroke."* (Somali Parent)

*"...the biggest problem is lack of sleep for both me and my husband. My husband has suffered from a stroke and as for me, my blood sugar drops, sometimes it goes up and sometime it goes down. All of these are caused by the hardship we are going through. I would like to get helped about the problems I have."* (Somali Parent)

They also described the stress associated with trying to juggle finding services for their child with work and the needs of the other children in the family, the intensity of which is compounded for single parents:

*"I am a single mother with five children. Three of them attend schools and are healthy. They don't have time to learn. They (the two with autism) cut their books and tear their clothes. We are constantly on the lookout at bathrooms, kitchen, and doors. We don't have a home of our own and we live with other people. My problem is ongoing and that is all I would say. Even we ourselves don't get sleep; I am on the lookout for all night. We are keeping them from the door or anywhere else. Even my other children those who are in high school don't have time to learn or do their homework."* (Somali Parent)

Being from a different culture and not proficient in English created additional stress for parents. Together, the emotional toll often leaves parents disengaged and not focused on getting services

for their children. To sum it up, as one parent put it,

*“It is something that destroyed our lives completely.”* (Somali Parent)

**Table 9: Most Common Family/Individual Challenges Associated With Accessing Services**

| <b>Rank</b> | <b>Hmong</b>                      | <b>Somali</b>                     | <b>Latino</b>                     |
|-------------|-----------------------------------|-----------------------------------|-----------------------------------|
| 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           |

Family stress also emerged as important in the Hmong and Latino communities. Parents in the Hmong community shared how caring for a child with autism often created or exacerbated their own medical issues:

*“I would rather take care of ten normal children than taking care of an autistic child. It is a big challenge and it is not easy at all when it comes to those autistic children. I am so stressed and it causes me a lot of depression. So, when we have problems and he made me so stressed, I honestly went to the mental hospital twice because he stressed me out. I was so stressed out and there was only one of him and he caused all sorts of work for me to do in the house. So, I am so stressed over that child. Honestly, those autistic children, they are not easy to take care of.”* (Hmong Parent)

Parents in the Latino community discussed the stress they felt being the caregiver for a child with autism. However, they also mentioned additional stress associated with their immigrant status:

*“I am afraid to ask for services because I do not have social security. Even when I sleep I am afraid that something is going to happen because I do not have a social security card. It is fear and that fear can be transmitted to the child as well. A psychologist told me that how I feel it will affect my child as well.”* (Latino Parent)

Across all communities, many parents reported feeling frustrated by not knowing what types of resources were available, how or where to access resources, and who to go to in order to get support and assistance. Parents felt that without knowing what types of resources or services were available, they did not know where to go to find help:

*“So I can’t say “Well, I want great service.” Well, it’s...what kind of service you know, would I like to receive? I don’t know because I don’t know services there are out there to receive...” (Hmong Parent)*

*“We don’t know the system....My issue is how I can look and how can you look for something that you don’t know? I don’t know what she is eligible for. How I can look?” (Somali Parent)*

*“You know something because you ask...but at the same time do not know what to ask for.” (Latino Parent)*

While parents talked about the stigma or the reactions of others to their child as adding to the emotional impact on the family, stigma emerged as particularly important in the Hmong community. Some parents talked about extreme isolation due to fear of the reactions of others in the community toward a child that may appear or act differently:

*“...most mostly, I...I notice that...that in our culture. I don’t know about other culture but mostly in our culture, we don’t want to have that label that our child have a disability. Some parents are embarrassed by that I think...cause usually I notice that they don’t take those kids out much.” (Hmong Parent)*

*“We have a culture issue. It, we cannot express and tell people, oh, I need this and this. It, we get shy about that. We don’t talk about it. Things...hurt.” (Somali Parent)*

While acknowledging the problems with shame or embarrassment, other parents were also able to actively resist stigma and not let it interfere with how they felt about their child or hamper their efforts to get services:

*“Me personally I’ve never been like ashamed of him, but I guess, I mean I do know some people who are ashamed of the child to state that he’s, that their child is autistic is like saying he’s dumb, but I, I disagree, I mean I can understand why some parents feel like that but I’ve always been very, I don’t know, very comfortable with it. If he’s like that, then he’s like that. There nothing you can do but love him and hopefully he does good.” (Hmong Parent)*

Parents in all three communities expressed fear for their children’s safety. Somali parents in particular described children of all ages who inflict injuries on themselves and on other family members, who run away from home or run out into streets and risk being hit by moving vehicles, and who are at risk for injuries or causing property damage in their homes:

*“I also reported to the housing company that my child will escape and requested if they can secure the doors. They declined my request due to the fact that the rules won’t allow it. ‘Whether he is runs away or not, you watch him.’ They said that it will ruin the décor and I am really fed up because my child is running away and is at risk of being hit by a car, or a train.” (Somali Parent)*

*“At that time, the child was six, seven years old. Five years old, six years old, seven years old, then he started...he goes then...he goes out the door, then he goes only, does not know to return home.” (Hmong Parent)*

*“He was naughty...he is like what I’ve mentioned, he...the paper toilet. He plays with it and makes the restroom so dirty. So, I have to clean it every day and if he sees knives laying around the here, he’ll take it and use it. He goes to the bedroom and cut the mattress. See that table clothes over there, he was the one who cuts it. He is very naughty. He will cut everything. So, I have to put the knives in a safe place. If not and if he sees it laying somewhere, he wouldn’t know that it will hurt him. And when he hits himself, he hits himself like this, he use all his strength to hit himself. I don’t know, he doesn’t know that it causes him pain.” (Hmong Parent)*

**Provider-related challenges associated with accessing services**

Table 10 describes the most common problems related to providers that parents felt made it difficult for them to access needed services. Across all three communities, parents identified language issues, which were most common in the Hmong and Somali communities:

*“The doctor’s environment has to have somebody who understands the people. Specially, community, Somali community, they have to have somebody who understands, because this is their second language. Even if you speak English it doesn’t matter, your friend may not speak English. So people need someone. Even if it is American doctor has to have you know, resource, helping people, translator or you know, who talk to their language whatever you know.” (Somali Parent)*

**Table 10: Most Common Provider Related Challenges Associated With Accessing Services**

| <b>Rank</b> | <b>Hmong</b>           | <b>Somali</b>              | <b>Latino</b>                      |
|-------------|------------------------|----------------------------|------------------------------------|
| 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                    |

Challenges with communication went beyond the fact that providers often did not speak the same language as the parent. Many parents felt that their provider was not completely honest, did not call them back or follow up, held back important information or treated them harshly. A Somali parent explains the frustration of communicating with a provider who seemed reluctant to fully explain the services that are available:

*“In my experience, I knew what services I needed. But the problem was [the] caseworker, who was not willing to tell me what my rights, the right that I have for my son. For example... There are a lot things that the county pays, like... respite care. There is something called respite care for the mother, not only for the child. And I knew that one. If I did not asked her, she will not tell me. So, the caseworkers and the nurses that come to your house, and then evaluate the child, they are not going to tell everything... they are withholding every information that you need it. So, if you do not know and you do not ask, you will never know, you will never find out. Plus the waiting list. The waiting list is too long even if you know.”* (Somali Parent)

Parents also told stories of repeated instances where providers or organizations did not follow-through with phone calls or information. Trying to continually contact providers of services, while balancing other demands, is challenging:

*“I’m a full time student and I don’t work. I get a little assistance for [name of child] because of her autism but for, for something like that, and, and that’s [name of organization] for, and when I called, I was like, and she has MA, I was like is there a scholarship, or you know, I asked about those stuffs, you know, and the lady said she would, the lady knew somewhat about what I was talking about, she said she would call me back, she never call me back.”* (Hmong Parent)

