Many Voices at the Table: Collaboration between Families and Teachers of Somali Students with Autism

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Many voices at the table

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MANY VOICES AT THE TABLE: COLLABORATION BETWEEN FAMILIES AND TEACHERS OF SOMALI STUDENTS WITH AUTISM
dissertation by
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Many voices at the table: Collaboration between families and teachers of Somali students with autism

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Family member-educator collaboration is envisioned as the “cornerstone” of the educational decision-making process for students with disabilities (e.g., Harry, 2008; Olivos, Friend & Cook, 2007, Gallagher & Aguilar, 2010). In the case of immigrant and refugee families, however, the ideal of coequal collaboration is often elusive for a variety of reasons (e.g., language barriers, disparate ideas about what familial involvement should be in educational decisions) (e.g., Lo, 2012).

This qualitative multiple case study design (Yin, 2009) relied on interviews with family members and educators as well as observations of IEP meetings to examine the educational decision-making process in the context of Somali-American families of boys with autism. Findings from the present study echo many conclusions of previous research in terms of factors that facilitate (e.g., thoughtfully designed IEP meetings, frequent family-educator communication) and impede (e.g., divergent beliefs about the cause and course of autism, language barriers) family-educator collaboration in special education decision-making.

The results, meanwhile, extended and challenged other aspects of existing literature. Analysis revealed, for example, the each school has a unique institutional culture whose norms (e.g., norms of parent participation in school activities, from dances and races to PTA meetings and in-class volunteering) can profoundly influence the ways in which family members and educators interact and engage in educational decision-making. In addition, while existing literature emphasizes the importance of cultural sensitivity among
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special educators (e.g., Harry, 1992; Lo, 2013), the present study suggests that in some cases, over-emphasis on cultural sensitivity can cause educators to be overly deferential and reluctant to actively engage with family members, in turn, leading to diminished or inauthentic communication.

autism, IEP meeting, immigrant students, educational-planning
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CHAPTER 1: RATIONALE FOR THE STUDY

“Culture affects the way we view autism...a global phenomenon...not only a biological disorder, but...a group of symptoms that have become especially meaningful in particular places and times.”
(Grinker, 2007)

I was new to teaching children with autism and only beginning to understand the condition. One of my students was Medi, a slender ten-year-old boy with floppy black hair. Medi loved letters and numbers—his greatest indulgence was sifting though a bin of refrigerator-magnet letters; Dr. Seuss’s ABC’s was always in his hand. He adored looking out the window—afterwards, it seemed nearly impossible to get him back to the table to work. He was a cute kid who always wore faded turtlenecks and slightly-too-short sweatpants. Yet even as Medi endeared himself to me quickly, he was difficult to manage in class.

Medi was as stubborn as any child I had ever met and aggressive. He had long elegantly rounded fingernails that he would employ as daggers when frustrated—he seemed always to aim for my neck. This aggression was not random but rather the only way he knew to communicate frustration and confusion, when he didn’t know what was going on, what I wanted him to do. As a teacher, I learned quickly to communicate my expectations clearly and to create predictable structures in the classroom.

Medi also had a sampling of classically autistic stereotyped behaviors, including hand flapping and rocking (these were of less concern to me than the aggression). But in both my school and the field of autism education, the prevailing belief was that stereotypy interfered with students’ abilities to interact socially. And so I began thinking of a plan to teach him appropriate alternative behaviors.
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Most parents in my classroom had been enthusiastic about similar types of interventions. But when I sat down with Medi’s father and paternal grandmother at his IEP meeting and proposed the behavior-change intervention, Medi’s father explained to me that he did not see his habits as a problem to be remedied.” I appreciate his quirky gestures, his unusual movements,” Medi’s father explained. “Why would you want to change his behaviors?” his grandmother followed.

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It was this IEP meeting, early on in my career, that made me stop and think. Several questions came to mind: “How educational goals are determined?” “How do negotiations occur when family members and educators have truly different ideas about what autism means?” “Who should decide which behaviors are problematic, which merely different?” Because the characteristics associated with autism are so intimately connected to notions about what constitutes “appropriate” social behavior, the condition is particularly likely to raise important questions such as these.

Autism

Autism, first officially documented in the 1940s by Leo Kanner (1943) and shortly thereafter by Hans Asperger (1944), is a lifelong developmental disability that affects social interactions and communication, although its manifestation is specific to each individual child. Symptoms range from mild social differences to severe disabilities, although intellectual impairments are present in the majority of cases (approximately 70 percent) (American Psychological Association, 2010). Certain characteristics typify autism: social and communication challenges, self-stimulation and other challenging behaviors, and sensitivity to
environmental changes (e.g., American Psychological Association, 2010, Smith, Belcher, and Wehman, 1997). 1

Communication Differences

More than 30 percent of individuals on the autism spectrum do not use speech to communicate (National Research Council, 2001), and those who do verbalize in a variety of idiosyncratic ways. Individuals on the autism spectrum tend to communicate differently from their peers without autism. In particular, individuals with autism struggle with the social use of language, known as pragmatics (Baron-Cohen, 1988; Eigsti, de Marchena, Shuh, & Kelley, 2011; Kanner, 1943; Tager-Flusberg, 1981, Tager-Flusberg & Caronna, 2007). 2

In addition to the ways in which people with autism tend to speak, the content of autistic conversations is often unique. For example, individuals on the spectrum often perseverate or over-focus on topics of personal interest (Frith, 1991; Ghaziuddin & Gerstein, 1996; Happé & Frith, 1994; Ozonoff, South, & Miller, 2000; Williams, 1995)—e.g., train schedules, heating systems, garage door openers. They also interpret other people’s speech very literally, which can make it difficult for them to understand and use humor as well as metaphor and irony. These particular communicative tendencies likely derive from deficits in theory of mind (ToM), or the inability to infer the mental states of others (Baron-Cohen, 1995; Bowler, 1992; Happé, 1993; Tager-Flusberg, 2001).

