

## Somali-Canadian Mothers' Experiences in Parenting a Child with Autism Spectrum Disorder

*This paper reports on the experiences of ten Somali-Canadian mothers parenting children with Autism Spectrum Disorder (ASD). Using focus groups and open-ended questions, the study asked the mothers to narrate their experiences and beliefs regarding the stresses they face in parenting a child with ASD. Many of the stresses reported by the mothers included anxiety over lack of developmental gains in their children with ASD and the resulting issues over safety and future independence. Tensions with key professionals such as teachers and doctors was also noted as causing considerable stress and was perceived to result from limited language skills on the mothers' part, and lack of knowledge of Somali culture on the part of the professionals. The absence of an extended family in Canada was also noted as causing undue hardship for these mothers and was complicated by Canadian immigration policies that were perceived as rigid. The mothers' negative experiences with the general public often led them to isolate themselves and their child. While parenting a child with ASD has considerable challenges, being an immigrant mother and a member of a visible minority appears to intensify those challenges.*

Mothering a child, albeit an experience that comes with rewards, is for most mothers a consuming, protracted challenge. It is not surprising that the challenge is even greater when the child has a disability. These facts are well-documented in the literature (Duarte et al., 2005: 416; Tarakeshwar and Pargament, 2001: 247). Within this general finding, there appears to be unusual stress impact on mothers where the children have autism (Bromley et al., 2004: 409; Hastings et al., 2005: 377; Sivberg, 2002: 397). Brian Boyd (2002) notes that, "as a group, mothers of children with Autism appear to be the most adversely affected by the stress-factors that result from rearing a child with a disability" (208). Jo Bromley and colleagues (2004) note that parents of children with ASD have

greater risks of serious psychological distress than do parents of children with other exceptionalities (411). In addition, the disruptive behaviours associated with the disorder, such as tantrums and obsessive compulsive behaviours greatly increase both the emotional and physical demands on a family (Higgins, Bailey and Pearce, 2005: 127). This reality is clear for mothers within the general Canadian population, with an estimated 1 in 165 prevalence rate (Autism Society of Canada). What is not clear in the Canadian context is whether the impact is the same for mothers from the minority immigrant population, as it is for those from the dominant population

A review of the literatures suggests that much of the research on ASD and parenting has largely focused on the experiences of families from the dominant culture. Little or no work has been conducted on examining the impact on immigrant families parenting a child with ASD (McGrath, 2006: 29, Dyches et al., 2004: 220). As Canada's population becomes increasingly ethnically diverse, the need for research addressing children with exceptionalities and their families in a variety of communities also needs to increase. Being a new immigrant and a member of visible minority group can increase the number of stressors with which a family must cope. Issues of racism and discrimination, limited language skills, cultural differences, and difficulties finding well-paying employment add greatly to the demands already present (Ali, 2008:150). Moreover, as Wei Wei Da (2008) notes "Raising children in a new cultural setting presents greater challenges to immigrant parents in the absence of kinship ties and the familiar support networks" (ii).

This paper reports an investigation of the stress factors related to raising a child with ASD in Somali-Canadian families and asks the question: what are the maternal experiences of Somali-Canadian mothers parenting a child with ASD? And, given our findings, are these mothers at greater risk of developing serious psychological distress than mothers of children with ASD who are part of the dominant culture?

## **Methodology**

Focus group interviews of one to one-and-one-half hours in length were carried out with ten Somali-Canadian mothers of children diagnosed with varying degrees of severity ASD. Focus formats do not discriminate against people who cannot read or write and they encourage participation from those who feel they may have nothing of importance to share or are hesitant to be interviewed on their own. (Slaughter et al., 2007: 6)

Two parents of the Somali Parent Support Group, a group which provides a forum for Somali parents with children with special needs, volunteered to recruit participants. Open-ended questions that invited the mothers to discuss any stresses they were experiencing were developed. All sessions were recorded, transcribed, and coded using the constant comparative method (Slaughter et al., 2007: 6). The study was approved by the Ryerson University Research Ethics Board.

Of the ten participants, seven were stay-at-home mothers, two were employed, (one full-time and the other part-time) and the third mother was a part-time student. Their children's ages ranged from six to twelve years of age. Eighty percent of the children were male and 20 percent were female. Nine of the children were born in Canada and one was born in the Middle East. All the children had siblings.