For some parents, especially in the Latino and Somali population, discrimination was the key problem with providers that made accessing services difficult:

*“[W]e decided to move because we felt discriminated against. Well, we thought that they did not want us in that school.”* (Latino Parent)

*“Our Hispanic children are discriminated against. We see reports that indicate that our children are not doing well. Our children are part of this country and they were born here. I was born here and I demand that our children should have the right to have education and therapies that other children are receiving.”* (Latino Parent)

*“Every door I knock is slammed in my face with harsh language and false remarks, ‘How can I help you?’ ‘Sit or there.’ Finally I get discouraged and leave. I cannot take a step forward not to mention I have the kids waiting for me.” (Somali Parent)*

### **System-related challenges associated with accessing services**

As shown in Table 11, across all communities, problems with wait lists emerged as important, and were the most common problem expressed by Hmong respondents. Even when services were available, accessing care within a reasonable period was difficult:

*“They could only operate on a small level. They only...oh...have about ...they can only intake about 30 clients. And cause they have like just...just only like certain amount of staff number just to maintain their quality. And of course there was a waitlist.... So it took a...another year ...took a year uh from the diagnosis to get him into...intensive therapy.” (Hmong Parent)*

**Table 11: Most Common System Related Challenges Associated With Accessing Services**

| <b>Rank</b> | <b>Hmong</b>                            | <b>Somali</b>                | <b>Latino</b>                           |
|-------------|---|------------------------------|---|
| 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                        |

Within the Somali community, the waitlists for waivers and accessing autism centers were particularly frustrating. Parents talked about being placed on waiting lists even though their child had been identified with autism years before:

*“Yes, now like waiver, I applied and did not get. I am waiting 2011 up to now and we are at 2013. Two years waiting list. I was waiting MA for a long time, even though I finally got it. Transportation problems always exist for couple three months. My child has MA which has a limitation and not many providers are accepting. All of those things.” (Somali Parent)*

Others told stories of finally getting to the top of the waitlist, only to find out that they were not eligible:

*“The hardest one was when I tried to enroll him in school called [Name of school]. I was waiting for three years and when I was allowed to the school, I was told that my child was too old for that school. I don’t know any other place to take him.” (Somali Parent)*

Insurance and the costs of services were also commonly mentioned problems by parents in all three communities. Concerns about insurance or costs covered a myriad of problems. First, some parents mentioned that although they had private insurance it did not cover the services they needed for their child or would only cover it for a limited time. For example, a family shared how their son was receiving Applied Behavioral Analysis (ABA) services but after a few months, their insurance stopped paying because their son was showing improvement so the insurance company determined that their son no longer needed ABA therapy. Soon after discontinuing services, the parents saw a noticeable decline in their son’s functioning:

*“...we found [name of school]. They were eight to ten grand a month too...but they have everything. They have ...everything in house. They had speech, occupational therapy, they had intense ABA....pretty much everything. And...they...you know, they accepted our insurance....And then January 2010, he started [name of school]. And he received intensive therapy. It was from nine to five. It was eight hours. He packed his own lunch as if he was going to work....Yeah, so...then he’s been at that program ever since and he’s ...he ended...we ended the program uh this year of July.... Because our insurance no longer---they no longer---our insurance just no longer...they said he’s, you know, he’s ...he would be...he’s doing fine without the services which I disagree 110% but...insurance discontinued services for us. He is back in the school system....So...that’s where we’re at right now and...believe me, we’ve appealed so many times to...our insurance company.” (Somali Parent)*

Some parents, finding that their private insurance was inadequate, tried to access insurance through Medical Assistance (MA). In some cases, one parent stopped working in order to meet the income threshold to qualify for MA, which only added to the stress within the family. Even those on MA encounter numerous cost related issues. Somali parents identified discontinuation of insurance coverage, MA not being accepted by most autism centers or not covering therapeutic sensory materials, and high cost to care as major factors contributing to problems accessing quality services. For example, parents relied on Personal Care Attendants (PCA), available through public insurance and found cuts in the program proved to be frustrating. Others explained that, although they had insurance, many of the best autism providers in the state did not accept public insurance:

*“We cannot get ABA because my child has MA. The centers that we went to only 2 of them accept MA and those 2 centers are overwhelmed with people and they put us on a waiting list.” (Somali Parent)*

*“I called [name of autism center], they said it is going to be a wait. Maybe 2 years. I talked to the [name of other organization]. They said I have to buy my own insurance, which is \$206 a month out of my pocket, and the wait is 5 months. I have to pay, \$206 a month for 6 months, then he can get it, and then after that, it is \$3000 deductible, unaffordable cost.” (Somali Parent)*

*“The biggest problem that I was faced with was that my child was denied speech therapy for 2 weeks because the insurance, MA, coverage expired...for example the insurance, MA, is discontinued and us not knowing that is discontinued, and you call for a ride and the response is no.” (Somali Parent)*

Even when parents were on public insurance, if their incomes were too high, they found that they were responsible for a ‘parental fee’ that presented an additional economic burden:

*“We always had to pay a monthly parental fee because... in correlation with our income. Month...you know...we’re to pay every month. And then, not only that but its, it’s the therapy alone requires a lot. I have all...I constantly had to get supplies or food or things to make his therapy get going...and you know we’re a one income family, always have to be frugal on budget and so that was a strain—that parental fee.” (Hmong Parent)*

In addition, among insured parents, many of the extra-supports that professionals recommended for their child were out of reach in terms of costs:

*“It’s like he needs, trampoline. He has so much energy. He needs [a] swing, swinging... which is, I cannot afford to buy it. He needs heavy blanket... school become a lot of things. They tell me he needs this and this and this and this at home and then when I total it, it’s, it’s, I can’t even afford to buy it right now. And the case manager I have, she really nice, but ... she can’t do anything about it. And, they told me... maybe they can only buy one thing out of the time and it’s like, maybe a year, like two things, and that time, you know, after a year, he gets older and older and we become frustrated, too. So, it’s so hard. We don’t know where to turn and go and find help.” (Somali Parent)*

The Latino community shared many of the same frustrations with coverage issues under both private and public insurance, but cited concerns about immigrant status as an additional burden:

*“For me, I want a PCA and they have not given it to us. The social worker has not helped us too much. I called the agency and I was told that if we do not have SSI we cannot get a*

*PCA. I was told that I need to ask my social worker to see if we qualify. I was told that we can qualify for a family grant but I do not see any help. I do not know information of any programs.” (Latino Parent)*

Some of the difficulties concerning costs and insurance were related to the difficulty of navigating the complex insurance system and finding providers who would accept their insurance. As one Hmong parent states:

*“Because it is not where you can just open up the yellow pages...All right, I wanna see a childhood autism psychologist that actually would accept my medical [insurance].” (Hmong Parent)*

Problems navigating the system went further and involved frustration with the amount of paperwork, knowing what services were available and overcoming the reluctance of some professionals to provide those services:

*“For example I had to deal with some who did not want to give the services...They put to many obstacle, well...a bunch of requirements...is that you have to file out. Papers, a whole bunch of papers...well.. I say ok... but they take a long time....and then one always has to wait...”(Somali Parent)*

Some parents talked about the need to bridge the gap between what parents were eligible for and what parents were receiving and suggested that having staff who knew the specific language and the culture would help to bridge that gap. Parents talked about what they needed in order to be able to better access services for their child:

*“...first for me to get informed about what my child has rights for. After I get informed about the services my child has rights for, then to get informed about where I can get those services. Once I get the information on where to get the services, show me the way to get it and that way could be a Somali person who knows my language and can bridge the gap. For instance that person can say, ‘You are eligible for that service, your son is eligible for those 5 services, that is where you can find it.’” (Somali Parent)*