Self-Stimulatory and Other Challenging Behaviors

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1 Among the most significant changes to the DSM-V (2013) are changes to the diagnostic criteria for ASDs. Among these changes, Asperger syndrome was removed as a diagnostic category.
2 Many individuals with high-functioning autism and Asperger's syndrome can perform certain pragmatic skills competently—e.g., noticing the violation of social rules, displaying politeness, participating in certain conversational sequences, etc. (Ochs & Solomon, 2004).
Students with autism exhibit a wide variety of challenging behaviors including: self-stimulatory behaviors, self-injury, aggression, and property destruction (e.g., Smith, Belcher, & Wehman, 1997). In many cases these challenging behaviors can be understood as communication. For students who have difficulty making themselves understood, behaviors (even maladaptive ones) allow them to meet their needs—gaining attention, escaping from non-preferred tasks, etc. (e.g., Shea & Bauer, 2011).

Self-stimulatory behaviors (e.g., hand-flapping, spinning in circles, finger flicking) are especially common in students with autism. Researchers have put forth several theories to explain high levels of self-stimulation among individuals with autism. Newsom and Lovaas (1987), for example, speculate that all individuals crave certain levels of stimulation but that because individuals with autism are limited in the tools that they have to access stimulation from the environment, self-stimulatory behaviors flourish.

Sensitivity to Environmental Changes

Many children with autism have a very difficult time adapting to changes in their environments or routines. In some cases, individuals may respond to unanticipated environmental changes by engaging in maladaptive behaviors. In an effort to create predictability for themselves, some children with autism may insist on doing activities in exactly the same order and way each time. They may resist altering a routine even if the change is easier or more efficient in some way (e.g., Smith, Belcher, & Wehman, 1997, Turner, 2003).

These features, that set individuals with autism apart from their neurotypical peers, have important educational implications. A variety of techniques have been developed to
address the particular learning needs of individuals with autism. These will be discussed in Chapter 2.

Autism diagnosis has increased exponentially in recent years. Current estimates by the Centers for Disease Control (CDC, 2012) indicate that 1 in 88 children are affected (and of these boys are approximately four times as likely to have autism as their female counterparts). Changes to the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V, 2013) include important changes in the diagnostic criteria associated ASDs—including the removal of Asperger syndrome and other related diagnoses. These changes underscore the fact that understanding of ASDs remain in flux.

Although the condition affects individuals across races and ethnicities, there have been speculations of high concentration within certain populations (Grinker, 2007). In particular, high levels of autism apparently affect Somali refugee communities, as reported in Minnesota and Stockholm (e.g., Barnevik-Olsson, Gillberg & Fernell, 2010; Estrem & Zhang, 2010; Kirby, 2008), although autism is virtually unheard of within Somalia itself: in fact, no word for the condition exists in the Somali language, and Somali-Americans have taken to calling the disability “The American Disease” (McNeil, 2009).

Data are inconclusive and several theories have been put forth to explain this pocket of elevated incidence (e.g., vitamin D deficiencies caused by the relocation of a population with high levels of melanin to a northern climate coupled with lack of sun exposure due to veil wearing; consanguineous marriages, duplicate vaccinations) (Barnevik-Olsson, Gillberg & Fernell, 2010; Delberto, 2011). And while it seems likely that autism was and is under-diagnosed within Somalia, there is not sufficient evidence to support this claim. Regardless

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3 No large-scale epidemiological research has investigated the prevalence of autism within Somalia.
Many voices at the table of the causes of autism within Somali refugee communities, the fact remains: many Somali-American students have diagnoses of autism are receiving special education services in American public schools (e.g., McNeil, 2009).

Illness and disability in the Somali Diaspora

Somali parents and American-born doctors and educators often hold decidedly different notions about what causes illness and disability and what types of education and treatment are appropriate (e.g., Groen, 2009). For example, while considerable discussion of and knowledge about disabilities exists in the United States, in Somalia, disabilities are highly stigmatized and infrequently discussed (Boynton et al., 2010; Ellis et al., 2010). Additionally, while disabilities are generally thought to have a biological basis in the Western context, Somalis generally view health and disability in holistic terms and in relationship to their daily lives (Pavlish, Noor, & Brandt, 2010) and in the context of religion—believing for example, that illness and disability may be caused by waddado (spirit possession) (Scuglik, et al., 2007) or reflect “Allah’s destiny” (Pavlish, Noor & Brandt, 2010, p. 355). Conceptions of mental health and disability are less nuanced in Somalia than in the United States. For Somalis, the concept of sanity has traditionally been viewed as a clear-cut binary: “sane” versus “insane.” Within this model, the term “insane” is reserved for those who are violent or whose behavior simply cannot be controlled (Ellis, 2010)—as a result, Somalis tend to accept a wider range of “normal” cognitive functioning. By contrast, Americans have increasing array of labels for people who deviate from what is considered typical (e.g., Grinker, 2007).

Autism and Somali Families
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Individuals with autism are one group who are perceived of as being outside of the realm of “typical.” In the Somali context, it is notable that the behaviors associated with autism (e.g., repetitive behaviors, unusual social tendencies) do not fit neatly in the “sane”/”insane” dichotomy. And even though autism supposedly affects Somali refugee children at high rates, little research exists to guide culturally competent diagnosis, education, and treatment for them.

Kediye, Valeo, and Berman’s (2009) work about the experiences of Somali-Canadian mothers of children with autism offers an important foundation for this line of inquiry. This qualitative study is based on focus groups and individual interviews with ten Somali-Canadian mothers of children diagnosed with autism. The findings establish well the fact that as both mothers of children with disabilities and members of a “visible minority,” this group faces a unique combination of stressors (Kediye et al., 2009). And although this work approaches important questions about the challenges faced by immigrant mothers of children with autism, it omits an integral component. Presumably, one of the major challenges for immigrant families of children with autism is navigating the special education system, and yet this topic is not a focus of Kediye et al.’s (2009) work.

Educating Immigrant and Refugee Students with Autism

Overall, very little empirical research addresses the educational needs of immigrant and refugee students (of any background) with autism (Dyches et al., 2004; Welterlin & LaRue, 2007; Wilder et al., 2004). Because many of the behaviors that are characteristic of autism (e.g., stereotypy, lack of eye contact, lack of emotional expressiveness) vary widely from one culture to another (Grinker, 2007) and because autism diagnosis is closely connected to language and communication skills, immigrant students are reportedly often
misdiagnosed (both under- and over-) with autism spectrum disorders (ASD) (Wilder et al., 2004).

