Research Article

Unsettling the Resettled: An Intersectional Analysis of Autism in the Somali Diaspora

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Abstract: This multiple case study uses intersectionality and neurodiversity as frameworks to understand the experiences of Somali American families and the educators working with their children. Three primary themes emerged—parenting: intersections among race, disability, and gender; cultural assumptions and family/educator communication; and diversity and agency among mothers. Practical implications for educating students with autism from non-dominant racial/ethnic, linguistic, religious, and cultural backgrounds are discussed.

Keywords: autism, Somali American, intersectionality, neurodiversity, culturally and linguistically diverse (CLD) students, IEP process

I had just started to recruit participants for a research study examining educational decision-making for Somali American students with autism. Recruitment efforts had led me to leaders in the Somali community in a large metro area in the Northeastern U.S. When I met Naïm, the head of a local educational nonprofit at his office, he launched into a story about his own daughter, Halima, by then a junior in college.

Naïm recalled one day nearly a decade earlier. Halima was a third grader at the time, and he was summoned to meet with the principal of her school. The administrators were worried about Halima’s defiant behavior due to the violence they assumed she had witnessed during the Somali Civil War. Naïm was quick to point out that Halima was American born: She had not lived through the civil war. As I listened to Naïm’s story, his memory of that day still vivid a decade later, I realized that he was giving me important advice for my own project—urging me to think critically about how race, ethnicity, religion, and country of origin intersect with behavior in shaping the experiences of students in American schools. My conversation with Naïm did not lead me to any study participants, but it did help me to reframe my research questions.

Introduction

A critical mass of Somalis—most of them refugees—began to settle in the U.S. starting in 1991 when military dictator Siad Barre was overthrown in a coup setting alight a civil war that continues today (Pavlish, Noor, & Brandt, 2010; Scuglik, Alarcon, Lapeyre III, William, & Logan 2007). Less than two decades after Barre’s overthrow, the population of Somali Americans exceeded 100,000 (Whyte, 2011), constituting the third largest group of
sub-Saharan Africans in the U.S.—after Nigerians and Ethiopians (Campacho, Dirshe, Hiray, & Farah, 2014). The median income for Somali Americans is among the lowest in the country: more than half (51%) live below the federal poverty level (Whyte, 2011) and 90% live in subsidized housing (Campacho, Dirshe, Hiray, & Farah, 2014).

**Autism in the Somali Diaspora**

Adding to these challenges, many children in the Somali diaspora have been diagnosed with autism spectrum disorders (ASDs) (Miller-Gairy & Mofya, 2015). In fact, research suggests that children of Somali origin born in Europe and North America are disproportionately likely to receive an autism diagnoses² (Bhagia & Kung, 2014; Fernell, Mohammed, Martin, Bagenholm, & Gillberg, 2015); to have co-occurring diagnoses of intellectual disability (ID) (Hewitt et al, 2013); and to receive late diagnoses and inadequate educational services (Miller-Gairy & Mofya, 2015).

Data are inconclusive but several theories have been put forth to explain this phenomenon, including: vitamin D deficiencies caused by the relocation from an equatorial region to northern climates with scarce sunlight; consanguineous marriages, and duplicate vaccinations due to time in refugee camps and transnational migration³ (Fernell et al., 2015; Delberto, 2011). Another possible explanation: because the diagnostic criteria for autism were developed in Western countries, their application to non-Western cultural groups like Somali refugees has resulted in an “artificial[ly]” high rate of diagnosis (Freeth, Shepherd, Ramachandran, & Milne, 2013).

While little information exists regarding the prevalence and incidence of autism in sub-Saharan African (Abubakar, Sseywanyana, & Newton, 2016), it is rarely diagnosed within Somalia. In fact, no word for autism exists in the Somali language, and Somali Americans have taken to calling the condition “The American Disease” (McNeil, 2013).

Somali parents and American-born doctors and educators often have different explanatory models about what causes illness and disability, and what types of education and treatment are appropriate (Groen, 2009). While disabilities are often assumed to have a biological basis in the U.S., many Somalis view health and disability in holistic terms (Pavlish, Noor, & Brandt, 2010) and in the context of religion—believing for example, that illness and disability are caused by waddado (spirit possession) (Scuglik, et al., 2007); the evil eye, or jins (spirits) (Bettmann, Penney, Clarkson Freeman, Freeman, & Lecy, 2015; Miller-Gairy & Mofya, 2015). Negotiating between two cultures with divergent notions about child development and disability can result in “cognitive dissonance” among immigrant parents of children with autism (Munroe, Hammond, & Cole, 2016).

**Autism and the Family System**
Having a child with a significant disability like autism has important implications for family systems. In the U.S., research has revealed that parents of children with autism experience higher levels of stress than children with other diagnoses (Bouma & Schweitzer, 1990; Dumas, Wolf, Fisman, & Culligan, 1991; Hall & Graff, 2011; Kasari & Sigman, 1997; Weitlauf, Vehorn, Taylor, & Warren, 2014; Wolf, Noh, Fisman, & Speechley, 1989). Researchers have also found that mothers of children with autism experience higher levels of depression than fathers (Hall & Graff, 2011; Rodrigue, Morgan, & Geffken, 1990, 1992). Little scholarship has addressed the unique experiences of Somali American families of students with autism, but we do know that this group is likely to encounter certain stressors. For one thing, many Somali parents have been separated from their extended families through the migration and resettlement process, leaving them with diminished support networks. In addition, Somali American parents tend to have gender-based differential roles in which children are viewed as living representations of the mothers’ “success” (or failure) (Miller-Gairy & Mofya, 2015).

Implications for Family/Educator Collaboration

Within the Somali American context, research suggests that besides differing explanatory models of disability, logistical impediments to authentic family-educator collaboration exist. These challenges include language barriers and divergent cultural/religious norms—for example, Islam’s precluding of extensive interactions between people of different genders as set against the American special education system’s basis in parent-educator interaction irrespective of gender. In addition, Somali American families have reported that an array of repeated negative experiences has left them feeling “alienat[ed]” from and “mistrust[ful]” of the U.S. school system (Miller-Gairy & Mofya, 2015). With growing numbers of Somali American students with autism, greater understanding of how Somali families and American-born educators collaborate to make educational decisions for these students is needed. The present study examines intersections among race, ethnicity, language, ableness, religion, and socio-economic status (SES) in the service of identifying barriers to effective collaboration and suggesting approaches that may lead to authentic and open communication. The intersectionality and neurodiversity frameworks are used to structure this investigation.