*“To have more things in Spanish, for me it’s been very hard to find help in Spanish. There is not accessible and one has to struggle a lot.... It does not exist for parents in Spanish, for parents with kids with autism, there are not programs.” (Latino Parent)*

*“I would like to have access to the same places that other communities have. I would like to have access to those places. Not to bring my child every day, but at least once per month to have that support and that security for him, a place where he can be safe and*

*where professionals can assist with his care. I would like that support and that safe place for the children who have this condition.” (Latino Parent)*

Both Hmong and Somali parents commonly described transportation as a problem. For medical appointments, MA should provide transportation services. However, many parents found they were often refused or were provided with unrealistic alternatives such as taking the bus:

*“My biggest problems include lack of transportation from the insurance. My sick child who runs away when I take him outside, when I have an appointment and ask them to give me transportation, their response is let him ride up with the bus. Ride the city bus, that all people ride, to his doctor. He is a young child who is sick. When I take him outside, I have to hold his hand and cannot let him out of my hand.” (Somali Parent)*

The inability to access transportation led, not only to frustration, but in some cases to children not getting the services. In other cases, incredible tenacity was required on the part of parents to get this basic service. One mother explained how she was able to finally get needed transportation, but only after going through an appeals process:

*“When his process started, the biggest problem was, as that sister mentioned, speech therapy was cancelled due to lack of transportation. Yes, transportation. Yes. Then now he does not have speech therapy. The girl who is in [Name of Clinic] helped me and told me to ride my son with the bus. I have taken an appeal. Before the judge spoke with them, they accepted and said to the judge, she will have the transportation. I still have the transportation, God’s blessings...” (Somali Parent)*

Parents were also concerned with transportation issues around non-medical appointments. Parents recognized the importance of their child attending activities outside the home, but could not provide the transportation because of competing demands such as work or other childcare responsibilities:

*“I work too and I...now I have my own medical sickness and then I work, I have medical sickness and he continues to bother and asks me to take him to places and I don’t have the time to take him. Then he’ll get angry at me too. So if I was to drop him off and go to work, then there is no one to pick him up later.” (Hmong Parent)*

Housing emerged as a particularly important problem in the Somali community. Space, safety, compromised rental history, financial issues associated with property damage and repairs, and alienating the neighbors were some of the issues the parents talked about. They discussed their fear of landlords who refused to fix property and of inspectors who might find that their property did not meet standards. Problems with housing were part of the every-day experiences of these

parents adding immensely to the level of stress these parents already faced and their ability to adequately care for their child with autism:

*“When he was two to three years, while we were living in our first house, when I was pregnant with my youngest child I developed blood pressure and sugar blood and I was looking after him. After the blood pressure and the sugar blood, my husband was working two jobs. The young child was up all night long. Never slept in his life. When he could not sleep, my husband quit one of the two jobs, initially I was looking after the child all night long, and then my husband switched was looking after the child all night long. Then, my husband had stroke. When my husband was being discharged from the hospital, and stayed home for three days, the landlord asked us to move out, because you have a young mad child who vandalize and destroys the property. You will burn our home and then you have to move out....The landlords whom we were trying to rent a home...couldn't rent us because she couldn't obtain any information on our rental history....Finally, the landlord rented us the apartment. And when he gave us the apartment, he has started hidden fighting with us. Sweep here, sweep there, Do this, do that, fix this and fix that. Every night he runs away from us. One night at 4:00 a.m., the child went through the window. The landlord refused to fix the windows.” (Somali Parent)*

Finally, parents from all communities commonly discussed lack of support services for parents and families. Parents felt isolated and described how having a child with autism affected the entire family, taking a toll on their marriage and on the siblings of the child with autism. Parents talked about the value of networking with other families who had a child with autism and being able to exchange ideas and just share frustrations:

*“You know, there's Hmong's, Hmong advocates out there for parents and family who have disability needs, but there is no specifically Hmong or cultural...parent support group, you know, and I was talking more about you know, my emotions, my frustrations and when I was you know, really heading down that emotional path... there was really no moral support to guide me back to focus on the bigger picture. The bigger picture was that my child is different. My child has a disorder, condition....and I, I guess if it wasn't really for my husband, then we wouldn't be able to move and shake all this stuff that's happening right now. But I, I felt like if there is something out there for parents, a group or something, you know...that we Hmong can go talk, to share ideas or just even to go express to just unload...would be really beneficial to our children who have autistic, who have autism. I think the better you ask, you just release or express or vent, you know, the more you're able to come clear on conclusions, cause that's how I felt, that the more I was able to express, release, and vent, I was able to be clearer on what I need for my*

*child. What I want for my child. And to understand that, it's not me, is that it's not about me. It's more about my child and how do you get there.” (Hmong Parent)*

*“Yes. I mean, maybe if they heard like, it started with three people one day and then maybe people listen and then they spread words, like, oh, today, I meet with somebody and I told this and this. We talked about this and then we make small group. They can get bigger, and if you provide uh, okay we gonna have lunch, like supper. Please come together. And the everybody talk and some people shy and will pass down to you and pass onto her and then maybe two or three people will come and say something and then the other person will come up, like share story. Maybe, maybe two or three words come today, tomorrow, then that's what helps.” (Somali Parent)*

### **Gaps in services:**

Parents were asked what services they would most like to receive that they thought would help their child. As shown on Table 12, many of the services mentioned such as speech therapy and personal care attendants should be available for those who have insurance. Yet, as detailed throughout this report, many are having difficulties accessing such services (e.g., experiencing waiting lists, limits on services, etc.).

Parents from the Hmong community most frequently mentioned family/support services as the type of service that they were not receiving that would help their family. Much of what they talked about went beyond traditional counseling services from a mental health provider. Instead, they expressed a desire to talk with other families who also had a child with autism. They saw the value of being able to share ideas with parents in a similar situation:

*“Yes. Like I want someone who is, it doesn't matter how many of them, but at least me and that person comes talk such as ‘oh, my child is just like your child as well’... this is how my child is child and that is how your child is,’ so, to exchange ideas such as ‘why it is that our children are like that? How did you seek services...how did you go about seeking services at school? Or oh, this is what you need to do, so they could provide the right services for your child. And, you child has the same problem just like my child, too.’ So, with this, and the concept of sharing ideas, the...I'll know how to take my child into see the doctor and for an evaluation to prove that ‘oh, your child is like this.’” (Hmong Parent)*

**Table 12: Most Common Services Needed by Families**

| Rank | Hmong                              | Somali                      | Latino                             |
|------|------------------------------------|-----------------------------|------------------------------------|
| 1    | Family support services/counseling | Housing                     | School services                    |
| 2    | Speech therapy                     | Speech therapy              | Respite                            |
| 3    | Occupational therapy               | Applied behavioral analysis | Family support services/counseling |
| 4    | Skills therapy                     | Respite                     | Personal care attendant (PCA)      |
| 5    | Services for adult children        | Occupational therapy        | Speech therapy                     |

The value of parents having an opportunity to share with other parents and knowing one was not ‘in this alone’ was also repeatedly brought up in conversations with Latino and Somali parents. Seeing other parents in the same situation and being able to share experience helped parents cope:

*“For the last two years I have been involved in the treatment of my children and looking for places where they can get therapies. I go to different places and I know that I am not alone. I know that we are not the only ones experiencing this situation and ... like me...there are other parents that are having the same experience. We know that we are not alone and that we can help our children.”* (Latino Parent)