Even when immigrant students are correctly diagnosed with ASDs, their families are often required to choose between specialized instruction for students with autism and the supports afforded to English language learners (ELLs). In most cases, disability status effectively trumps all other learning needs (Yu, 2010). Language barriers between immigrant families and special educators, lack of culturally sensitive assessment and diagnostic tools, and discrepant notions about autism itself can impede the development of treatment plans and the identification of appropriate educational placements (Tincani, Travers, & Boutot, 2009; Welterlin & LaRue, 2007).

In contrast to families of regular education students, families of children with autism often work intimately with educators starting at a young age and continuing for many years (Tincani, Travers, & Boutot, 2009). Before children with autism turn three, many receive intensive home-based early education services. And after their third birthdays they are educated through the public school system until they turn 22.

Notably, however, scholarship indicates that immigrant and other non-white families tend to be less involved in the special education process than their European American counterparts (Zhang & Bennett, 2003). This decreased level of family involvement reportedly puts immigrant and minority students with autism at increased risk for low educational attainment (Rodriguez, 2009). In order to offset this trend, it is important to investigate the nature of collaboration between immigrant families of children with autism and educators, thinking about both factors that may impede collaboration and
those that might facilitate partnerships between immigrant families of students with autism and educators.
CHAPTER II: LITERATURE REVIEW

The white wooden door swung open and the dazed African villagers stepped into their new home. It was a modest apartment with secondhand furniture and a stove in need of repairs. But to Osman Yarrow, his wife and five children, refugees from Somalia’s civil war, it seemed like a place of miracles.

Clean water coursed out of gleaming faucets, an astonishing luxury for a rural family who had spent more than a decade in mud huts without indoor plumbing. “Red for hot,” Mr. Yarrow repeated wonderingly as he held his fingers in the steady stream. “Blue for cold.”

...But what Mr. Yarrow treasured most on his first day in his American home was a sense of security. In Somalia, he witnessed the execution of his father and son by marauding militias. In Kenya, his family huddled in bleak refugee camps while bullets sang in the night.

(Swarns, 2003)

Introduction

Osman Yarrow and his family, as recounted in a 2003 New York Times story, are among the more than one million Somali refugees\(^4\) who have fled their homeland in the two decades since civil war broke out in Mogadishu in 1991 (Sheikh & Healy, 2009). The journey to the United States for such families has been anything but direct. Osman and his wife and five children started out in one of innumerable lawless villages that characterize the failed Somali state. The family then traveled southward on foot over some of the world’s most inhospitable terrain—blazingly hot and peppered with dry volcanic rock and

\(^4\) According to the United Nations High Commissioner for Refugees (UNHCR), a refugee is a person who is outside of his/her habitual homeland and unable to return to that state “owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership in a particular social group or political opinion.”
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bandits—to the Kakuma refugee camp in Kenya. (*Kakuma* means “nowhere” in Swahili, bespeaking the desolation of the camp.) While the family was still in the camp, the International Organization for Immigration (IOM) began to prepare the Yarrows for eventual resettlement. The family studied English and learned about modern appliances. They received lightning tutorials on U.S. culture. And then their turn came. The family, whose members had never flown on an airplane, traveled from Nairobi to New York City, where they would make a new home (Swarns, 2003).

*The Geography of this Chapter*

At the heart of this chapter is a systematic review of a body of literature that examines the collaboration between immigrant and refugee families of students with disabilities and educators. This corpus of scholarship outlines in detail several obstacles to authentic collaboration between educators and families. Because this study centers specifically on the collaboration between families from a particular background (Somali-American) and on a specific disability (autism), I preface the literature review with information that may give context to the experiences and perspectives of the actors in this proposed research.

Therefore, this chapter introduces background information about Somalia (geographic, historical, political) and about the Somali community in Boston. Next, in order to understand the set of ideas that educators of students with autism might have, I overview autism education (from a Western perspective) and the evolution of special education in the United States. To emphasize the degree to which American educators and Somali-American’s experiences with education differ, I provide a brief overview of the
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educational landscape in contemporary Somalia and in the refugee camps from which many Somali-Americans come.

*The Somali Landscape*

Somalia is the easternmost state on mainland Africa and extends along the entire arcing 1,800-mile coastline of the Horn of Africa (so called for its resemblance to a rhinoceros’ horn), from Djibouti all the way along the Gulf of Aden south to the Kenyan border (see figure 1). The Somali landscape is mostly flat, except for the northern coast, where the Karkaar mountains rise to nearly 6,000 feet. The climate is hot and dry year-round, lending itself to the traditional nomadic pastoral lifestyle practiced by most Somalis (Putnam & Noor, 1993). About 60 percent of the population are semi-nomadic herders of sheep, cattle, goat, and camels (Shepard, 2008).

Figure 2.1  
*Placing Somalia*

The population of Somalia is primarily ethnic Somalis (85% of the population), whose heritage reportedly can be traced to a group of Arabs who settled in the Horn of Africa roughly a millennium ago, when the region was famed for its production of
frankincense and myrrh. Somalia was known to the Egyptians as the Land of Punt, or “spices.” (Shepard, 2008).

Until recently, “Somalia was portrayed as one of the few countries [in Africa] where nation and state were synonymous, an island of ethnic homogeneity in a sea of multi-ethnic states” (Menkhaus, 2010). This perception has since been challenged. The Somali Bantus, who constitute roughly 5 percent of the country’s population and live primarily along the Jubba and Shabelle rivers of southern Somalia, gained international attention when they were given priority status for U.S. resettlement in 1999.5 “Bantu” is only a recent label for this group—coined by foreigners in the 1990s and then adopted within Somalia itself.6 Somali Bantus are a diverse group who do not share a common language, homeland, nor history (Menkhaus, 2010). Some are descendants of East African slaves (from the modern-day states of Tanzania, Malawi, and Mozambique) (Swarns, 2003) who arrived in Somalia during the 19th century via the infamous Zanzibar slave market. Others are aboriginal inhabitants who have lived in the country for centuries, long before ethnic Somalis moved into the Southern region of modern-day state (Menkhaus, 2010).