Theoretical Frameworks: Neurodiversity and Intersectionality

Our understanding of autism and of this data have been shaped by the notion of neurodiversity. The Neurodiversity movement emerged in the U.S. in the 1990s—around the same time as the Somali civil war. Neurodiversity proponents, many of them individuals with high-functioning autism, believe that autism “is not a disease to be treated, and if possible cured, but rather a human specificity (like sex or race) that must be equally respected” (Ortega, 2009, p. 426). This framework highlights the fact that autism is not only a static diagnostic category, but a construct that is subject to interpretation and dispute. Because of the various positions and identities of the participants in this research (i.e., individuals with
autism, family members, and educators) and because autism affects the three students in this study in very different ways, the concept of neurodiversity is more relevant in certain parts of our analysis than in others.

Another theoretical framework guiding this study is intersectionality theory, which grew out of feminist sociological theory. It operates on the assumption that biological, social, and cultural categories (e.g., race, gender, ableness) are “multiple and interlocking” (Bowleg, 2012, p. 1267) and allows us to understand “the outcomes of these interactions in terms of power” (Davis, 2008, p. 68). This orientation is especially relevant in the domain of special education where, the concept of “diversity” has consistently been framed in terms of “diverse abilities rather than the gamut of social identities” (Garcia & Ortiz, 2013, p. 32) and “has frequently failed to account for non-paradigmatic (e.g., non-male, non-White, non-heterosexual, non-cis-gendered, and non-middle or upper-class) people with disabilities (Goldberg, 2015, p. 61).

The neurodiversity framework complements intersectionality by illustrating the ways in which ableness as an identity category is not simply a fixed biological category but rather “a group of symptoms that have become especially meaningful in particular places and times” (Grinker, 2007). We use these two theoretical frames together to uncover the ways in which different social identities are related in the lives of Somali American students and their families, and outcomes of those interactions.

The leading research questions were: 1) In what ways do culture, language, race, ethnicity, gender, social class, and ableness interact with one another and shape the educational decision-making process among Somali American mothers and American-born educators of students with autism? 2) How do the notions of neurodiversity and intersectionality contribute to an understanding of the experiences of Somali American boys with autism?

Method

The data presented in this paper constitute a subset of data from a larger study investigating the nature of educational planning for Somali American students with autism. The first author obtained approval from the institutional review board (IRB) prior to the start of the study. A multiple case study method was selected for this research because: a) the case study approach is useful in illustrating intersectionality as an epistemological orientation and is well-matched with experiential knowledge (McCall, 2005; Stake, 1978); b) the design allows us to derive meaning about complex social phenomena while “retain[ing] the holistic and meaningful characteristics of real-life events” (Yin, 2009, p. 4); c) it facilitates “multi-perspectival” analyses which portray the voices of actors or groups of actors as well as the interactions among these actors.

Setting
This study takes place in a metropolitan area in the Northeastern U.S. The three families in the study live in different parts of the same metro area—including an upper-middle class suburb and two urban working class communities comprised primarily of Black Americans and immigrants and refugees. All three families had ties to the Cedar Grove neighborhood, a hub for Somali businesses and cultural institutions. Dris’ family lives in the outskirts of Cedar Grove and although Bilal and Aadan’s families live outside the neighborhood, they come in to pray at the mosque, shop at the halal markets, and meet with social service providers.

**A Portrait of Cedar Grove.**

One of the original “streetcar suburbs,” this neighborhood has been settled in waves: from 19th century Irish and German settlers to Jewish immigrants in the early 20th century followed by African Americans starting in the 1940s. At the time of this study, Somali Americans were well represented in the local community. The 68,000-square-foot Masjid (mosque) Al Hakim, which accommodates up to 3,000 worshippers is a focal point. Building the mosque was a major feat, reflecting both steadfastness and a successful campaign against resistant and often intolerant voices in the local area. When planning began in 1989, civil war had not yet begun in Somalia. But when the project was completed two decades and $15.8 million later, the path from the Horn of Africa to New England was well trodden, and the mosque had become central to the city’s Somali community.

Across the street from the mosque, within a subway station, a more modest establishment also illustrates the area’s Somali influence. The Somali-owned River Bend Café attracts urban professionals commuting to jobs downtown who stop for an egg sandwich or a cup of fair trade coffee, alongside older Somali men with hennaed beards and skullcaps who are in no particular hurry and drink Somali chai and eat **helwa**. One of the café’s walls is lined with traditional Somali banquettes; another hosts a service that allows patrons to wire money back to Somalia.

**Participants**

Participant selection was *purposeful or criterion-based* (Creswell, 2006; Maxwell, 2004; Patton, 1990). At the outset, three criteria for inclusion were established: (a) diagnosis (autism spectrum disorder), (b) ethnicity (Somali American), and (c) gender (male). Participants were recruited through contacts at agencies within the local Somali American community. The first author contacted Somali professionals within these agencies, and they approached families of boys with autism in their networks. Four families were invited and three elected to participate in the study.

Once the three boys had been identified, we set up meetings with their families and asked the families to identify and put us in touch with “the child’s primary educator.” We selected mothers (as opposed to fathers) as the family participants in this study for two reasons: (a) two of the families who agreed to participate in the study happened to be headed
by single mothers (one widowed; the other divorced) and (b) because child-rearing is seen as being primarily the mother’s domain in Somali families, mothers were more likely than fathers to be actively engaged in their children’s education on a day-to-day basis.

The three discrete student/mother/educator case units that resulted from this selection process are: (1) Idris, a high school aged student, his mother Saida and his teacher John; (2) Bilal who was about to enter kindergarten, his mother Amina and his teacher Katherine and (3) almost three-year-old Aadan, his mother, Nadifa, and his early intervention (EI) therapist Kim. (See Table 1 for detailed demographic information). Within the bounded demographic category (i.e., Somali American boys with autism) the cases represented a range of ages (i.e., 2.11 to 17.11) and ability levels (e.g., from minimally- to highly-verbal; and from co-occurring intellectual disability to above-average academic skills). On the family level, all three of the boys were born in the Somali diaspora (U.S., Sweden, & Canada) to Somali-born mothers. But the mothers’ backgrounds and experiences were different from one another. This boundaried variability across participants allowed researchers to both examine similarities and capture diversity across participants (Creswell, 2006; Maxwell, 2004; Patton, 1990; Stake, 2006).