Finally, some parents focused on the need for further services for young adult children with autism. One mother talked about the desire for her child to go to college, but her worry that there was no way he could go since he would have no one to guide or direct him:

*“Well, he wants to go to college but I can’t...I can’t you know, walk him, hold his hand daily and do that so I want someone to be there to direct him, guide him to do now that ...now that he’s an adult and he...he understands that he needs to be on his own but he doesn’t know how to move on his own and as a mother, you know, I ...I’m afraid that what if something happened to me? Who’s going to be there for him? Who’s...who’s going to guide him and things like that? Even though he has his siblings, you know, everybody has their own life and...so right now there’s no service whatsoever and I...am frustrated.”* (Hmong Parent)

Another mother from the Somali community worried that her adult child with autism was left with a lack of services or meaningful activities:

*“My daughter is 19 years old, and she is just sitting at home. She does not go to school. She needs a lot of activity. It does not matter whether it is respite or it is day program,*

*anything. She needs different activity...she has few PCA hours, but she needs other activities.” (Somali Parent)*

For the Somali community, many of the services mentioned fall within what is covered through health insurance— but parents are still not able to access these services. Interestingly, however, it was not a traditional medical service that was the most often mentioned as a need within this community – it was housing. As discussed early in the report, Somali parents saw housing as essentially important to their ability to provide appropriate services for their child. One mother recounted an unnecessary stay at the emergency room due to unsafe housing:

*“So the lady at the emergency said that they were not going to release him from the emergency unless the housing people have done something with the windows and for the fire safety people to go there and close off the windows. It was a weekend and she coordinated for all of them to meet and advised that the child be kept at the hospital until the windows were secured.” (Somali Parent)*

More importantly, the issues with housing stemmed from living in a confined apartment with a large number of family members including a child with severe autism who has problems with self-regulation, sensory and sleep issues. Parents described patterns of damage to the house, self-injury and injury to others, and disturbances to the rest of the family and neighbors:

*“In my case, I and my child live in two small bedrooms. And I have three other children may Allah bless them. They sleep together and he jumps while others are asleep. It would have been nice if I could get help in getting three bedroom apartment and assistance in housing.” (Somali Parent)*

*“There is not one person she didn’t beat up on. Personally, all my front teeth are false; she broke all my front teeth. There is no one in the family that wasn’t taken to the emergency by an ambulance or have their blood shoot up.” (Somali Parent)*

Parents in the Latino community discussed a wide range of services that they felt could be offered in the schools from tutoring through sports and other extracurricular activities. Some Latino parents indicated that they want their children to have the same opportunities as any other child at school:

*“To get some sport activities. Our children are overweight and they do not have opportunities to do exercises. I would like to get sport activities, they like to do repetitive task. If we teach them how to play soccer they will do it well. Sport activities will help them relieve stress. They have stress, they get depressed. I want to see sport activities to be included in their treatment.” (Latino Parent)*

*“I would like to get more speech therapy. My son gets one hour of speech therapy per week. I want to get a speech therapist that speaks Spanish. There are no services that are in Spanish. They gave us an interpreter but, I think that he understands but it is not the same as if the therapist knows Spanish.”* (Latino Parent)

## **The strength and resiliency of families:**

One of the most compelling themes that emerged from our interviews, although we did not include specific questions about it, was the demands that having a child with autism placed on the family, and the love these parents have for their children. Parents described numerous examples of their devotion to pursuing care for their children. Parents told stories of resourcefulness and tenacity, as well as a sense of hopefulness that with services and treatment their child’s condition and the family’s quality of life can improve. One Somali parent described a long wait to receive needed services:

*“For 7 years I have been trying for my child to get skills training. Just now! that I got chance that they tell me that my child can start at the autism center. Those 2 weeks that I have been taking him there, I felt a huge improvement.”* (Somali Parent)

Parents recounted extensive travels to find the right services, profound dedication of economic resources, commitment to both healing religious practices in combination with western medical treatments, and a willingness to speak out on the topic despite stigma:

*“I took him to [name of clinic]. At [name of clinic], they found a tumor in his brain. Thank God that cured the seizure and now he doesn’t have the seizures that used to knock him out and fall. I did also read the Quran on him; a lot of people suggested that. Of course, we are Muslims and Quran is inevitable. We do recite the Quran on children. I took him to the pilgrimage, Haj and took him to Arafat and prayed for all. I took him to Germany hoping.”* (Somali Parent)

Many families with two working parents made the difficult decision to go down to one income, so the other parent could stay home to care and provide support for the child. As a result, many parents encountered financial struggles but this did not deter them from taking initiative to proactively seek help for their child.

While acknowledging the high levels of stress and demands that caring for a child with autism brought to the family, parents were also able to draw strength from the experience:

*“Uh this child has done nothing wrong only to better us, make us try hard, you know...and then that’s what we have on our little thing ‘Try a little harder’ so we could try, we could love a little more, you know, we could try harder. It’s nothing...more*

*compassionate and...show love and...and he's changed everything to the core of me. Before (name of child) came, I wanted to do this and that and I mean... (deep sigh) all of you know me, me, me and...and now I see things in a completely different light...I'm so very grateful for it. I mean the ...I...I...I can only express it in so many words but...the way I feel, it the way that I feel is ...like a million times more.” (Hmong Parent)*

For many Somali parents, the strength they felt and drew on was tied to a belief in God:

*“But luckily your child begets his own luck in which Allah has allocated for him. To help your child depends on you.” (Somali Parent)*

### **Recommendations of parents:**

The survey asked parents what would they most like to tell decision makers (e.g., the government, or the Minnesota Department of Health) to do to improve services and reduce barriers for their family and child (Table 13).

**Table 13: Most Common Recommendations Parents Made to Improve Services and Reduce Barriers**

| <b>Rank</b> | <b>Hmong</b>  | <b>Somali</b>  | <b>Latino</b>   |
|-------------|---|--|---|
| 1           | Financial support/grants                              | Culturally sensitive services                          | Culturally sensitive services                                 |
| 2           | More awareness or education about autism in community | Culturally appropriate community center/ autism center | Support services for parents/families                         |
| 3           | Support services for parents/families                 | Housing  | More awareness or education about autism in community         |
| 4           | Increased funding for autism organizations            | Support services for families                          | Improved insurance coverage for autism services & therapies   |
| 5           | Continued funding for existing insurance program      | More awareness/ education about services available     | Temporary legal status for families with children with autism |

Parents from the Hmong community most commonly cited the need for additional financial support or grants. Since many families were single parent earners, additional financial supports would be helpful in obtaining the services needed as well as assist in providing a better quality of life for their child/children. Parents stated they could use extra financial assistance for their child with autism to buy clothes, special diet/foods, activities for the child to join in order to provide social interaction, and assistive technology equipment (i.e. iPad applications used to help communicate):

*“If you get money to help in ways...for the parents to take the child out...money for this child...uh...so he uh...has ways uh...to learn other things and attend different programs to help him, then this is one way to help the parent. Also, as parents, you ...don’t have good jobs so ...sometimes you ...you need the money to come...you can have the money to come...to come take...take the child out to play outside and take out for activities, take him to the movies, take him to the zoo, take him to rent movies to watch, buy him clothes, because he is very messy...pees in his clothes... If there is no money, if we came to this country and there weren’t these money, our children will suffer like when we were in our native country.” (Hmong Parent)*

Parents from the Somali and Latino community emphasized the need for more culturally sensitive services in their recommendations. This included both more providers from these communities, who spoke the language and understood the culture as well as educating providers about Latino and Somali cultures. Parents repeatedly emphasized the value of having people from their culture who speak the language who could help them navigate the system, learn more about autism and overcome the obstacles to getting needed services:

*“What can help them [families with a child with autism] is, it is a fact that we are people from a different culture and language. We have language, cultural, financial barriers and everything. We don’t understand how the system of the country functions. Therefore, even though the teachers are giving you the services; and you get services everywhere you go, but at the same time we don’t understand. We don’t know how to utilize these services and get mainstreamed. We need Somali people that bridge the gap of schools, centers, ABA providers, doctors, as well as DHS. We need Somali people who know and understand our problems, well trained not just interpreters, who work for the above mentioned so they can bridge the gap. I think that is how we can overcome or surpass this.” (Somali Parent)*

Many Somali parents also recommended a culturally appropriate community center or autism center operated by experienced Somalis. This center would serve as a place where the parents would go to find culturally and linguistically appropriate employees that they can trust who will help in every aspect including helping them navigate the complex system of getting services and resources. Such a center would provide comprehensive services encompassing all their needs whether for the parents, siblings, or the children with autism, and would serve as a focal point to connect them to service providers and to bridge the gap:

*“If I have to tell the government what the community needs, in sum, to open autism community center for the Somali people. That is the place where any mother can come and get all the information and services her child needs in her own language. All the services that the government provides and the people who will help them navigate the*

*system. To open for them a Somali autism community center that the parents own.”*  
(Somali Parent)

*“To enact a law that will give a person who has been diagnosed with autism to be able to access services regardless of differences.”* (Latino Parent)

Parents from all three communities thought further efforts to increase awareness about autism were needed. They felt such efforts could help on many levels. Empowering people to be more knowledgeable can assist with recognizing the signs and symptoms of autism at an earlier age which may lead to children getting help sooner rather than waiting until they are in school. Less stigma and shame may be associated with children with autism if people better understood the diagnosis and how to work with individuals with autism. As one Hmong parent described the impact of increased awareness on early identification:

*“Providing better awareness...knowledge, education....Be searching the...I don’t know, medical practices ...making sure everybody’s more aware of how to detect these symptoms and early...you know, kids can show autism symptoms as ear-early as nine to ten months maybe at most. Sometimes, maybe even earlier.”* (Hmong Parent)

Other parents recommended greater education about the types of services available. Again, however, parents emphasized that outreach and education should come from persons within their own community:

*“Information for parents to be able to better understand what we can do for our children, especially in Spanish. We need more programs and specialists in Spanish.”* (Latino Parent)

Given the emphasis that Somali parents put on housing problems as making it difficult to get their children the services they needed, it is not surprising that housing emerged as a priority area in the recommendations. Parents saw the need for programs that make home ownership possible, and recommended programs such as Habitat for Humanity that would allow the flexibility to customize their home to their child’s needs:

*“For habitat to facilitate home ownership. My sister above has to vacate her apartment. I myself am to be evicted soon. Most of the people have been evicted. Therefore, to facilitate habitat housing, and for the government to meet with habitat and convince them that they should exempt these people from stipulations such as income and what not.”*  
(Somali Parent)

# Discussion and Recommendations

A goal of this research was to hear from parents in the Hmong, Latino and Somali communities about their experiences getting services for their children with autism. We were interested in the factors that impede early identification of children with autism, and the factors that make it difficult for parents to connect with services that can improve outcomes. Equally important, the purpose of this project was to help develop concrete recommendations that could inform next steps to improve services for persons with autism. These recommendations are outlined below.

## Recommendation 1

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

Parents provided an enormous wealth of information about the obstacles they faced from initially trying to get their child identified or diagnosed through trying to connect their adult children with autism to supportive services. Only one of the seventy parents indicated satisfaction with the level of services she was getting, and she was comparing her current experiences getting services for her child to her prior experiences in a refugee camp.

Parents' frustration came from numerous areas, from communication with providers and long wait lists to feeling discriminated against and being treated disrespectfully. But one of the most important messages that we heard in the interviews with parents was that despite enormous frustration, 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.

These parents saw many of the failures of the system having to do with the lack of people that they could trust - providers and staff at agencies understand neither their language nor their culture. Going forward, it is essential that we ground outreach and educational campaigns around autism within different cultural communities. For example, instead of having staff from state agencies provide outreach into the community, it would be more effective to train community members to provide such outreach. Laypersons from these communities who are trained on the early developmental signs of autism, the resources that are available to parents, the evidence around what services are effective and reducing the complexity of navigating the

system can do much in helping families overcome the challenges of getting services for their children.

One potential model is to expand the purview of community health workers (CHWs). CHWs represent an emerging workforce. They are trained and trusted members from the communities they serve, who are described as providing access to culturally competent care, particularly for chronic conditions, and improve the health knowledge of those they serve (Minnesota Community Health Workers Alliance, 2013). CHWs are not only in a position to educate and support families of children with autism but they can also educate state agencies about ongoing needs of these families – offering two-way communication between the community, providers and agencies such as a Department of Human Services who make decisions about coverage for autism services. Providing CHW care to families of children with autism is both attractive and feasible given that Minnesota has approved Medicaid payments for CHW-delivered services for other diagnosis-related services (Minnesota Department of Human Services, 2014).

A similar model for autism would involve parents from these communities acting as ‘Community Autism Workers’ (CAWs). In contrast to CHWs, this role would be very narrow and specialized and would not necessitate certification. CAWs may be emerging leaders among parents of children with autism - recognizing and rewarding (via part-time employment) the current role parents play connecting with and supporting other parents in their communities. Training for CAWs can be co-created with DHS and community members, with DHS providing specialized training in the signs and symptoms of autism, health insurance benefits and enrollment processes, waivers, a comprehensive listing of available services, etc. and community partners ensuring that this training is understandable and accessible within their language and culture. Through the creation of a CAW role, parents of children with autism with valuable first-hand experience can be enlisted to help reduce and eliminate what interviewed parents described as intractable problems with the health care system. In the absence of providers from these communities, CAWs are a cost-effective way to begin to overcome these challenges. CAWs training could evolve into a system of peer education and mentorship (parents training parents). It is possible that success within the narrow role of CAWs, that facilitates early and effective use of autism-related services, may spillover into greater trust of the health care system in general, leading to timely use of other health care services. That is, once the demand for autism care is met, parents can focus on their own and other family members’ health care needs.

Empowering parents to help each other also requires that parents from these communities have a full seat at the table as existing problems are tackled and solutions are formulated. Parents must have a position, voice and decision making power on task forces, grants making, and policy-making to ensure that priority setting and solutions are relevant and applicable to families of and children with autism from diverse cultural communities. The involvement of parents (and potentially young adults with autism) from these cultural communities is consistent with

innovations such as the push toward patient-centered care touted by the Patient-Centered Outcomes Research Institute (PCORI) and Minnesota's Accountable Care organizations and future accountable communities for health (Minnesota Department of Health, 2012a).

## **Recommendation 2**

### **Develop resource centers housed in the community.**

Many of the parents told us about the challenges of finding information and resources to help their child. To overcome these challenges, a one-stop resource center located in a community center or non-profit agency that is already established and trusted within each community should be established. These 'one-stop' resource centers could be places to connect with other families and access information about autism and services that are culturally and linguistically tailored to each community. Given the competing demands that parents juggle from childcare through employment, they cannot go from place to place trying to find necessary resources.

Aside from medical services, such resource centers should also provide information and connections to social services. For example, many of these parents face economic hardship, employment instability and problems with housing. While these sectors do not traditionally come under the purview of medical care, problems in these areas impact the entire family and impede parents' ability to get needed services for their children. Housing emerged as a central concern in the Somali community. Connecting parents to housing resources, including Habitat for Humanity, making sure they understand their rights, and providing information about how to deal with difficult landlords can be done within the community. Such centers should also include education and resources about how to achieve home ownership, given that this was a prominent concern of the Somali community.