Contemporary History

As for the colonial legacy in Somalia, the late nineteenth-century “scramble for Africa” left Somali territories split among British, Italian, French, and Ethiopian rule (Besteman, 1999; Shepard, 2008). And it was not until 1960 that the Somali Republic claimed independence and named the country’s first president, Aden Abdullah Osman Daar,

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5 The first group of Somali Bantus was resettled in the U.S. in 2003. Osman Yarrow and his family were among this group.

6 Ironically, only one small group of so-called “Bantus” actually speaks a Bantu language. Many Bantus speak the Af-Maay dialect of Southern Somalia and others speak Af-Maxaa, or standard Somali (Menkhaus, 2010)
who would lead the country until 1967. His successor, Abdirashid Ali Shermarke, ruled for just two years, only to be assassinated and replaced by General Siad Barré in a military coup. Barré’s leadership was initially cause for pride for many Somalis, as demonstrated by a poem recited on the coup’s first anniversary:

\[
\begin{align*}
\text{Allaahu akbar waa Oktoobar} \\
\text{Wixi aadna amartaana} \\
\text{Oggol weeye moyee} \\
\text{Kuma lihin iinyow}
\end{align*}
\]

Hallelujah! It is [the month of] October
Whatever orders to give us
we will respond with a yea!
never uttering a Nay!
(Ahmed, 1996, p. 127)

But Barré’s military dictatorship would ultimately pit one group against another until the country was overcome by interclan tensions and violence (Pavlish, Noor, Brandt, 2010). By the end of the 1980s, the Somali military had disintegrated and former members joined their respective clan-based militias. Even the Somali capital, Mogadishu, was divided among various clan strongholds.

In January of 1991 armed opposition forces finally drove Barré out of power (he died in exile in Nigeria in 1995) (U.S. State Department brief). This coup led to the complete collapse of the Somali state (Pavlish, Noor, & Brandt, 2010; Scuglik, 2007), and over the past two decades, the country has not had a functioning central government. The end of Barré’s reign coincided with a drought that devastated crops and is estimated to have killed between 240,000 and 280,000 inhabitants (Slim, 2012). The combination of state failure and famine sparked a bitter and unending civil war along with mass exodus.

Somali Exodus
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Since 1991, hundreds of thousands of emigrants have crossed the Somali-Kenyan border on foot (others exited via Ethiopia), where many are sheltered en masse at the enormous Dadaab refugee camp and others, like the Yarrows, have settled at Kakuma. The unending inflow of Somalis to Dadaab (in 2011, the average was 1,400 a day) has stretched the camp borders into the arid scrublands of northeast Kenya (Rice, 2011). But for many Somali refugees, Kenya is only an intermediary stop en route to more permanent North American, European, or Gulf state residences (U.S. State Department Brief).

Somali Diaspora

According to American Community Survey data, 85,700 Somalis were living in the United States in 2010. Of those, approximately one-third live in Minnesota. The other two thirds are spread among places like Lewiston, Maine, Syracuse, New York, Kansas City, Missouri, and the Boston metropolitan area, which is home to more than 6,000 Somalis (Wolford, 2011).

Boston. In Boston and across the state, which hosts a total of 10,000 Somalis (Martin, 2011), the Massachusetts Refugee Resettlement Program oversees the resettlement of Somalis. Arriving families are met at Logan Airport, provided with basic furnished accommodations, and offered employment and language-learning assistance by local agencies, such as the International Institute of Boston (IIB), Refugee and Immigrant Assistance Center (RIAC), and Catholic Charities (www.massresources.org). After an initial six-month period during which arrivals receive government assistance, they must care for their own needs. Ethnic enclaves and informal networks of support therefore become primary.

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7 Dadaad, comprising three distinct camps (Dagahaley, Ifo, and Hagadera), represents the largest settlement of refugees in history—more than 400,000 as of 2011 (Rice, 2011).
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*Roxbury crossing, portrait of an enclave.* Today, the neighborhood of Roxbury is at the center of Somali culture in Boston. Although Somali families live in communities throughout the Boston Metropolitan area, from Lynn to Mattapan, and Roslindale, and even outlying suburbs, many visit Roxbury for the religious and cultural institutions it offers. A visit to the Roxbury Crossing subway station and its environs offers a firsthand sense of how Somalis are settling in to their new surroundings. The station sits roughly at the crossroads of the Mission Hill and Dudley Square neighborhoods of Roxbury.

A hub for Roxbury’s Somalis is the 68,000-square-foot red-brick mosque and Islamic cultural center that opened its doors just in time for Ramadan in 2009. Sitting at the corner of the Columbus Avenue thoroughfare and Malcolm X Boulevard, just across from the Roxbury Crossing subway station, the mosque accommodates up to 3,000 worshippers (Paulson, 2009). Building the mosque was a major feat for those involved, reflecting both steadfastness and a successful campaign against resistant and often intolerant voices in the Boston area. When its 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 had become well-trodden, and the mosque would be central to Boston’s Somali community.

Across the street from the mosque, within the T station, a more modest but perhaps equally striking establishment shows the area’s Somali influence. The Somali-owned *Butterfly Café* attracts urban professionals commuting to downtown Boston who stop for an egg sandwich or a cup of organic coffee, alongside older Somali men with hennaeed beards and skullcaps who are in no particular hurry and drink Somali chai and eat *helwa* (a gooey sweet). One of the café’s walls is lined with traditional Somali banquettes;
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Dahabshil—a service that allows patrons to wire money back to Somalia—is stationed across the room.