**Table 1**

**Participant Demographics**

<table>
<thead>
<tr>
<th>Child Name</th>
<th>Gender</th>
<th>Age</th>
<th>Country of Birth</th>
<th>Mother Name</th>
<th>Profession</th>
<th>Mother Language</th>
<th>Father Language</th>
<th>Member</th>
<th>Religion</th>
<th>Teacher Name</th>
<th>Gender</th>
<th>Race/Language</th>
<th>Education Level</th>
<th>Years of Teaching Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Idris</td>
<td>M</td>
<td>17.11</td>
<td>Sweden</td>
<td>Saida</td>
<td>Medical Case Manager</td>
<td>Somali, English, Swedish</td>
<td>Somali, English, Swedish</td>
<td>Grad</td>
<td>Muslim</td>
<td>John</td>
<td>M</td>
<td>White/English</td>
<td>M.Ed.</td>
<td>8</td>
</tr>
<tr>
<td>Bilal</td>
<td>M</td>
<td>5.6</td>
<td>Canada</td>
<td>Amina</td>
<td>Scientific Writer</td>
<td>Somali, English, Somali, Arabic</td>
<td>Somali, English, Somali, Arabic</td>
<td>Grad</td>
<td>Muslim</td>
<td>Katherine</td>
<td>F</td>
<td>White/English</td>
<td>M.Ed.</td>
<td>11</td>
</tr>
<tr>
<td>Aadan</td>
<td>M</td>
<td>2.11</td>
<td>USA</td>
<td>Nadifa</td>
<td>Stay-at-home-mother</td>
<td>Somali, English</td>
<td>Somali, English</td>
<td>No formal</td>
<td>Muslim</td>
<td>Kim</td>
<td>F</td>
<td>White/English</td>
<td>BA</td>
<td>6</td>
</tr>
</tbody>
</table>

*Note. DX=Age at diagnosis, EL=Educational Level, CB=Country of Birth, PF=Profession, LH=Languages spoken at home (listed in the order in which they are most often spoken), G=Gender, M=Male, F=Female, R/L=Race and Language, YT=Years of teaching experience*

**Idris’s family**

Idris lives just outside of Cedar Grove with his mother, Saida, who had studied medicine first in Somalia and later in Sweden (where the family was living when Dris was born). Dris also lives with his older brother and cousin – both college students (Dris’s father, Mohammed, had died before this study began). Saida did not notice any red flags in Dris’ early development. It was his Swedish daycare providers who noticed his developmental trajectory was atypical. When he was diagnosed with autism, Saida and Mohammed decided that in order to access the best autism treatments they would move to the U.S. where they already had a sizeable extended family network. When they first arrived in the U.S., Dris started at his neighborhood school but Saida was not
satisfied with the progress he was making in that placement so he moved to one out-of-district placement and then another. By the time of this study he was a student at the Hope school, a substantially separate school for students with ASDs.

John was Dris’ classroom teacher at Hope. John himself had had an older brother with autism who had been a longtime student at Hope. John’s brother had died as a young man a couple of years before this study took place. But having been a brother of a Hope student gave John a unique family member/educator perspective.

**Bilal’s Family**

Bilal lives in an affluent predominantly White suburban community with his mother, Amina, a chemist, who had separated from Bilal’s father when he was only a baby. Amina grew up in a wealthy Mogadishu family and as a child had traveled extensively in the Middle East. Her family came to Canada as refugees when Amina was a pre-teen.

Bilal lived with his maternal grandparents in Canada for a year while his parents were separating. Amina felt that her mother, starting to notice Bilal’s developmental differences catered to him too much and tried to shield him from uncomfortable events. Amina’s approach was different from her mother’s. She believed in pushing Bilal and exposing him to as many types of experiences as possible – concerts, a weekend trip to New York City, etc. Amina was very happy with the public preschool Bilal attended. He was making huge gains socially and academically and spent most of his day in an inclusive classroom where he received support from a paraprofessional and pullout special education services.

Katherine, Bilal’s special education teacher emphasized the ways in which being a parent (she had a toddler and a preschooler at the time of the study) had changed her perspective on working with her students’ parents. “I’m more hesitant,” she said. “They know their child best.” She was effusive in praising Amina’s efforts and accomplishments in raising Bilal.

**Aadan’s Family**

Aadan lives with his mother, Nadifa, his father, Abdi, and six older siblings—two of whom are also on the autism spectrum in a small formerly industrial city that is now home to a large diverse immigrant and refugee population. The family had come to the U.S. as refugees after a long period at a refugee camp in Africa. Unlike his older brothers, Aadan received an autism diagnosis early enough (at 2.9 years) that he was able to receive formal EI services and his expressive and receptive language skills were starting to improve. For example, he could use the signs “more” and “all done” to communicate about what he wanted to play with during EI sessions.

Kim, Aadan’s EI provider had initially thought that she would like to be a classroom teacher but realized that she was drawn to working one-on-one with children and their families. As an EI therapist, she worked with students with a range of needs and disabilities
but felt particular affection for students with autism. Most of her clients were immigrants and nonnative English speakers because of the geographic area she served. She really liked working this community but as a monolingual White woman she sometimes felt it was hard to communicate openly and she grappled with the expectations of family involvement in the EI model. For a mother like Nadifa, who has seven children, Kim doubted that the ideal of parent participation was “feasible.” She questioned the idea that she should be telling “the mom to sit on the floor and play with her son” in light of so many competing household demands.

**Data Collection**

The data-gathering process consisted of interviews, observations, documents, and field notes (Denzin & Lincoln, 2011; Stake, 2006; Yin, 2009). Data collection occurred over a ten-month-period.

**Interviews**

Three interviews were conducted with each mother and educator: one before the annual IEP review; one during the week following the educational meeting (either IEP or EI meeting); and one between the first and second months after the educational meeting. Mothers selected convenient, comfortable locations for their interviews: their homes, workplaces, and area restaurants. Interviews with two of the educators (John and Katherine) were conducted in their school offices. Kim’s busy schedule of providing home-based early intervention made it difficult to identify a time and location for in-person interviews. She requested that we do phone interviews instead so that she could fit them in between home visits and we agreed. Although phone-based interviews are not ideal in the sense that interviewers are not privy to the non-verbal information that can be seen in person, in this case, because the first author had observed Kim doing EI sessions with Aadan, we already had an idea of how Kim interacted professionally. Interviewing each participant at multiple time points allowed the researcher to gauge subtle shifts in participants’ perspectives over time. A bilingual (English-Somali) interpreter attended all interviews and observations with Aadan and his family.

Interviews followed semi-structured protocols and questions were designed to be specific enough to guide participants to speak about particular topics while being general enough to allow participants to introduce their own ideas (Stake, 2006). Questions (e.g., “Can you tell me a little bit about when [child’s name] was diagnosed with autism?”) were followed by a series of prompts to elicit additional responses (e.g., “Who made the diagnosis?”; “What information did s/he use to make the diagnosis?”; “Did you agree/disagree with the diagnosis?”). Interviews were recorded with handheld digital voice recorders.

**Observations**

Before the interviews, the first author observed each case student at home and in school. Observations lasted approximately 30 minutes, were informal (i.e., not guided by a formal observation protocol) and took place during a typical academic activity (as identified
by the teacher). Non-educational observations were designed to allow the researcher to observe students interacting with family members as well as general language practices and family dynamics within the households. The first author also observed the decision-making process at educational team meetings for each of the boys. During these meetings, the researcher sat among participants but did not contribute to the conversation and took copious field notes both of verbatim dialogue between parents and educators and of impressions of the meetings and the negotiations. All fieldnotes were transcribed into a computer file immediately following the interaction. This immediate transcription allowed the researcher to remain mindful of initial impressions (Bogdan & Biklen, 2003).