## **Findings**

There were several key maternal experiences reported by the mothers in this study that were perceived to negatively affect their ability to parent their child with ASD, and significantly contributed to high stress levels. Many of the experiences are specifically related to the characteristics inherent in the disorder known as ASD, such as significant delays in language development and communication skills. Delays in adaptive skill development often mean that a parent spends a great deal of daily time dressing, feeding, and caring for the child with special needs. In addition, approximately 75 percent of children with Autism also have substantial cognitive delays with IQ scores below 70 (Wodrich, 2005: 303). Delays in cognitive development can limit speech and language and further compound the child's need for assistance from the family. Furthermore, public and professional awareness and understanding of ASD are limited and incomplete, and further compound the difficulties that many families of children with ASD face.

It can be said, that certainly the mothers in this study were affected by these factors related to the characteristics of the exceptionality itself. However, it is also apparent in this study that there are other stressors at work for mothers of children with ASD who are newcomers and members of a visible minority living in Canada. The isolation, sense of desperation, economic hardship, and lack of support appear to be intensified for this group. The impact of these factors as they play out in the context of the lives of mothers who are part of the Somali community in Toronto will now be discussed.

*Lack of developmental gains*, especially in the areas of communicative functioning, was noted by all the mothers as the single largest cause for concern and stress for several reasons. First, their child's inability to interact or communicate, and the lack of progress in this area, limited interaction with family members and called into question the child's ability to become an independent adult who would be able to contribute meaningfully to the family unit, and especially towards supporting the parents later in life. As one mother commented:

*Anab: ... The most difficult one is their future, children supposed to take care of their parents; it is not that the parents have to take care of them for the rest of their life.*

The Somali culture emphasizes that all family members contribute to the family unit and the family is a major resource in establishing financial

and emotional stability. Somali culture expects children to be responsible for securing a stable financial future for their parents. Parents expect to be able to rely on their children when they themselves are no longer able to earn a living for themselves, and this cultural expectation created considerable stress for these mothers.

More worrisome for the mothers, however, was the realization that *the children might not be able to look after themselves* should the child outlive the parents. The stress resulting from this realization was compounded by the lack of informal support structures that would have been in place in Somalia where the family would have been able to rely on extended family in times of duress and crisis and this is reflected in the following comment:

*Shukri: I also worry, God forbid, if something happen to me or my husband, I really don't know where my children will end up and this worries me a lot. If we were in Somalia, we would have had parents and relatives who would take care of them, so I wouldn't worry as much as I worry now.*

The lack of an extended family presence in Canada and the sense of being alone to cope with the potential crisis that may befall a family were particularly significant concerns for this group of mothers and is a theme that runs through out the findings. Many felt that they had brought the situation unto themselves by choosing to emigrate and this only intensified feelings of guilt and anxiety.

But an even stronger issue for these mothers concerned *the child's safety*. Most expressed the realization that communication difficulties and cognitive delays made the safety of their child a much greater issue. Many of their children with ASD had difficulty following directions and/or understanding the inherent dangers in many situations creating a need for constant vigilance and monitoring of the child's activities. These mothers emphasized that their main, short-term concerns about their children was their safety. Two of the mothers, Shukri and Warda, indicated that their children were able to leave the house during the night no matter what precautions were taken. Shukri commented:

*Shukri: ... There is no night that my husband and I spend the night in our own bedroom together ... one of us has to sleep in the living room to keep eye on him [middle son with autism]. In order to do that ... you have to be half asleep; no one understands what we go through.*

This situation clearly increased the stress on the family as a whole and on the marital relationship in particular. Somali families have large extended families that help with child rearing and support each other emotionally. Access to extended family in their home country may have allowed them to share this burden.

The constant need to keep the child with ASD safe also puts stress on the siblings as was noted by the following mother:

*My younger daughter, said ... "you and abo [dad] give all the attention to Aden. When you come from work you say [where is Aden?]. When abo wakes up [he says], "Aden." Everything is Aden." I told her, "but he is sick." You know what she said ... "He is not sick, he is only silent, he eats, drinks, and runs like everybody else." I told her many times that he is sick; she will say "you love him more than me"... I feel we are favouring one from the others and is overwhelming to see my children think we are neglecting them.*

Again, the presence of extended family members in Somalia may have allowed the mothers more time with each child in their home country. However, immigration and immigration policies have resulted in a disruption of this situation and many of the mothers in this study were not able to avail themselves of this kind of informal support. As one mother noted:

*Shukri: There is no time that I could spend with my other children. If I could find a person who could stay with other children I could take him to the park, or if the person stays with him, I could have time with my other children. It would have been something for me. But we are stuck to each other. In Somalia this wouldn't have happened, there is always a relative, neighbour or friend willing to help out.*

For many of the mothers, *inflexible immigration policies* were to blame for the lack of family supports available to them. The participants indicated that they would like to bring a family member to Canada to help them, especially a female relative, as Somalis are accustomed to receiving help from female relatives but they stated that immigration will not allow them to do so unless the person is a minor (under 18 years of age) and an immediate family member. They stated that there are cousins who do not meet this criteria set by immigration but are more experienced, which could help the family better in the long run. Somalis treat their nephews and nieces as their own children, while immigration policies only view them as distant relations. The extended family serves as a social safety net in the Somali tradition, and its absence was keenly felt by the mothers in this study.

These mothers were also aware of the dangers to their own sense of self and health as a result of the constant stress of looking after their child with ASD. The following mother commented:

*Zamzam: It is not only the children. Sometimes I need some rest, or spend sometime with other people [adults]. Staying inside 24 hours per day really will change you. You will forget yourself and you will forget what life is all about.*

The Canadian Community Health Survey indicates that, compared to Canadian-born women, immigrant women who had been in Canada for less than two years were less likely to report poor health, while those who had been in Canada for at least ten years were more likely to report poor health (Vis-sandjee et al., 2003). The contributing factors to this deterioration of health status include social isolation, changes in family roles and norms, language barriers, lack of information about resources, and unemployment (Fowler, 1998). Given what we know regarding the stressors involved in raising a child with ASD and the poor health of immigrant women, it appears the health of these mothers is certainly an issue.

*Several key professionals and institutions were named by the mothers in this study as causing considerable stress and anxiety.* First among these institutions are the schools. Many of the mothers who had school-age children reported feeling extremely stigmatized by the attitudes of the school system towards them and their child with ASD. Efforts to enroll their child at their neighborhood school, attended by their other children, were met with resistance. Some of the mothers felt that rejection of their child with Autism meant rejection of the family as a whole and this is reflected in the following comment by one mother:

*Amran: ...after I shared with them that my son was Autistic, the vice principal with no consideration or attempt to welcome my child, told me that my son did not belong in their school. He said to me that there are special schools for children like him. My son then was transferred in a school in different neighborhood. And before the end of the school year, I took out my other children from that school and moved out the area because I felt they didn't want my son or my family as they said my son didn't belong in that school.*

This echoes findings from Sara Green's (2003) study where parents discussed the impact of stigmatization on their lives and the lives of their children: the perception of stigma proved to be a barrier to full participation in social activities, relationships, and so forth. As Patricia McKeever and Karen-Lee Miller (2004) argue, "Mothers share in the stigma and marginalization of atypically developing offspring" (1182). The relationship between the mothers and their child's teacher was also fraught with tension. In Somali culture, educators are highly respected professionals. For this reason, many of the mothers reported feeling quite hurt by the constant negative assessments of their child by teachers, but felt helpless to approach a teacher. The following is one mother's perception:

*Runn: For me what depresses me is, the teachers always tell[ing] me bad things that my child did. I respect them, they are the teacher of my child, how can I say to them tell me what he learned. I am afraid they may take in wrong way, so I don't do anything. And everyday I am worried what*

*else they say to me, it is not good feeling but there is not much I can do. Sometimes I want to go somewhere else but that's what the teachers want and I am not going to do it.*

The comment above appears to support the findings in the literature that while minority parents can contribute an understanding of their child's behaviour to the classroom teacher, the rate of parental participation for minority parents is much lower than that for Caucasian parents. Limited English language skills, lack of familiarity with the school system, respect for teachers as the experts, and discomfort in dealing with teachers are cited as some of the contributing factors (Lai and Ishyama, 2004: 105).

*Doctors and the medical establishment were also characterized as lacking in the knowledge and empathy required to adequately address their child's needs, a finding that has been reported elsewhere in the literature on families with children with exceptionalities (Berman and Wilson, 2009). In Somali culture doctors are the most trusted professionals in the field of medicine. Yet the mothers in this study felt that they were unable to trust doctors because of the lack of knowledge that doctors appeared to have about ASD, as well as their lack of ability to connect with a mother from a non-western culture. Amran commented:*

*I swear, there is no doctor that I trust. They treat you like you are a child because you come from different part of the world and don't speak English they way English speakers do, they think that we are not worthy to be informed what they are giving to our children....*

Another mother feels that she is not treated the same way as the persons from the dominant culture:

*Faisa: At age three, I knew something was wrong with my son, like he wasn't developing like my other children. But his pediatrician continued saying he will be alright, some children develop differently or give him time.... Now I really blame myself listening him. My son was diagnosed when he was 6 years old; imagine what a waste of precious time. I get knots in my stomach when I hear doctors.... I am sure if I was normal [typical] Canadian he would have done something the first time I told him about my suspicion.*

On the whole, these mothers' experiences with formal service providers can be summed up by the following comment by one mother:

*Jamila: ... The most challenging are the schools and agencies (that offer programs) they tend to destroy all the hope you have. They drain you emotionally. The schools suppose to be where the children get the help they need*



*and it is the challenging part not for the child but for the whole family... Truthfully, we are still fighting. When they refuse to help your child they also reject you. Teachers and doctors supposed to be the most trusted people but here is the opposite.*

The unusual behaviours and sensitivities often displayed by children with ASD combined with the fact that the mothers were from a culturally diverse background resulted in the mothers' perceptions that they were being *unfairly judged by strangers*. For example, one of the school age children in the study had severe sensory issues that made him highly sensitive to foods and he would eat very little. As a result, the mother often fed him in an effort to get him to eat anything at all. This mother felt that her parenting skills were being judged as inadequate. Others often felt that their parenting was constantly being monitored for child abuse. One mother described undergoing an investigation of child abuse because her son had a rash on his back. Other mothers described instances of being in public and having their child with ASD act out only to be given icy stares by members of the public. All of the mothers felt that they were being unfairly judged because they were a visible minority and because those from the dominant culture had little understanding and appreciation of autism in general and of Somali culture in particular. Because of these reactions, many of the mothers described a desire to isolate themselves and their child with ASD from public scrutiny. As one mother noted:

*Shukri: When we are outside and my child screams and other people stare at us is the biggest thing that worries me. The worst thing is when we are in the mall and my child starts picking up things such as potatoes chips. People just look at you and they don't understand. The only thing they see is an older child that looks healthy that has behavior problems... people don't have knowledge about autism.... Going outside is what worries me the most and because of it I don't go out.*

The mothers indicated that they are very proud of their parenting skills, but are frustrated when strangers confront them or start sharing unsolicited behavioural strategies and conclude their statements with comments such as, "this is how we do in here in Canada." While many mothers with children with exceptionalities report experiencing the same kind of scrutiny and open disapproval of their mothering, the painful public experiences of these Somali mothers are compounded with racism. Not surprisingly, many of the mothers in the focus group preferred to stay indoors and *out of the public eye* as much as possible. Nasro commented:

*That is one of the reasons why some of the parents don't leave the house with their children (with autism). When all the people are staring at you like you are a bad mother you are not going to enjoy to go out with your child.*



Thus the mothers felt that this constant public humiliation forced them to isolate themselves from the outside world and the children ended up missing precious, educationally enriching outdoor activities. Social exclusion has been cited by John Bynner (2001: 289) as one of the most significant factors contributing to parental stress for families of children with exceptionalities.

The mothers in this study also believed that insufficient and inadequate services contributed to their children's lack of skill development. Many shared feelings of hopelessness when the services that they fought so hard for are not what they hoped for. The lack of knowledge on behalf of professionals did little to give the mothers in this group any comfort in their services. These mothers sought treatments and answers but felt that there was little hope of either. Jamila commented:

*...Many things bring us stress, for example, teachers, doctors and other professionals don't know much about Autism. It is hard when there is no one that you can trust with your child, one person will tell you something and another one will tell you something else.... There is also a long waiting list, everything you will be placed in a waiting list. So even though you know your child needs help there is nothing you can do to help. That is really heart breaking. I want to do everything for him but there is nothing I can do. It is frustrating and I feel useless. A parent should not feel this way at all.*

In addition, many of the parents found that their *limited understanding of the English language* often meant they could not converse as well as they would have liked with the professionals treating their children. In particular, they felt that because of limited language skills, they were unable to develop the kind of rapport or relationship with professionals and this left them feeling unsatisfied with the service and their own ability to help their child at home.

## **Discussion**

We began this paper by noting that the experience of mothering is a challenge, but that this challenge is even greater when the child has a disability, particularly for mothers of children with ASD. Are those experiences compounded for mothers who are immigrants and of a visible minority?