For the Somali community, there were also calls for an autism center specifically designed to provide direct services (speech, occupational, applied behavioral analysis etc.) for children. Many parents talked about the lack of space in existing autism centers for Somali children. Given findings that autism is particularly severe within this community (Hewitt et al., 2013), such a center would provide an opportunity to provide intensive services to children tailored to the culture and language of the community.

## **Recommendation 3**

### **Provide resources to form support groups for families.**

Our interviews with parents clearly convey the strain of raising a child with autism - the financial stress it places on families; worries about neglecting other children who demand less of their parent's attention; fears about gaining and maintaining safe housing; the isolation associated with caring for a child with autism who is difficult to safely take out in public; the isolation associated

with leaving the workforce to provide care or qualify for needed services; the shame and blame they felt from other family members; and the stigma associated with having a child with cognitive or mental health problems. Add to this the stress parents described as they struggled to understand the array of services available for children with autism so that they would know what to ask for and the additional pressure of asking about, and for, these services in a language other than their own.

For many parents, the process of finding out their child had autism was similar to grief. Parents often went through a process from denial through acceptance. Many parents felt a loss of the hopes and dreams that they initially had for their child with autism. They questioned themselves, wondering if they had done something wrong, and worried about the reactions others in their family and in their community would have when finding out their child had autism. Many parents also expressed feeling very worried about their child's future, especially when/if they can no longer be around to care for the child. This emotional stress sometimes prevents parents from taking their child to a professional early and impedes seeking services.

While nothing can fully alleviate the emotional pain many parents experienced, parents expressed enormous relief associated with finding out they were not alone—that other parents shared their fears, frustrations and hopes for their children with autism. Parents appreciated finding fellow parents who could tell them how to navigate the health care (and school) systems, what services worked well, and what was less effective. In fact, we observed parents reaching out and supporting one another in the focus groups. Even in the Hmong community, where parents were reluctant to participate in focus groups as part of the research, they often talked about the desire to know other parents who shared their experience. A specific example of support services parents desired from within their own community included respite care. They voiced dissatisfaction with current respite services. Parents preferred leaving their children in the care of people like them, who understood the symptoms and difficulties of caring for a child with autism as well as shared common values and a common language, or go without respite care altogether.

We repeatedly heard that parents want support that is located within their communities, sponsored by trusted agencies, and staffed by professional and lay people from within their community. However, parents also recognized an abundance of misconceptions and misunderstanding within their community about child development generally, as well as specific signs and symptoms of autism. Parents also voiced their confusion and frustration about accessing services for their children and families. Therefore, there is a role for MDH to convey information and clear confusion about accessing services; partner with community members to ensure the clarity of communication; and develop the most effective ways to provide information across diverse cultural communities and languages.

This partnership has great potential to serve the interests of these communities as well as MDH as they continue to work to better serve these families and improve the health of Minnesotans. For MDH, the experience of working closely to improve supports and services to parents of children with autism in the Hmong, Latino and Somali communities will expand their network of community representatives and leaders. MDH staff will gain knowledge about what does and does not work well within these communities, expanding their capacity to listen and engage a broad group of parents and other stakeholders in policy and practice decisions around innovations in the delivery of autism-related services.

#### **Recommendation 4**

### **Build capacity in the system to provide culturally sensitive services and decrease waiting times.**

Many parents told us of delays in getting their child identified or diagnosed due to long waitlists or waiting times to see the necessary professionals. Similarly, they told of long waitlists to access therapeutic services once their child was diagnosed. There are no easy solutions to the shortage of mental health providers generally, and autism specialists more specifically in Minnesota or elsewhere. However, the state can support workforce development efforts in the area, including programs for paraprofessionals such as Community Autism Workers who can help families navigate the system and more quickly connect to professionals.

Counties where large numbers of children with autism live should have dedicated staff who are specialists in autism and related neuro-developmental conditions in an effort to bridge the existing gap in service/resource acquisition families with children with autism. This unit's workforce should reflect the diversity of the communities served, and services should be tailored to these communities. Specialized staff could act as a resource to Community Autism Workers in helping to increase knowledge about what services are available and to help parents navigate the system of services.

The state should implement an autism surveillance system that includes statistics about wait times to receive a diagnosis by individual cultural communities. The state, with full involvement of community stakeholders, should set a target and timeline for reaching that target. The state should have a clearly defined strategy to decrease wait times (for example, increase the use of primary care doctors in evaluation and further use of paraprofessionals). Wait times and efforts to decrease time to diagnosis should be monitored and evaluated.

Parents told of many experiences where they went to the doctor with concerns about their child's development and behavior but were initially or repeatedly told that nothing was wrong. Part of solution to reducing wait times is to educate doctors, particularly primary care physicians, on proper screening and evaluation of autism. Programs can also bring evaluation services into the

community, through mobile screening clinics staff by autism specialists and culturally and linguistically competent staff.

There are relatively simple, evidence-based strategies that can improve communication between parents and providers. For example, The 'Right Question Project' (RQP) is a model that has been used to improve individuals' ability to fully engage with professionals. Through education, the RQP focus is to : "teach patients how to generate and prioritize their questions and focus on decisions about healthcare concerns and treatment; encourage reluctant and hesitant patients to ask their questions; support patient efforts to participate more actively in their own healthcare; and promote more patient-provider shared decision making who may have more knowledge" (The Right Project Institute, 2013). The intervention, involving teaching individuals how to ask 'the right questions' has been adapted to a number of different cultural groups and settings including mental health and autism (AutismOntario, 2012; Polo, Alegria and Sirkin, 2012). The state should consider developing and testing a pilot program based on RQP to build capacity in parents to have more successful outcomes with primary care physicians, specialists, mental health providers, and service providers.

The state should report statistics and monitor trends in the use and intensity of services received by children enrolled in public insurance programs- including use of waivers. Information from administrative files is reasonably accurate for identifying the cultural group of the child, allowing the state to monitor disparities. Where disparities are observed, the state should fully partner with community groups in developing programs to decrease these disparities.

The school system is responsible for a large part of services for children with autism. Yet, we repeatedly heard complaints from parents that they did not really understand what services the school was providing, did not believe that the services were adequate or of high quality, and were treated disrespectfully by school staff. Meetings between parents and staff should be more frequent than a yearly Individualized Education Program (IEP) meeting, and interpreters should be available. Having Community Autism Workers available to accompany parents to these meetings might help with communications. Schools must ensure that children are getting appropriate autism-related services such as speech, behavioral and occupational therapy. Schools must be held accountable for the special education services that they provide and should be held to standards of evidence-based practice. Parents were highly skeptical of the ability of school programming to meet their child's needs; it is up to the schools to demonstrate that they can provide quality services and are not just segregating these children. Many of these parents lack the financial means to seek services in the private sector and will remain in the public school system. They and their children have the right to have the highest quality services delivered. A public school for children with Autism is slated to be opened in 2014 in Blaine Minnesota; an innovative approach to serving children with autism within the public school system. However, one school will not meet the needs of the growing population of children with autism, and it is

not clear how it will address the cultural and linguistic needs of diverse ethnic communities. The Department of Education should be transparent with the community about what services are available in the current public school system, how services and outcomes are evaluated, and the training of persons delivering the services.