**Document Review**

Documents collected included: draft and final IEPs, and assessments and other documents from the diagnostic and educational files of the case students. Evidence from these documents was not a primary source of data but instead was used to “corroborate and augment” evidence from interviews and observations (Yin, 2009). For example, a comparison of the draft and final IEPs yielded information about the ways in which parent and educator input are reflected in the IEP revisions. Notable characteristics for assessment documents include: topics addressed, the level of detail included, and source of assessment (e.g., internal vs. external).

**Data Analysis**

Once all of the data for this study were collected, we coded the data for all instances of intersectionality—moments in which participants experienced recognition or marginalization based on not a single identity category but because of the intersection of multiple categories. We used several approaches to coding, including: attribute, in-vivo, pattern, and selective coding (Charmaz, 2006; Miles & Huberman, 1994; Saldaña, 2013; Strauss, 1987). For instance, the attribute coding method was used to identify incidents related to the participants’ social identity categories, such as race, autism, gender, and language. In vivo coding served to preserve participants’ interpretation of their experiences using the participants’ own words. Pattern coding and selective coding techniques allowed the researchers to organize interpretations into meaningful clusters.

To start, we independently coded the first interview to generate sensitizing concepts or pre-existing codes related to intersectionality (Denzin, 1971). The majority of codes were identity categories, such as ableness, race, religion, language, and socioeconomic status (SES). Using this attribute coding method, the two researchers independently coded all interviews. When we had coded all of the interviews with a given participant, we met to discuss codes and to reconcile any differences.

After the initial coding, we used pattern coding and selective coding to articulate themes and implications (Miles & Huberman, 1994; Saldaña, 2013). In addition to compiling the codes in the code list, we also marked other themes and recorded field notes and memos.
Across the entire data collection process, we brought pre-existing categories or “sensitizing concepts” to the sites (Denzin, 1971). The sensitizing concepts guided initial research before definite ideas about the data had been formed and helped shape and modify conceptual frameworks (Denzin, 1971; Patton, 2002).

**Trustworthiness and Reflexivity**

Qualitative research is not underpinned by positivist assumptions. Therefore the researchers used techniques to ensure the “trustworthiness” of the data including researcher bias, reactivity, and respondent bias (Guba & Lincoln, 1985; Morrow, 2005; Padgett, 1998). Padgett (1998) suggests that several measures can be taken to limit the effects of reactivity and respondent bias. The first is *prolonged engagement* and multiple interactions with research participants (Janesick, 2013). The present study allowed us to interact with participants over a ten-month period (at initial observations and interviews, IEP meetings, and post-IEP meeting and follow-up interviews). Multiple longer meetings between researcher and participants are believed to mitigate the extent to which researcher’ presence is obtrusive, thus promoting more honest interactions (Padgett, 1998).

In addition, by collecting data from multiple sources (observations, interviews, and educational documents), we were able to *triangulate* diverse pieces of evidence to explore the same phenomenon (Golafshani, 2003). For example, field notes collected during IEP meeting observations in conjunction with interviews with two individuals who had attended that meeting were used to understand nuances of the decision-making process. Interviews with Aadan’s mother and teacher, for example, revealed a critical misunderstanding (to be discussed in the results section of this paper).

Our own lived experiences positioned us in relation to the participants (Bogdan & Biklen, 2003). Specifically, as a European-American, US-trained special educator, the first author shared certain experiences and perspectives with the three educators in this study. The second author is a bi-lingual/cultural mother living as an immigrant in the U.S., which afforded her certain overlapping experiences with the Somali mothers in the study.

**Results and Discussion**

In the subsequent sections of this paper, data from this study are divided into three overarching themes: 1) *Parenting: intersections among race, disability, and gender*; 2) *Cultural assumptions and family/educator communication*; and 3) *Diversity and agency among mothers*. Each of these themes is further divided into subthemes where results (i.e., quotes from interviews, observations from field notes, information from educational documents) are analyzed alongside both one another and the findings from previous research.

**Theme One: Parenting Intersections Among Race, Disability, Religion, and Gender**
All three of the mothers in this study described the ways in which they perceived judgment in relation to their sons’ behavior at the intersection of race, disability, and gender. Among the most important tenets of the neurodiversity movement is the notion that people with autism should not be forced to conform to neurotypical norms, and made into “neurotic simulacr[a]” of their peers without autism (Solomon, 2008). And yet the data from this study reminds us that in our neurotypical-dominant society, the behavior of individuals with autism is often labeled as unusual, atypical, and maladaptive (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2012). Because of the “invisible” nature of the autism (Milton, 2012), naïve on-lookers may attribute the behavior of children with autism to “poor parenting” rather than seeing it as a manifestation of the child’s disability. Skin color and gender also appear to add layers of marginalization for these Somali American students and their mothers.

“You are a Bad Mother, and You Spoil Him”

As mentioned previously, maternal stress is correlated with their children’s “problematic” behaviors (Hastings, Kovshoff, Ward, Degli Espinosa, Brown, & Remington, 2005). Saida’s experience echoes this finding while also suggesting that the relationship between child behavior and maternal stress is mediated by the interpretations of other people. When Dris was young, Saida painstakingly researched treatments and techniques to mitigate the symptoms associated with his autism—trained as a medical researcher, she was drawn to systematic research.

Once she took Dris to a faraway clinic to participate an expensive experimental therapy. While on the plane, Dris started kicking the seat in front of him, Saida recalls the passenger’s irked plea: “Tell him to stop kicking.” Saida dutifully coaxed: “Okay, Dris, stop.” But it was to no avail. “He cannot really understand,” Saida remembers calmly explaining to the passenger, who was unmoved: “He has to [stop]. He has to,” she maintained. But Dris’ behavior continued, Saida remembers the woman then calling a flight attendant to complain: “She’s not a good mother…She doesn’t know how to raise her kid.” Saida interpreted this interaction in the following way: “[Dris] looks okay, so the people think you are a bad mother and you spoil him … because they cannot tell [that he has a disability].”

This incident suggests that the interaction of several identity categories, including: Dris’ disability-related behavior/presentation, the “invisibility” of his disability, gender, and race. This combination of factors produces an environment in which Saida is scrutinized and surveilled. Regardless of Saida’s own understanding of Dris’ behavior, she is subject to the reactions of the people around her. Ironically, this accusation of being “a bad mother” came while Saida was in the process of taking what could be considered an extreme measure to help her son. Most parents of children without disabilities do not expend this level of emotional energy or money in raising their children.