Between Roxbury crossing and Dudley Square are a pair of small Somali restaurants, Anshur and Dayib café. The two restaurants are owned by Somali brothers and offer similar menus of stewed meats accompanied by *bariis* (Somali rice akin to Indian biryani) or overcooked spaghetti, a salad of Iceberg lettuce and sliced tomatoes, and ripe bananas. The kitchen at Anshur has a Moroccan chef, so its menu tends toward the Maghreb with chicken *tagine* and *harira* (soup) intermixing with the traditional Somali fare. And directly above Dayib café is the neighborhood’s other, much smaller mosque—Masjidun Li Hamdi Allah, which has occupied the unassuming three-story brick building on Shawmut Avenue since 1970. Even with these institutions, which allow Somalis to maintain a connection to home, refugee communities are of course also shaped by the realities of American life. Community members shop for food and clothes in American megastores, send their children to school on yellow buses, and find jobs as taxi drivers, line cooks, and factory workers.

*Autism in the Somali Diaspora*

One surprising consequence of the contact between Somalis and Western culture is the not-yet-fully-understood autism cluster among Somali refugee children. This connection has been researched in the Somali populations in Minneapolis–St. Paul and Stockholm, Sweden (e.g., Barnevik-Olsson, Gillberg & Fernell, 2010; Delberto, 2011; Kirby, 2008, McNeil, 2013). As noted in Chapter 1, autism is virtually unheard of within Somalia: the Somali lexicon has no word to describe the condition (McNeil, 2009).
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Autism is generally believed to affect individuals equally across racial, cultural, and ethnic groups (Fombonne, 2005). However, as mentioned in chapter 1, some research has shown that autism diagnosis varies across ethnic and racial groups (e.g., Donovan & Cross, 2002, Estrem & Zhang, 2010, Schieve, Rice, & Boyle, 2006). In the case of Somali refugees, several hypotheses have been put forward to explain the pocket of high rates of autism diagnosis; these include consanguineous marriage, duplicated vaccination, and vitamin D deficiencies among an equatorial group resettled in low-sun northern climates (e.g., Barnevik-Olsson, Gillberg & Fernell, 2010; Kirby, 2008).

Almost a decade ago, a Somali refugee named Idil Abdull was living in Burnsville, Minnesota, when her son, Abdullahi, stopped talking at age two-and-a-half. Abdullahi was diagnosed with autism, a condition of which his mother had never heard. In the years that followed, Abdull met more and more Somali-American mothers of children with autism. And in 2009 she cofounded the Somali American Autism Foundation to support families like her own. In closing the wide gap between Western diagnostic tendencies and Somali resistance to such diagnoses (and often perplexity at the fact of them), each year Somali parents like Abdull join American-born special educators at public school conference tables across the United States to develop academic goals at annual IEP meetings.

Education for Students with Autism

In the past several decades, researchers have devoted considerable attention to studying education for students with autism spectrum disorders. Students on the autism spectrum tend to share certain characteristics (e.g., communication challenges, restricted interests) and yet they also represent a tremendous diversity in terms of strengths and needs. Educational programs for children with autism address a variety of skills—from
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Many voices at the table academics, social skills, to communication, and daily living skills. In addition to having particular educational goals, students with autism also tend to represent certain learning styles. They are generally visual, as opposed to auditory, learners and linear thinkers who struggle with abstraction.

Many methodologies have been developed to meet the particular learning needs of students with autism. Among the most popular are: (a) applied behavior analysis (ABA), (b) treatment and education of autistic and related communication-handicapped children (TEACCH), (c) floor time—the developmental, individual difference relationship-based model (DIR) (Zager, Wehmeyer, and Simpson, 2012), and (d) daily life therapy (DLT) (Tutt, Powell, & Thornton, 2006). Appropriateness of these and other approaches for teaching children with autism depends on a variety of factors including— (a) the child’s age, (b) child’s ability level and particular symptoms, (c) family preferences, (d) knowledge of providers and resources available locally.

Applied Behavior Analysis (ABA)

ABA is an evidence-based method for understanding and changing behavior and is grounded in Skinner’s (1953) notion of the direct relationship between human behavior and the environment. Researchers and practitioners have studied the principles of behaviorism and have drawn from them teaching strategies as well as programs for treating maladaptive behaviors that have been applied quite successfully to students with autism. The work of Lovaas (1987) is the most famous example of using the principles of ABA to teach children with autism. Lovaas pioneered an instructional approach called discrete trial training (DTT). DTT breaks skills into their component parts, prescribes leveled prompts and relies on positive reinforcement to facilitate skill acquisition (Scott &
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Bennett, 2012). Other teaching strategies that have come out of ABA include: chaining, shaping, video modeling, and differential reinforcement. ABA has been criticized by members of the autism rights movement for attempting to “render the autistic child indistinguishable from his peers” (Solomon, 2008, p. 7) by eliminating harmless behaviors and teaching socially acceptable skills at the expense of enhancing students’ natural tendencies.

TEACCH

The TEACCH program, developed in 1972 at the University of North Carolina at Chapel Hill, is based on the principles of structured teaching and is designed to capitalize on “visual strengths and personal sense of order” which characterize children with autism (Mesibov, Shea, and McCasskill, 2012). At its core, structured teaching is based on four principles: (a) individualize all strategies and goals, (b) provide external organization of space, time, and design of tasks, (c) use visual supports to supplement (or substitute for) verbal language, and (d) use special interests to engage attention and learning. Critics of TEACCH have argued that the model’s specificity makes it difficult to implement in mainstream educational settings, rendering it incompatible with the philosophy of inclusion (Mesibov et al, 2012).

Floor time/DIR

Floor time/DIR is a developmentally-based model of autism education, which emphasizes the importance of understanding children’s interactions and relationships with caregivers. Instead of focusing on isolated behaviors or skills (like ABA or TEACCH), DIR focuses on the underlying developmental processes and on the essential differences that underpin behavior (Greenspan & Wieder, 1998, 2000, 2006). Programs based on the floor
Many voices at the table

time/DIR approach often begin with playful interaction between child and caregiver (or therapist) on the floor. The primary criticism of floor time/DIR is that there simply is not enough empirical evidence to support its effectiveness and that it is best suited for young children (Greenspan & Wieder, 1998, 2000, 2006).