## **Recommendation 5**

### **Continue to address problems with insurance coverage and costs.**

Problems with insurance coverage and costs come in the form of lacking insurance altogether and, as noted above, limits on benefits among families that do have insurance. For persons with insurance coverage, the autism insurance bill that was signed into law in May of 2013 requires coverage for many types of autism services for large group insurers (will eventually cover state employees), reduces the ‘parent fees’ that many families in our study found onerous and improves services for children on Medical Assistance. The impact of the autism insurance bill on families should be tracked with particular attention to whether access to services improves for all children with autism, and whether gaps between cultural communities narrow or widen. The state has access to data for children enrolled in Medical Assistance, and can track use of services among children with a diagnosis by cultural group.

While many welcomed insurance reform for autism services in Minnesota, it left a number of insurance problems unresolved. First, it only includes large group health plans, leaving out about 19 percent of the private insurance (i.e., small group and individual market combined) in MN (Minnesota Department of Health, 2012b). Second, it requires coverage of services for children, and does nothing to address coverage of services for adults with autism.

The persistent problem of lack of insurance also remains. Latino residents are three times more likely than the general population of Minnesota to not have health insurance (26% compared to 9% in 2011). Similarly, 28% of Minnesotans not born in the US do not have health insurance, compared to about 7.7% of Minnesotans who are US born (Minnesota Department of Health, 2012c). The Affordable Care Act (ACA) will expand access to affordable coverage to some but not all of the uninsured. For example, recent legal residents (i.e., have lived in the US less than 5 years) and unauthorized immigrants are not eligible for public insurance through Medicaid or subsidized insurance available through the Minnesota insurance marketplace (MNsure). In Minnesota, unauthorized and recent legal immigrants represent approximately 3% of the non-elderly adult population (19-64) but 10% of the low-income (0-138% of federal poverty guidelines) uninsured population. Furthermore, lack of access to coverage and fear of deportation may also prevent parents from seeking coverage for their eligible US born children (State Health Access Data Assistance Center. 2013). Safety-net clinics will continue to serve the uninsured and the ACA includes several provisions designed to increase the funding and capacity of these

providers (Commonwealth Fund, 2012). However, safety-net clinics may not be capable of serving the complex needs of children with autism. Therefore, we recommend that Medicaid be extended to uninsured children with autism in order to remove barriers to early detection and needed therapies. School district staff and CHWs are in a good position to provide parents with enrollment and benefit information that may be viewed as trustworthy and non-threatening (this will require a change in the scope of reimbursable services for CHWs which is currently diagnosis driven).

In addition, comprehensive autism services are not part of the Essential Health Benefits that must be provided by the health insurance exchanges. Minnesota will have the opportunity to address this and may add such services to MNsure in 2016. Under the ACA, health insurance plans can no longer deny or limit coverage to people with pre-existing conditions, such as autism, and plans must cover autism screening for children 18-24 months at no cost (US Department of Health and Human Services, 2013). The short eligibility time frame for free screening reinforces the need for community-driven, culturally appropriate education to increase awareness of autism and help families to seek early testing and treatment.

Finally, as parents we interviewed emphasized, insurance did not cover many of the extra supports such as weighted blankets, trampolines, and other special learning tools that providers recommended to parents – but which parents cannot reasonably afford. These are economically disadvantaged families – moreover, in some families, one parent had to leave employment just so they could qualify for insurance that would provide coverage for medical services for their child. To expect that they will be able to afford the supports that are needed but which are not covered by insurance is unrealistic. MNsure, with income thresholds above Medicaid and access to premium subsidies, may change the situation of persons having to leave employment to get insurance by providing access to affordable insurance for those parents who want to continue work. Expanding the Essential Health Benefit to include comprehensive autism-related services will further enhance MNsure-enrolled parents' ability to obtain needed services for their children with autism. However, there remains a need for further financial support to provide families with auxiliary supports not covered under traditional insurance such as educational aids and modifications to the home (i.e. gates and childproof locks to improve safety).

# Conclusions

Recently, researchers released a long anticipated report about the prevalence of autism in Minneapolis (Hewitt et al., 2013). The researchers concluded that the prevalence rates for autism are high in both the Somali community and White communities. While overall rates of autism in Minneapolis were about 1 in 48 for children ages 7 to 9 years of age, the rates for Somali children were 1 in 32 and for Whites were 1 in 36. While lower, the rates in the Hispanic community (1 in 80 children) are also of concern. The researchers had too small of samples to estimate rates for the Asian community. Although, based on our research, there is a clear need to address autism in the Hmong community. Importantly, the report also found that the severity of autism or the percentage of children with autism who had an intellectual disability was much higher in the Somali community (100%) than the other communities. Across all the communities that they studied, the average age of when children are diagnosed with autism was about 5 years, although outcomes are much better with earlier identification and intensive services.

The reasons behind the high prevalence of autism in Minneapolis, and the greater severity of the disorder among Somali children are unknown. The parents we interviewed believed that it is important for researchers and policy makers to continue to devote attention and resources to investigating the etiology and epidemiology of autism across cultural communities and particularly the greater severity of autism in the Somali community. However, it is equally important that we address the challenges these families routinely face when trying to access quality services.

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 in 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 clearly voiced what they need; it is incumbent on decision- and policy-makers to not only listen but to help move us to solutions.

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# Appendix A: Interview Guides

## Key Informant Interview

### [Opening Question]:

1. Let's start with talking about your role working with parents or children with autism from the [Hmong/Latino/Somali] community. Can you describe your role?

[Note to interviewer: Screening questionnaire identifies which cultural communities the respondent has experience working with. Questions should only be focused on communities he/she has experience working with. If more than one, remember to ask about similarities/differences across communities]

- a. How long have you been working with the [Somali/Hmong/Latino] communities?
- b. What types of services/programs do you offer [if relevant]?
- c. Are these programs/services that you offer culturally specific for families from the [Hmong/Latino/Somali] communities or are they available for any family/child with autism?

**[Key Questions:** Note: focus on Somali/Hmong/Latino communities that the respondent has worked with. Focus is on understanding how children get into services; understanding the process of identification; pathways into care; barriers and facilitators of access to resources]

2. We are interested in your opinions about how people in the [Somali/Latino/Hmong] communities view Autism. Generally, how do you think people in [Somali/Latino/Hmong] communities view Autism?

Probe: Do people in this community think of autism as primarily a medical problem, a mental illness, a spiritual issue, is it talked about within the community etc.

3. How do families with a child with autism from [Hmong/Somali/Latino] communities get connected with you/your agency? [Note: Trying to understand typical pathways into 'care' and early identification issues]
  - a. Are the ways that [Hmong/Somali/Latino] families get connected to you different than the general population?  
- If yes - Describe the most important differences?

- b. Do you think children from [Somali/Hmong/Latino] communities are getting into services early enough? (Explain)
- c. What are the barriers to early identification of a child with autism from [Somali/Hmong/Latino] communities?

Probe: How early should a child be identified? (age?)

- 4. What types of things do you think assist [Somali/Hmong/Latino] families to get the resources/services they need? [Focus on Perceptions of Resources that help families]
  - a. Of the things that you mentioned, which are the TWO most important? (Explain)  
 Probes: Do families benefit from having access to reliable transportation, insurance, family and community support, social acceptance, schools, interpreters, language services etc.
- 5. What do you think makes it difficult for [Somali/Hmong/Latino] families to get the resources/services they need?
- 6. Of the problems you have mentioned; which are the TWO most important. Why?

Probes: Is access to resources/services made more difficult by stigma, lack of community support; lack of insurance, discrimination, language, parental barrier – time, knowledge, transportation, providers knowledgeable about where to refer families, etc. immigrant

- a. Are there particular barriers for immigrant/refugee groups from the Hmong/Latino/Somali (e.g. documented/undocumented; duration of stay, language, lack of knowledge of system; family separation)?
- b. Are there challenges related to interpreter services?