We argue that several of Saida’s own social identity categories intersect with Dris’ disability/behavior exacerbating the experience. First, mothers (as opposed to fathers) tend to perform the majority of everyday parenting tasks, which means that they disproportionately
encounter parenting stressors. Also, because mothers from non-dominant backgrounds are more vulnerable to censure than White mothers (Kediye, Valeo, & Berman, 2009), we hypothesize that Saida and the other mothers in this study are disproportionately likely to have experiences like this one.

An Accusation of Child Abuse

Like Saida’s experience, another mother, Nadifa experienced parenting-related stress at the nexus of gender, socio-economic status, and autism. As a recently arrived refugee living in temporary housing and without access to transportation, Nadifa had few options for medical care for her seven children. And because three of these seven children are on the autism spectrum, their needs for medical and educational services were high.

When Ali—the eldest of the three boys who would ultimately receive autism diagnoses—was a baby, Nadifa remembers noticing that his development was different almost from the start. She already had four older children and unlike them, Ali, “didn’t cry… he would not cry for hunger” so she would just put him in her lap and feed him when she thought he would be hungry. In spite of Nadifa’s observations about her son, the pediatrician was hesitant to grant her request for a referral to see a specialist. Nadifa had to “insist” that her son needed a more thorough assessment and Ali did not receive a diagnosis until years later when he was nearly four years old: too old to receive EI services. As mentioned previously, children from immigrant and minority families tend to receive autism diagnoses at a later age than their White, English-speaking counterparts. Research suggests that practitioners’ implicit biases may be a driver in this disparity (Morgan & Farkas, 2016).

In spite of already having one child with an ASD, Nadifa’s second-to-youngest child, Yusuf also received an autism diagnosis too late to participate in EI services. Aadan, for his part, was diagnosed with autism at 2.9 just three months before aging out of EI. The diagnostic experiences of Nadifa’s three sons are consistent with the pattern that Somali American children, in spite of being disproportionately diagnosed with autism, tend to be identified later than their White counterparts (Miller-Gairy & Mofya, 2015). Lack of/delayed access to high-quality EI services is closely correlated with slower social, cognitive, and communication development all of which tend to lead to higher incidences of maladaptive behaviors in children with autism (Estes, Munson, Rogers, Greenson, Winter, & Dawson, 2015; McEachin et al., 1993). Parenting three boys with autism and having few resources creates a demanding and stressful environment for Nadifa.

However, as with Saida’s case, the stress that Nadifa experienced in parenting three boys with disabilities was heightened by other people’s judgment of her parenting. When the first author was at Nadifa’s house observing an EI session, an official report of “possible child abuse and/or neglect” arrived in the mail. Astur, who was interpreting the EI session translated the letter. In attempting to make sense of this unsettling piece of mail, Nadifa speculated that the receptionist at her pediatrician’s office had filed the claim during a routine appointment the previous month. Because Nadifa was not able to access timely and effective
autism services for her three boys with autism, they were still learning how to communicate functionally. In the absence of effective communication skills, the boys engaged in “maladaptive” behaviors to express themselves. Ironically, the very system that prevented Nadifa from accessing the resources that her boys needed is the same system that labeled her boys’ behavior as problematic and accused her of being a “neglectful” mother.

“He’s a Black Man in America”

In addition to the scrutiny of parenting skills experienced by the mothers in this study, Amina articulated that she perceived that Bilal’s constellation of identity categories (i.e., being Black, male, Muslim, and autistic) influences how people respond to him. In her opinion, “[Bilal is] different, no matter what…like his culture, his religion, just the way he looks, he’s a Black man in America.” While Saida and Nadifa’s experiences point to the gender-related-implications of being a mother of a child with a disability, Amina’s comment highlights the fact that the child’s gender—being a boy with a behavior-related disability—is meaningful. Black boys are punished more harshly in US schools than any other demographic group (Noguera, 2009). Although Amina and Bilal had only been living in the U.S. for a couple of years at the time of these interviews, she already understood how they were positioned in the racialized U.S. landscape. This corroborates Bigelow’s (2010) finding that for Somali Americans race quickly eclipses other identity categories like religion and nationality.

In addition to the reality that parenting a child with a disability is correlated with increased levels of maternal stress and depression, research suggests that Black women and immigrants of those who are immigrants and refugees experience even higher levels of stress based on how other people judge them (Kediye, Valeo, & Berman, 2009). The results of the present study bring these two trends together by showing the powerful marginalization experienced by Black Muslim mothers of Black boys with invisible disabilities that manifest in visible “maladaptive” behaviors.

Theme Two: Cultural Assumptions and Family/Educator Communication

Whereas the mothers in this study made spontaneous comments about race in relation to their sons (e.g., “[Dris] was the only Black one … six White kids and my son” [Saida]; “Bilal is a Black man in America” [Amina]) and others (e.g., “The White lady at the last meeting was very hard to me … she is the boss of the other one: the Black one” [Saida]). The (all White) educators in this study, for their parts, never initiated discussions of race: they only commented in response to explicit interview questions or prompts. In a representative example, when asked to describe his early experiences with people from other racial/ethnic backgrounds Dris’ teacher, John, described his hometown as … “[not] strictly lily White.”
Discrepancy in Racial Awareness

This imbalance between the mothers’ acute racial awareness and the teachers’ corresponding color blindness had important implications for the educational decision-making process. Amina, for example, put forth the idea that the unique combination of autism-related behaviors and being a “Black man” creates a context in which learning to behave “appropriately” is more urgent for Bilal than it is for his White and/or female counterparts. She reported believing that not pushing Bilal to behave appropriately would constitute doing him a “disservice” and even “failing as a parent.” Bilal’s autism profile and his highly developed social and communication skills are similar to that of many individuals who have grown up to be outspoken autism advocates and leaders in the neurodiversity movement. And yet Amina’s comments suggest that the racism Bilal will likely experience as a Black boy in the U.S. may affect Bilal’s ability to participate in the neurodiversity movement, which is premised on embracing behaviors that deviate from the norm.

In contrast, Katherine did not discuss Bilal’s race when talking about his educational needs and did not express a need to treat Bilal any differently than his non-Black classmates. From this vantage point, she believed that Amina was putting undue pressure on Bilal:

“[Amina] uses every minute of her day to work him…[he] needs to play blocks when he gets home like he needs to have down time … I think you should be playing outside and I think he needs to run around and have an opportunity to just laugh and be silly.”

Katherine responded to Bilal’s learning needs based on his age and (dis)ability alone without regard to his racial/ethnic/religious background. Katherine’s perspective is in line with the American special education system, in which “disability [often] overshadows other identities of students” (Young, 2016, p. 86). In spite of their apparent inattention to race, we contend that special education service providers often unconsciously filter information about their students based on the racial, ethnic, linguistic, and religious information. The (inaccurate) assumption, for example, that Halima (as depicted in the opening vignette) was traumatized by the Somali Civil War is evidence of this phenomenon.