Daily Life Therapy (DLT)

The DLT method was developed in Japan and the first school founded on the orientation opened in Tokyo in 1969. The method is premised on the idea that children with autism should be educated in a holistic way and benefit from being part of a group (this is very much in contrast to the approaches to autism education described above which focus on individualized interventions and one-to-one teaching. Another important part of DLT programming is its emphasis on physical exercise, which is intended to increase both strength and concentration. Researchers (e.g., Howlin, 1998) have proposed that exercise benefits individuals with autism because the endorphins released by activity reduce both anxiety and hyperactivity. Studies have shown benefits to students educated in the DLT method, including: decreased aggression and other maladaptive behaviors as well as improvements in daily living skills (Howlin, 1998). However it has also been argued that the emphasis on conformity to the group might compromise individuals’ abilities to develop based on their own potential (Howlin, 1998).

ABA, TEACCH, Floor time, and DLT are among the models that have been influential in shaping instruction for students with autism. In reality, most children with autism are taught using an eclectic approach with educators drawing on these and other approaches to inform their instructional practices. All educational decisions pertaining to students with autism (e.g., What skills will be taught? How will teaching occur? What setting is most
Many voices at the table

appropriate?) can be understood within the context of the American special education system, which has a very particular culture and is defined by important documents (e.g., the IEP) and legal parameters (such as those outlined by IDEA).

How We Got Where We Are: The Evolution of American Special Education

The contemporary American special education system is the result of decades upon decades of legal decisions aimed at protecting the rights of a very vulnerable population (e.g., Smith, 2004). As recently as the 1970s, students with intellectual disabilities were essentially warehoused in enormous institutions where true education was scarcely a goal (e.g., D'Antonio, 2004).

Pulitzer prize-winning journalist, Michael D'Antonio (2004) portrays the Fernald State School (in Waltham, Massachusetts) in his book-length exposé, *The State Boys’ Rebellion*. The book depicts the atrocious condition of the institution, which (like many other similar institutions) “applied the principles of animal husbandry—attempting to weed out bad stock—to troublesome boys and girls” (p. 5). The children enrolled in these institutions (based often on misused IQ tests) “endured isolation, overcrowding, and forced labor, and physical abuse including lobotomy, electroshock, and sterilization” (p. 5) and left undereducated. *State Boys* is uplifting in its own way, though, portraying a group of boys who succeed at freeing themselves from the system. And the story of how special education has evolved in the U.S. since then is promising, too.

The concept of inclusion figures strongly in contemporary American special education (e.g., Algozzine & Ysseldyke, 2006, Katsiyannis, Yell, & Bradley, 2001). In this context, students with disabilities are expected, as much as possible, to be educated alongside their peers and to be held to comparably high standards as students without
disabilities (Berry, 2010, McGuire, Scott, & Shaw, 2006). However, these dramatic changes have come with a set of complicated processes and safeguards.

The “culture” of American special education is defined by protections afforded to people with disabilities by IDEA. IDEA is founded on six foundational principles—(a) zero reject, (b) non-discriminatory identification and evaluation, (c) free and appropriate public education [FAPE], (d) least restrictive environment [LRE], (e) due process safe guards, and (f) parent and student participation in shared decision making—are ingrained in special educators through their preparation and practice and govern the proceedings of IEP meetings across the country. These principles along with more specific state-level guidance dictate how special education “happens” in the U.S. The way that educational decision-making happens at IEP meetings is influenced not only by families and educators but by the IEP document itself and by the legislation that led to the creation of the IEP other documents.

The *IEP Process Guide* (Massachusetts Department of Education, 2001) articulates the special education process, dividing it into three overarching phases: (1) eligibility determination, (2) IEP development, and (3) placement. Each of these three phases is described in detail and divided into its component parts.

*Eligibility determination.* The first step in the eligibility determination process is to ensure that the school has provided the student with a solid core curriculum including “sound instructional practices and instructional supports” (p. 6) If a parent, caregiver, or professional is concerned that a student might have a disability, (s)he may refer the student for an initial evaluation to determine if the student needs special education services. The school must receive parental consent for this evaluation [603 C.M.R. §28.04(1)]. The school
is required to conduct the evaluation within 30 days of receiving parental consent [603 C.M.R. §28.04(2)]. A comprehensive evaluation should include information from a variety of sources including: (a) information provided by parents, (b) observation, (c) work samples, (d) interviews, and (e) cumulative record review.

**IEP Development.** Once a student has been evaluated and found eligible for special education services, an IEP must be developed. An IEP is an individual document designed to meet the needs of a particular student. Therefore, the document should be “responsive to the parents’ concerns and the student’s vision” (p. 11). At the heart of the IEP process is the IEP team meeting. According the Massachusetts Department of Education process guide (2001), “a well-managed team meeting will:

- Obtain parent/student input.
- Think about the student’s future dreams and goals.
- Understand how the student’s disability (ies) affect the student’s learning.
- Know how the student performs today.
- Address the area(s) that are affected by the student’s disability (ies).
- Provide focus for the student’s learning during the designated IEP period.
- Reflect high expectations for the student.
- Stay as close as appropriate to what the student’s peers are learning and doing.
- Identify supports and services the student needs for success”

(http://www.doe.mass.edu/sped/iep/proguide.pdf, p. 12)

The IEP is developed in its entirety before a placement decision is made because it is the IEP that guides placement decisions.
Many voices at the table

Placement. Once the IEP team has decided on the student’s educational needs and related services, the school district will collaborate with the team to make a placement decision. In accordance with IDEA-2007, the student must be placed in the least restrictive environment that will meet his/her educational needs. It is notable that family participation is seen as being important across all three phases of the special education process.

The Somali Educational System

The educational system in Somalia (and in the refugee camps where many Somalis have lived since 1991) is markedly different from the U.S. educational system. For one thing, no such thing as a special education system exists in Somalia. No relevant studies in English can be found covering the education of students with disabilities either in Somalia proper or the Dadaab or Kakuma camps across the border in Kenya.

All the same, a very few English-language sources point to trends that have shaped general education in recent Somali history. And, several key points in the U.S. discussion (e.g., protections for students with disabilities, the importance of parent involvement in education) are all but irrelevant in the Somali education system. Children with significant disabilities, for example, almost certainly received no formal education at all before arriving in the United States. So the encounter for Somali parents and children alike with America’s highly formalized system likely creates its own dissonance.