Probes: e.g. Are these challenges related to access to an interpreter, access to a good quality interpreter, continuity with the same interpreter family vs. professional interpreters, confidentiality issues that make families feel uncomfortable with the interpreter, taboos that impact what/how information gets interpreted etc)

- 7. What resources, policies, or programs do you feel are MOST needed in order to serve families from [Hmong/Latino/Somali] communities with autism more effectively?

Probes: Do you think that the services, policies or programs that families need are access to insurance, understanding insurance coverage, bilingual staff, outreach and educational materials, culturally specific considerations/supports, planning, team building, clinical intervention, staff

training, family education, practices for involving Somali/Latino/Hmong families).

- a. Why do you think families need this the most?
8. We are going to be recruiting parents of children with autism for focus group discussions. Do you have any ideas about **HOW** we might reach parents from the [Somali/Latino/Hmong] communities to ask to participate?
- a. What recommendations do you have for us about asking S/L/H parents to participate?
  - b. What do you think our biggest challenge will be in recruiting parents?
  - c. Which organizations/locations do you think we should recruit from?
  - d. When we are recruiting parents, may we contact you to give you recruitment materials?
9. Thinking about our interviews with parents, what would you **MOST** like to know from parents that would enable families with autism to receive better services?

### **Closing Question**

10. Is there any other information that you would like to share with us?
- a. Is there anyone else that you think we should talk to?

**Thank you for taking the time to talk with me.** If you have any questions you can contact me (NAME OF RESEARCHER) at [CONTACT INFORMATION]. You can also contact the principal investigator for this research Dr. Donna Mcalpine. She can be reached at 612-625-9919 or by email at [mcalp004@umn.edu](mailto:mcalp004@umn.edu).

# English Version of the Parent Demographic Questionnaire

## Demographic Questionnaire Families of Children with Autism

Answers to these questions will help us to describe the types of people we interviewed in our final report. We will not share your answers with anyone. You will not be identified by name in our final report.

1. How old are you?
  - \_18 to 30 years old
  - \_31 to 50 years old
  - \_51 years or older
  
2. How do you identify yourself:
  - \_Male
  - \_Female
  - \_Other
  
3. How many children do you have?                      # of children
  
4. How many children do you have who you think have autism?                      # of children
  - 4a. How old are these children now?
    - Child 1 :              # of years
    - Child 2 :              # of years
    - Child 3 :              # of years
  
5. Thinking about your oldest child with autism, how old was this child when you first thought she or he might have autism?              # of years
  
6. What is your ethnicity?
  - \_Latino/Hispanic
  - \_Hmong
  - \_Somali
  - \_Other (Please specify):
  
7. In what country were you born?
  
8. In what country was your oldest child with autism born?

9. How long have you lived in US? # of years

10. Are you now:

- Single, never married
- Married
- Living with a partner in a marriage-like relationship
- Separated or Divorced
- Widowed

11. What is the highest grade or level of school you have completed?

- Never attended school
- English as a Second Language
- Elementary school (grades 1 through 8)
- Some High School (grades 9 through 12)
- High School Graduate or GED
- Some college
- College Graduate

Thank you for taking the time to answer these questions.

# English Version of the Parent Interview Guide

## Discussion Questions:

[Note: Instructions in square brackets are for facilitators/note-takers; they are not to be read]

[Differences/similarities in perceptions]

1. People have different ideas about autism. What do you think autism is? I'll go around the table so we hear from everyone.

[Instructions: Go around the table in Round Robin style to get a brief description] We are trying to get at perceptions that facilitate/hinder access; cultural differences in beliefs such as whether it is a spiritual, medical, or mental health condition] [Time: 10 minutes]

[Transition to Early Identification]

2. Now we want to hear more about when you or someone else first started noticing a difference in your child's behavior or development...

a) What were the types of behaviors did you/someone else first noticed?

b) Did you go to see someone – who did you go to see?

[Trying to understand if they waited until school; saw a medical professional or alternative healer and how long they waited; Remember this is round robin style; we are hearing from everyone]

Probe [as necessary]: Did your child see a professional at school or a doctor/other health care professional?

Probe [as necessary]: How old was the child then? [How long between when noticed something and saw someone] [We want to get at when child is 1<sup>st</sup> identified/diagnosed]

Probe [as necessary]: Did you see someone else for your child [spiritual healer; alternative medicine etc.]?

3. People often wait to go to see someone after they notice differences in their child; what are some of the reasons parents wait?

[Trying to get at two things: whether it is information (i.e. don't know development milestones) or problems in connections (insurance, etc.) Would like to get at most important things we can do to improve early identification]

Probe: Is there anything else you think makes people wait?

Probe [as necessary]: Do people wait because of shame or embarrassment [Stigma] – because it is difficult to talk about with family or friends?,

Probe [as necessary]: Do people wait because they are confused or unsure of what steps to take next? They don't know what services are available?

Probe [as necessary]: How much is health care insurance a problem? Is it not having insurance or being not sure what it will cover?

Probe [as necessary]: Do people wait because they do not know the signs of autism? Do they think that it is just normal behavior?

Probe [ as necessary]: Do people wait because they don't trust the schools or doctors?

- a) What do you think is the MOST important thing that could be done to help families get to see someone or get them services sooner?

Probe [as necessary]: Provide information about available services

Probe [as necessary]: about signs of autism and importance of early intervention

Probe [as necessary]: Help navigating system that is complex

Probe [as necessary]: Culturally sensitive services/outreach/education

Probe [as necessary]: Better insurance

Probe [as necessary]: If insurance a problem, what other resources have helped

Probe [as necessary]: Transportation/childcare

[Transition to Services]

4. We would like to know about your experiences getting services for your child with autism. We will first go around the table and hear from everyone then we will talk more about the types of problems people have had getting services.

[Trying to understand what they have used in past and now, and what problems they have had] [Trying to understand if they are knowledgeable about range of services available]

- a. First, where do you mostly receive services and what types of services have you received/are receiving? [Remember this is round robin style, we are hearing from everyone]

[Details about what they rely upon and the types of services they have received  
[Examples: speech, occupational therapy, physical therapy, Applied Behavioral Analysis (ABA); school or doctor; Autism/Disability Center; Community etc. ]

5. Tell us more about a time when it was difficult or you had problems getting services that your child or family needed?

[Trying to understand the most important barriers and solutions – This is a Key Question – make sure you give them time to explain about the problem – make sure you cover the areas in the Probes]

Probe: Insurance Problems (is in lack of access or copayments or doesn't cover certain services?)

Probe: Language Barriers [staff don't speak language; don't understand forms]

Probe: Interpreters: [access, quality, trust of]

Probe: Problems with service providers; problems with doctors/schools

Probe: Lack of information about what services are appropriate

Probe: Lack of community-based resources [lack of resources specific to the community they are in; run by community members]

Probe: Problems with transportation

Probe: Services only being for a short time; not continuous

Probe: competing Demands: problems with childcare; time with other children

Probe: Waiting lists are too long

- a. What services would you most like to receive that you're not getting that you believe will help your child? (i.e. speech, occupational, applied behavioral analysis (ABA), Personal Care Attendant etc.)

Follow-up: What is getting in the way of him/her getting that service?

- b. What would most help your family get the services you need?

[Transition to specific recommendations]

6. If you could talk to someone making decisions/government/Department of Health [choose words most appropriate for your community], what would you most like to tell them that they should do to improve services/reduce barriers for your child and family?

[Try to get as specific as possible – we will use the answers to build actionable recommendations]

[End question]

7. Is there anything else you would like to tell us about yourself and about how autism has affected your family?