Cultural Assumptions Curb Communication

Implicit biases related to race, ethnicity, religion, language, and other social categories affect how family members and educators engage with one another (Artiles, Sullivan, Waitoller, & Neal, 2010; Burkett, Morris, Manning-Courtney, Anthony, & Shamley-Ebron, 2015; Wilkinson, Ortiz, Robertson, & Kushner, 2006). Because these preconceived notions are often subconscious, they can impede communication between the families and educators. For instance, Katherine purports that the fact that her educational priorities for Bilal differ from Amina’s is evidence of a cultural difference (“I mean [Amina] works [Bilal] really hard, so that’s the piece I think, I think that’s a cultural difference from what we would expect.”)
We argue, that in fact, Amina’s views on Bilal’s education are very much grounded in the American middle-class notion that families should be primary advocates for their children, especially during the special education process. Amina clearly viewed advocating for Bilal as being her own responsibility (“I always feel inadequate, because I always feel like am [not] I fighting enough for him”). In spite of working full-time and being a single mother, Amina frequently volunteered in Bilal’s classroom. As a scientist, she particularly liked to bring her professional knowledge to the school. “I’m going in this Thursday to do three experiments: elephant toothpaste, a volcano, and Coke and Mentos” she mentioned in one interview. Amina’s emphasis on parent participation in special education is very much in-keeping with middle-class American values (Harry, 2008; Olivos, Gallagher & Aguilar, 2010; Turnbull & Turnbull, 2001).

Because we do not view Amina’s beliefs about special education as being “culturally different,” we put forth the notion that Amina’s physical/visual presentation—being Black, wearing a headscarf—(mis)cue Katherine to see “cultural differences.” Because Katherine labels their divergent perspectives as a “cultural difference,” she worries that pushing back on Amina’s ideas would be “culturally insensitive.” In our own experiences as special educators, differences of opinion between family members and educators are commonplace and can issue from many different places. But shying away from conversations when differences of opinion arise inhibits productive dialogue.

A similar trend exists in the communication between Nadifa and Kim. EI is intended to take a family-centered approach (Crais, 1991), and so the extent to which Nadifa’s voice is absent from Aadan’s educational decision-making is particularly notable. Specifically, Kim assumes that because of Nadifa’s “cultural background” she would not have opinions about or desire to participate in the educational decision-making process. Kim imagined that Nadifa was thinking: “Oh, the teacher’s here. The teacher’s gonna teach him.” Furthermore, Kim worried about how families would see her: “I don’t want to step on her toes and be constantly telling her what to do, it’s I don’t know…. And then I sort of feel like it’s cultural too….” Our interviews and observations reveal that although Nadifa was largely absent from the EI sessions (e.g., “[Nadifa] kind of like stays in the other room when I’m working with [Aadan]”), she actually had well-formulated opinions about Aadan’s education. For instance, Aadan’s OT and PT followed a simultaneous service delivery model (i.e., the two therapists would come to Aadan’s house at the same time to provide therapy). The OT explained to the researcher that this was intended to facilitate collaboration and consistency. But Nadifa was not privy to the rationale for this service-delivery decision, and she wished that the therapists would come at different times so that Aadan could “gain more” by spending more time with therapists rather than doing both therapies at once.

Midway through the study, Aadan became eligible for applied behavior analysis (ABA) services instead of the traditional/eclectic EI services he had been receiving. Nadifa assessed: “[the ABA] was very helpful. More helpful than the [traditional] early intervention … it’s longer, and they were really focusing, how to improve his speech, they were very well
rounded.” Nadifa, who had two older children with autism was particularly aware of the importance of him learning as much as possible at a young age. And based on the gains that she saw Aadan making in his ABA sessions, she felt that this was the best path for her son. Nadifa’s comments reveal a thoughtful understanding of her son’s educational program. Kim’s belief that Nadifa would not want to be involved in the EI sessions coupled with Nadifa’s own reluctance to partake resulted in fractured communication and arguably a less-than-optimal EI experience for Aadan.

In each of these cases the educators’ beliefs that the mothers are acting based on “cultural values” led to diminished rather than enhanced or “culturally sensitive” communication. The educators in this study had pre-existing ideas about the ways that “culture” might contribute to the mothers’ ideas about autism and education (e.g., the commonly held belief that families from many cultures do not see it as their role to be actively involved in educational decisions), which colored their interpretations of the mothers’ words and actions. In Nadifa’s case, there was a sort of self-fulfilling prophecy: Kim did not expect her to weigh in on educational decisions, which reified the passive role Nadifa was already comfortable taking. Perhaps Nadifa would have benefitted from more structured or specific invitations to participate in the educational decision making process.

Theme Three: Diversity and Agency Among Mothers

While the participants in this study have important commonalities including: their country of origin (Somalia), the special education eligibility category (autism) and the gender (male), the three families’ experienced the educational decision-making process in very different ways. The families’ demographic differences (e.g., education levels, professional backgrounds, immigration trajectories, and SES), the extent to which they have acculturated in the U.S. along with their support networks, and the access they have to the educational services for their children with autism can, at least partially, explain their divergent experiences.

Diverse Trajectories

International migration trajectories can have complex influences on an individual or family and can reveal the way in which SES is, in fact, a fluid and multifaceted rather than static identity marker. Amina, for example, grew up in an aristocratic Mogadishu family: “Like I remember having like nannies and chefs ... and the chef was like ‘What does the princess want today’?” She described the decline in terms of wealth and status that her family experienced when they resettled in Canada. It was hardest on her mother, who “left everything behind.” In spite of having very limited material resources, the family brought with them a strong belief in the importance of education and the prospect that their children and grandchildren would be highly educated and professionally successful: “My mom said that [she would] pay whatever it takes for tutors and things like that.” Amina’s story is helpful in decoupling economic from the social and educational capital. It reminds us that thinking of SES as an indivisible unit is not very useful in understanding people’s lived experiences.
Saida’s story shares elements with Amina’s. Unlike the other two families in this study, Saida did not come to North America with refugee status. At the time the Civil War started in Somalia, she had already been living in Scandinavia as a student. Her husband (also Somali) was already a U.S. citizen and was able to sponsor Saida and their sons when they decided to come to the U.S. to access autism education and treatment resources for newly diagnosed Dris.

On the other hand, Aadan’s family’s trajectory aligns with the majority of Somali Americans living in the U.S. today. They came to the U.S. via Kakuma Refugee Camp in Kenya and were resettled in temporary housing in a low-income area with many other immigrant and refugee families. Although all three families experienced difficulties in locating local resources for their children with autism, Aadan’s family had significantly less access to the information and supports than Dris’ and Bilal’s families.