Traditional Education

In Somalia, it is estimated that in the 2011-2012 school year, only 710,860 out of 1.7 million (42 percent) primary-school aged children were enrolled in school. Of these, 36 percent are girls (www.unicef.org, Retrieved 9/21/2012). While contemporary American education emphasizes the importance of student participation and child-centered learning,
Many voices at the table

in traditional Somali education (i.e., outside of school) students are not expected to participate in discussions but rather to learn by listening and observing. In the Somali context, educational expectations of boys are distinct from those of girls. An example of an educational opportunity for boys might be to sit behind a circle of elders to watch how the decision-making process occurs. Girls’ education has traditionally been centered on domestic skills such as curing meat, raising livestock, weaving, and so on (Lewis, 2002).

Colonial Education

During the colonial era, two different Western-style school systems were introduced to Somalia—British (in the north) and Italian (in the south). In the British schools, instruction was in Arabic at the primary level and English at the secondary level. Italian schools, for their part, emphasized technical training (e.g., in agriculture, commerce, aviation). Like in the English schools, Arabic-language instruction in the early years was replaced by Italian later on. Following the withdrawal of the English and Italian colonial governments, education in Somalia roughly followed the respective models that had been established by the Western occupiers.

Education in Refugee Camps

For most Somali-American parents, their most recent experience with education occurred within the refugee camps. As of 2002, only 51 percent of Somalis living in refugee camps in Kenya attended school at all while there (Shepard, 2008). Initially the camps only had elementary schools, but as the conflict has worn on and the settlements have become more permanent, secondary-level schools have been added. Since 2004, graduates of these schools have been awarded Kenyan secondary-school certificates (Shepard, 2008).

A Vision of Collaboration: Parental Participation and Special Education
In the U.S. system (in contrast to the Somali system), parental involvement is viewed as being important across at three phases of the special education process (outlined previously). Indeed, educator-family collaboration is envisioned as a cornerstone of high-quality education for students with disabilities (e.g., Harry, 2008; Olivos, Friend & Cook, 2007, Gallagher & Aguilar, 2010). Friend and Cook (2007) emphasize the importance of collaboration in the context of special education decision-making and put forth the following definition (which will be the basis for all future discussion of the term in this piece): “a direct interaction between at least two coequal parties [educators and parents/guardians] voluntarily engaged in shared decision-making as they work toward a common goal” (p. 5).

Parental involvement in the special education decision-making process is not only an ideal, it is also one of the six founding principles of special education as outlined by IDEA (Lo, 2012, p. 15; see also Hess, Molina, & Kozleski, 2006; Jung, 2011; Olivos, Gallagher, & Aguilar, 2010). This principle is reflected in the IEP document itself, which includes a section for parents concerns and vision for the future of their child’s education. Because these areas for parent communication are outlined so explicitly within the IEP document, it could be hypothesized that parent participation is shaped by the document itself.

Despite both this legal emphasis and the philosophical orientation of the American special education system, true collaboration between family members and special educators is rare (Jung, 2011). In fact, research suggests that parent-teacher relationships are often defined by “passive” patterns as opposed to “genuine collaboration,” where both family members offer true opinions and decisions made reflect input from both parties (Harry, 1992; see also Hess, Molina, & Kozleski, 1996; Kalyanpur, Harry, & Skritic, 2000;
Studies show that educators frequently perceive parents as being to blame for the lack of collaboration (Friend & Cook, 2007), even as educators generally have more clout in setting the tone of the parent-teacher dynamic (Olivos, Gallagher, & Aguilar, 2010). These dynamics, are particularly pronounced in the arena of special education for children from immigrant and refugee.

The term “culturally and linguistically diverse [CLD]” is used frequently within special education literature. Findings from my review of the literature indicate that this term is used imprecisely—its meaning appears to vary from one context to the next. In some cases, CLD seems to be used to talk about immigrant and refugee families and first-generation students while in other places it is an umbrella term that also includes American-born families who are ethnic or racial minorities. Where applicable, I will specify literature that is related to immigrant/refugee families and first-generation students. In other places I will preserve the term CLD as used in a particular study.

A close analysis of the literature yields four important subthemes for understanding collaboration between immigrant and racial minority families and special educators: (1) language and other logistical considerations, (2) family beliefs about disabilities, (3) notions regarding collaboration and educational decision-making, and (4) characteristics of autism educators and their attitudes toward immigrant families. These four overarching themes have guided the development of the research questions for this proposed study (to be presented in chapter three). Although this literature review is grounded in special education scholarship but also includes research from related fields (e.g., psychiatry, medicine, anthropology, social work, speech and language pathology).

*Logistical Challenges: Language and Otherwise*

The most concrete category of barriers to collaboration between families and educators in decision-making involves logistics (language, scheduling, dissemination of information). These logistical obstacles are mentioned in many special education articles (e.g., Harry, 1992, Harry & Kalyanpur, 1994, Hughes, Valle-Riestra, & Arguelles, 2002, Jung, 2011, Lo, 2012, Nehring, 20076, Olvios, Gallagher, & Aguilar, 2010, Rogers-Adkinson,
Many voices at the table

Ochoa, & Delgado, 2003, Salas, 2004, Sontag & Schacht, 1994). However, they are generally not the emphasis of entire studies or conceptual pieces. In taking a closer look at these barriers, I have culled the following themes: (a) language, (b) timing and scheduling, and (c) provision of information.

Language

The most widely discussed impediment to participation of immigrant and refugee families in educational decision making is lack of fluency in English. Indeed, understanding special education discussions can be particularly challenging for non-native English speakers given the high level of technical jargon that such discussions entail.

One of the most obvious remedies for this language barrier is providing families with interpreters for oral communication and translation of written documents. However, the practices of interpretation and translation introduce another set of challenges (Harry, 1992; Jung, 2011; Rogers-Adkinson, Ochoa, & Delgado, 2003). Translators, for example, are hired by the school district. And this fact, coupled with the generally much higher level of education of translators than parents, creates an atmosphere in which parents be suspicious of the translators themselves and of the information that they convey. In short, “families may be sensitive to intrusions by community members who they do not trust” (Harry & Kalyanpur, 1994, p. 157).