On the surface, it can be stated that the Somali-Canadian mothers in this study share the same experiences and concerns as mothers from dominant, mainstream cultures who also parent children with ASD, but with some significant differences. In order to highlight these differences Shannon La Shell's 1998 study of interviews with six women parenting children with ASD will be used as a comparison. Safety and the stress of looking after children who run away are noted here and in La Shell's study. Both sets of mothers are frustrated by the lack of developmental gains and poor communication skills of their children. Both sets worry about their children's future and their ability to

be independent adults. However, in this last regard, the Somali mothers seem to be more distressed and apprehensive than the mothers who came from the dominant group in La Shell's study. Because of the lack of extended family in Canada, the mothers in this study feel they have few resources with which to cope in times of crisis involving their child or them. This void in having family that can assist both emotionally and physically is an extremely serious factor for these mothers and this is missing from studies with parents from dominant cultures. In addition, while many of the mothers in La Shell's study expressed feelings of self-doubt and self-criticism, for the Somali mothers this self-doubt included feelings of guilt over making the decision to immigrate and leave extended family behind.

Interactions and relationships with medical personnel and peripheral professionals are also noted by the mothers in La Shell's study and those in this study as equally problematic. All six mothers in the La Shell study reported difficulty with doctors and professionals; many reported that the doctors they dealt with were insensitive, unknowledgeable about Autism, often condescending, patronizing and abrupt in manner; peripheral professionals rarely offered solutions—only diagnosis. These experiences appear to be identical to the mothers' experiences in this study. Both groups found it difficult to access knowledge about their child's disability and have constructive interactions with doctors regardless of level of language skills. But while the mothers in La Shell's study blamed the system, the Somali-Canadian mothers in this study felt their treatment was a result of their minority status and weaker English language skills. Whether or not their perceptions are accurate is beside the point; the personalizing of these interactions in terms of cultural differences appears to heighten the vulnerability and helplessness these mothers feel thereby compounding their stress and leading to decreased willingness to engage with the system on any level.

While Shannon La Shell's study did not discuss mother's experiences with the education system, the literature on the education system's unwillingness to accept children with disabilities in general has been well documented (Winzer, 2007: 21) and echoes the experiences of the Somali-Canadian mothers' relationship with teachers in this study. Again, rather than thinking of the education system failing their children because of its inherent structures and prejudices, the mothers in this study personalized those difficulties and felt they were directly related to the fact that they were immigrants with weaker English language skills and culturally different. Thus they expressed feelings of deep helplessness in the face of those difficulties.

Lucie Lawrence's (2008) discussion of the pressures brought to bear on parents of children with disabilities who dare to go out in public with their children echoes the stress felt by all the mothers in this study. Lawrence notes that, "public space presumes normalcy" (531) and talks of "the constant struggle of navigating public spaces" (536). This "navigation" of the public domain is a factor in the lives of all mothers who have children with disabilities and it

is particularly problematic for children who appear to be “normal” but behave in unconventional ways and do not respond to prompts as typically developing children do. Many mothers in this situation feel that their competency as mothers is judged and often condemned. The Somali-Canadian mothers in this study felt particularly chastised when out in public with their children with ASD and while their experience does not differ from that of mothers from the dominant culture, there appears to be a tone of racism that accompanies responses to them which is absent for mothers from the dominant culture. Not only are they judged as mothers, but comments made by some of the participants in this study indicate that Somali mothers were being doubly judged on their cultural background. Isolation of mothers parenting children with ASD is a significant risk factor for all mothers parenting children with ASD, regardless of cultural or socio-economic status. However, given the lack of extended family ties available to the Somali mothers, the threat of isolation is far more intense and prevalent for them.

In her study of depression among East Africans in Western Australia, Farida Tilbury (2007) notes the words of Jayasuriya, Sang, and Fielding that “migration itself does not necessarily threaten mental health. The mental health status of immigrants and refugees becomes a concern when additional risk factors ... combine with the stresses of migration” (qtd. in Tilbury, 2007: 437). For Tilbury (2007) some of these factors include the loss of the family and cultural support, low socioeconomic status, culture shock, language problems, prejudice and discrimination. These factors are all operating in the lives of the mothers in this study, in combination with the additional factors inherent in parenting a child with ASD. The sense of desperation and frustration expressed by all of the Somali-Canadian mothers in this study is absent from the general literature on mothering and disability. Given this, Somali-Canadian mothers in this study appear to be at greater risk in trying to cope with their child’s disability and their ability to adjust to parenting a child with ASD appears to be much more precariously situated than the experiences of mothers from the dominant group.

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