The immigration histories also influenced the parents’ occupations. Saida and Amina are both highly educated professionals. Saida was trained as a physician/medical researcher in Sweden. Although her credentials did not transfer completely when she came to the U.S., she was able to find a professional job in the medical field as an OB/GYN case manager. Amina is a Master’s level chemist and was working as a scientific writer at the time of this study. In contrast, Nadifa, a monolingual Somali speaker and a member of the Bantu ethnic minority group, was raised in rural Somalia where she was not formally educated. In the U.S., she was a full-time mother of her seven children.

The residential areas where the families live also reflects the diversity of (re)settlement patterns among Somalis in the U.S. The participants in this study do not represent the average demographics of Somalis living in the U.S.; whereas 90 percent of Somalis in the U.S. live in subsidized housing (Campacho, Dirse, Hiray, & Farah, 2014), in this study only Aadan’s did: Saida owned a single family home, which she had helped to build through the Habitat for Humanity program; Amina lived in a market rate rental in an upper-middle-class suburb. Although Amina would have liked to have lived in a more diverse urban community (she had lived previously in Mogadishu and Toronto) she chose to live in a well-to-do, suburb where the majority of the families were White, because of the reputation of its schools. In contrast, Aadan’s nine-person family lived in a small apartment through a temporary housing program.

Indeed where the families live had important implications in terms of the specialized autism services available to their children. Although Dris was districted to a large urban school system and Amina was lucky (or skillful?) enough to convince the district to pay for an expensive out-of-district placement when she deemed that the local school system was not meeting his needs adequately. Bilal attended a well-resourced public preschool program where he spent the full day in a fully inclusive classroom with support from a special educator, OT, PT, SLP, as well as a 1:1 aide. Aadan was preparing to enter a public preschool program in the not-so-well-resourced public school in his neighborhood.
Networking and Advocacy

The families’ SES added another layer of intersectionality in terms of the mothers’ abilities to establish networks and to advocate for their children’s needs. Many parents—not only immigrants and refugees—find it difficult to navigate the byzantine American special education and many seek out official and unofficial sources of support as they pursue assessments, placements, and accommodations for their children. This study illustrates the ways in which residential location, professional status, and many other factors can influence the types of networks to which parents of children with disabilities belong.

Saida was very involved in the parent teacher association (PTA) at Dris’ publically funded out-of-district school, and her involvement with the group shaped her mindset about disabilities and education. At the outset of Dris’ education in the U.S., Saida remembered having subscribed to the notion that parents should take care of their children with disabilities at home indefinitely. Saida’s extended family still held this belief and reminded her of it frequently. But Saida’s perspective had started to shift as she had more contact with other parents at The Hope School. She met parents who “…have good jobs. They’re good mothers. They’re very involved.” These mothers were convincing when they described their reasons for enrolling their children in the residential program at the Hope School. Through conversations with these parents, Saida began to question her initial assumptions.

At the other end of the spectrum, although Aadan was in a “toddler group” run by his EI agency, Nadifa did not have the opportunity to network with other parents of similar-age children with disabilities. Because she did not have a car, two-year-old Aadan was transported to the group by bus. Even if Nadifa had been able to attend, the language barrier likely would have prevented her from communicating with other parents. One concrete area where we can see the effects of the mothers’ networking (or lack thereof) is in their process of enlisting educational advocates. Advocates played important but different roles in each of the three cases.

Someone who Speaks “legalese”

Amina and Saida also used their networks to enlist educational advocates. Saida got the idea to hire an educational advocate from other parents at Hope. She was able to hire an advocate used by other families at the school who was already familiar with the nuances of the program. She had been offered a free lawyer from the non-profit organization Advocates for Children, but she worried that a free lawyer might not be as good, might not “come on time.” And she felt like this meeting was simply too important for her to cut corners: “I don’t have to think about money. But I have to think about what’s good for him,” she reflected. In this case, although Saida was living on a single—fairly modest—income, she had enough discretionary resources that she felt like she was able to decide to spend money on something that was very important to her. Amina’s professional network produced a recommendation:
“I was just telling [one of my co-workers] ‘Oh my god, I have a huge IEP meeting coming up and I’m hyperventilating … and I’m thinking of hiring an advocate. But I don’t even know how to go about it … I don’t even have the money to pay the hundred and thirty dollars an hour.’ And [my colleague] was like: ‘My friend is an advocate, and she’s very affordable’.”

Amina’s statement illustrates the ways in which financial and social capital interact with one another. Specifically, as a single mother, Amina worries about the high costs associated with raising a child with a disability. However, because she is a highly educated professional working primarily with middle- and upper-class Americans, she has access to information that most Somali refugees living in immigrant and refugee communities would not.

In spite of Amina’s obvious sophistication in terms of understanding the special education process, she valued having an advocate who “speaks IEP” and who can decipher the “legalese.” Amina also envisioned an advocate as a way to ensure that her child’s needs would be met while also safeguarding her own relationship with the school personnel:

“You don’t want them to not like return your phone calls, and you don’t want them to be like ‘oh my god, here comes bitch on heels!’ kind of thing. So you hire these advocates that can be the dog and be like all aggressive.”

In her appraisal, employing an advocate to play the role of “bad cop” would free her up to be agreeable and would allow her to let her guard down knowing that someone else was scrutinizing the school’s decision-making with regard to Bilal’s education. It is important to note the role of power inherent in Amina’s description. Her fear of being perceived as “a bitch on heels” implies that for parents to exercise power is seen as out of place by school personnel. The gendered nature of her comment also implies that perhaps her experience would be different if she were a father as opposed to a mother. In any case, she believes that hiring an attorney protects her relationship with the school.

For both Amina and Saida, enlisting an advocate was helpful on technical and emotional levels. Dris’ teacher, John noted that Amina’s advocate gave her “a little more confidence going in.” Fieldnotes from the IEP meetings revealed subtle ways in which the advocates supported their clients—a tissue passed across the table (“I’m not a rookie” Amina’s advocate said as she pulled a package of Kleenex from her purse), a hand to hold (note that both of the parents who had paid advocates were single mothers and, presumably, would have otherwise been at the meetings alone).

The Self-Appointed Advocate

Aadan’s family did not hire an advocate to attend his IEP meeting. However, Kim, the EI provider attended his IEP meeting. She described herself as “someone who’s not directly
involved and can step back and ask the right questions,” implying more neutrality, perhaps, than represented by a paid advocate who inherently has her clients’ (i.e., the parents’) interests in mind.

Kim explained that she has found that as families of children with disabilities approach their child’s first IEP meeting—the official entrée into the public school system—they are generally “apprehensive about the whole thing” and that they are “very intimidated” in the meeting itself because they “don’t know what to expect.” So as with Amina and Saida’s advocates, Kim saw herself as an emotional support for parents.

Although Kim functions, in some ways, very much like the paid/official educational advocates in the first two cases, her role is also different in important ways. To begin, because she is self-appointed instead of being hired by the students’ parents, it is much less clear to whom she should be responsive. For example, if she and the parents do not have the same exact view on a particular educational decision – as happened in subtle ways a couple of times during Aadan’s transition from EI to preschool – is it her role to advocate for what the parents want? Or for what she sees as being in the best interests of the child? In this case, it becomes very important that both financial resources and social clout affect the ways in which parents advocate for their children.

Access to Early Treatment and Intervention

For students with autism, early access to intervention services has been shown to have positive impacts on communicative and behavioral outcomes (Estes et al., 2015). The interviews in this study illustrate a wide range of impediments to effectively enlisting services. In the case of these families, the barriers to accessing care are related to different facets of their social identity categories—from immigration trajectory to educational background, and language. It is easy to extrapolate that the intersection of multiple marginalized identity categories can be particularly powerful in blocking access. Dris’s family first came to the U.S. expressly because his family felt that it was the best option in terms of education/treatment options for a child with autism. His mother, Saida went to the children’s hospital within 24 hours of arrival in the U.S., but Dris was already seven and could not receive EI services. Although the parents were well educated and had economic and legal ability to immigrate to the U.S., the family did not have enough information to understand the local education systems completely before they arrived.

In Aadan’s case, the parents were unable to seek EI supports for Aadan’s two older brothers. And even though Aadan was their third child on the autism spectrum, it was a social worker, who helped them to receive diagnosis and special education services. For non-English speaking families from low-income families like Aadan’s, the autism diagnosis process can be a big hurdle. Because usually autism diagnosis occurs in early childhood (Diagnostic and Statistical Manual of Mental Disorders-5 [DSM-5], American Psychiatric Association [APA],
limited access to medical services in areas around refugee shelters and families’ lack of English skills often prevent children from receiving timely diagnoses.

Conclusions

This study examines the experiences of three matched sets of Somali American families of boys with autism and the boys’ teachers. Results show both the many ways in which the families’ multiple marginalizing identity categories interact with one another creating barriers to effective participation in the special education decision-making process. Perhaps equally importantly, the study shows that the educators—all three well-educated and empathetic—take an essentially colorblind approach to the educational process. For the most part, these educators have little awareness of the fact that the boys’ disability status interacts in complex ways with race, gender, religion, socio- and economic status and produces unique challenges that their White, non-Somali, and/or female counterparts may not face. The findings of this study do not apply just to the narrow demographic of Somali American boys with autism, but rather they encourage us to think more critically about the experiences that children and families from various non-dominant groups may have in U.S. public schools.

Implications for Practice

In recent years, the American education system has emphasized “culturally responsive” teaching. Results of this study suggest that in trying to be “culturally sensitive” teachers inadvertently created barriers to authentic communication and collaboration. For example, both Kim and Katherine expressed reluctance to “step on [the parents] toes” or engage in open dialogue with the parents for fear of saying something that could be interpreted as culturally insensitive. Although their intentions are good, the result of this behavior was that educators and parents had stilted interactions and missed opportunities to engage in meaningful conversations that could have produced even better or more individualized educational goals for the students in the study. We suggest, therefore, that rather than receiving (often inaccurate or incomplete) information about various “cultures,” that teachers be trained to ask questions in ways that allow parents to explain their ideas and employ specific and concrete invitations when soliciting input from families.

In the case of this study, targeted, honest questions would have revealed that Amina’s ideas about working tirelessly to teach Bilal were not Somali ideas, but rather grounded in Amina’s understanding of what it means to be a Black boy (with autism) in America. And closed ended questions for Nadifa (e.g., “Now that Aadan’s been receiving two different types of services do you think one of them is more effective than the other?”; “Do you think that it is helpful when I come at the same time as the OT does, or would it work better for us to come at different times?”) might have signaled to her that it was truly ok to express a preference or share an observation and might have given her the scaffolding to do so as she navigated a foreign educational system.
At the outset of this study, we did not realize the complex ways in which the behaviors associated with autism interact with other identity categories including race, ethnicity, gender, and religion to produce experiences of marginalization. In analyzing interviews with mothers and teachers as well as through observations of educational planning meetings, it became clear that the ideal of truly embracing neurodiversity and de-stigmatizing the behavioral differences associated with autism may not—at least not in this time and place—be equally accessible to all people with autism. As Amina articulated so clearly, being a Black boy in America carries with it a particular burden where any instances of behavior that deviate from the norm become particularly problematic. Interestingly, although all three of the educators in this study had lived their whole lives in the U.S., it was the mothers who quickly figured out—probably out of necessity—what it means to raise a Black boy in America.

Therefore, in addition to the need for more professional development around working with culturally and linguistically diverse families, these cases revealed the need for White special educators to be able to think more critically about how race, religion, ethnicity, and gender along with disability shape their students’ experiences. If the mothers in this study had felt that the educators were working with understood the urgency that they felt in relation to teaching their sons appropriate behavior they might not have felt quite so isolated. They may have experienced a little less stress.

Finally, the tremendous diversity that these cases reveal within what initially appears to be a narrow demographic serves as an important reminder that it is utterly impossible to know another culture or to be able to predict what a person might believe based on her culture/race/religion/ethnicity. Amina’s experiences, for example of her own rarefied Mogadishu education are so very different from Nadifa’s education in rural Somalia that it should come as no surprise if what they hope their boys’ educations will look like is different. Nor can we assume that just because Nadifa is not herself educated nor familiar with the American special education system that she will not have well-formed opinions about her son’s education. Her explanations of what she liked and objected to about Aadan’s EI therapy revealed that she was observant and thoughtful. Parents who have intimate knowledge of their children often have good insights about educational programming.

Limitations

This research is limited in the number of participants and the fact that the significant differences across the three families are both a strength in terms of allowing for a breadth of conclusions but also a limitation in terms providing for deeper analyses. Despite these limitations, the present study is an important starting point in terms of revealing the intersectional experiences of Somali American families of boys with autism. It also suggests promising avenues for future research including the need for a more in-depth investigation on educators’ knowledge and beliefs around thinking about students’ race and ethnicity in relation to their dis/abilities and special education trajectories.
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References


### Endnotes

1. The opening vignette is excerpted from the first author’s fieldnotes.
2. In contrast, research has shown that Black children in the US, in general, are less likely than their White counterparts to receive ASD diagnoses (Mandell et al., 2009).
3. Although the vaccine theory has been discredited, many in the Somali-American community still subscribe to it.
4. The gender requirement was introduced because of the complex interactions among behavior, race and gender and by focusing on a single gender we were able to do a more targeted analysis. Because boys are significantly more likely to be diagnosed with autism (CDC, 2014) we decided to focus on them as opposed to girls.
5. Pseudonyms are used for all people and places to protect the privacy of participants.
6. Due to timing, only two interviews were conducted with the mother and educator in Case 1. In these cases, the questions from the first two interview protocols were combined in a single interview.