Complicating matters further, several unprofessional practices have been reported among translators. Chief among these are: (a) abridgement of parents’ comments (even when the comments of school personnel are translated in full), (b) independent attempts to get parents to agree to or comply with professional opinions, and (c) imprecise translations due to lack of knowledge of special education processes and terminology (Harry, 1992).
Provision of Information

Even when language is not an issue per se, the way in which information is conveyed to families may pose problems. For example, “Some educators balk at the idea of providing too much information, perceiving that the information is complex and the procedures time-consuming” (Olivos, Gallagher, & Aguilar, 2010, p. 37). Research shows that immigrant and refugee families of children with disabilities often know relatively little about the services available to them (e.g., Nehring, 2007; Sontag & Schacht, 1994).

In fact, Sontag and Schacht (1994) surveyed 536 families and found that while parents of children with disabilities are likely to receive information about their child’s “medical or disability condition” (p. 429), they are less likely to receive information about services (e.g., educational, family support, rehabilitative). The researchers concluded that families seem to want more specific information about services available so that they can make more informed decisions about how to meet their children’s needs. More specifically, the study found that different racial and ethnic groups tend to have different levels of success in obtaining information about their children: Hispanic and American Indian parents report the highest levels of difficulty.

Schedules and Timing

Even when parents are well informed about the services available to their children, making the time to attend meetings and conferences can prove difficult. Most immigrant and refugee families of students with disabilities have many competing demands—from jobs with inflexible hours to the need for child care to medical and intervention appointments for the children with disabilities. The special education process itself constitutes a demand, which, as outlined previously, consists of many steps. Complicating
matters further, explain Olvios, Gallagher, & Aguilar (2010), is that “Too often CLD families are turned away from the school during times that are convenient for them because of school professionals’ lack of sensitivity to the reality of families’ schedules” (p. 36).

*Families’ Beliefs about Disability and Education*

Even as these logistical factors no doubt limit the possibilities for genuine collaboration between American-born educators and immigrant and refugee families, they are certainly not the only set of obstacles. Perhaps more significant are those intangible factors such as beliefs and perceptions held by both educators and families. Interestingly, the literature of special education (and related fields) attends to the beliefs of families and educators in notably different ways.

For example, a well-developed body of literature looks at the relationship between families’ ethno-cultural background and their beliefs about disability and appropriate education for students with disabilities. Yet little literature investigates educators’ beliefs in the context of their ethno-cultural background. In contrast, special educators’ stereotypes of families from different cultural backgrounds have been examined closely while families’ perceptions of educators have not received the same attention.

Many non-Western cultures have different definitions of medical and mental disorders and their causes based on their unique social, economic, and political history... and may qualify what is normal and abnormal functioning differently than do people in western nations. (Welterlin & LaRue, 2007, p. 750)

One fundamental assumption about the interaction between special educators and immigrant and refugee families is that discordant parent-educator views about the nature of disabilities often hinder harmonious collaboration. In short, “conflict may occur when
families disagree [with professionals] on the view of disability and treatment” (Zhang and Bennett, 2003, p. 55).


Mickelson, Wroble, and Helgeson’s (1999) precise literature review of parents’ beliefs about disability articulates that, for many children with intellectual disabilities, “there is no clear etiological cause for the disability...[and] this uncertainty intensifies the search for a cause because people have a difficult time that no reason exists for a traumatic event” (p. 1263). Because of this uncertainty, parents often develop their own theories or “causal attributions” to make sense of a child’s disability.

Harrington, Patrick, Edwards, and Brands (2006)’s quantitative study relies on survey data to assess parental perceptions of the causes of autism. The results indicate that the beliefs of parents⁸ of children with autism as related to the etiology of the condition fell into eight distinct categories (listed in order of perceived importance): (1) immunizations, (2) genetic predisposition, (3) environmental exposure (mother or child), (4) early

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⁸ The ethnic backgrounds of these parents were not described within the study.
Many voices at the table

childhood illness or injury, (5) pregnancy complication, (6) antibiotic taken by child, (7) other medication taken by child, and (8) premature birth (p. 456). And although the causes of autism are not well understood by anyone, professionals and even researchers included—there is an implicit suggestion within scholarly literature that parents’ perspectives are more varied and capricious than the corresponding views held by professionals (e.g., that autism is caused by genetic and/or environmental factors).

In particular, the perception exists that parents’ (unlike professionals’) attributions of disabilities are yoked to their ethno-cultural background. In noting this trend almost two decades ago, Harry and Kalyanpur (1994) remarked that “many professionals from non-mainstream cultures [hold] the assumption that the school’s view of disability reflects an objective or, at least, a universal truth, and that remedies they will prescribe reflect state-of-the-art practice” (p. 145). I extend this argument, contending that scholarly literature, which studies parents’ beliefs but not those of teachers, serves to reinforce this assumption.

In examining literature on parents’ beliefs about their children’s disability, we find that beliefs can be divided into three subsections: (a) cause or etiology, (b) the course of the disability, and (c) appropriate treatment or remediation.

Furthermore, Patricia Hill Collins’ notion of intersectionality, which posits that individuals have complex and interlocking experiences that are differentially centered and marginalized through power structures, provides the framing mechanism as we proceed through this section. Central to Collins’ principle is the idea that our beliefs are informed by multiple identities and lived experiences (Collins, 2000) I therefore caution readers not to use the explicit information presented to draw sweeping conclusions (e.g., “Mothers of children with spina bifida believe X”; “Chinese-American families of children with
Many voices at the table

disabilities think Y”). Rather, particular findings are presented in the service of portraying the spectrum of possible beliefs and spurring critical thinking about how conceptions of disability figure in the educational decision-making process.

Etiology

At the most basic level, individuals’ beliefs about disability include thoughts about what causes disabilities to occur in the first place. Although the causation of disability may seem straightforward, in fact, disabilities can be attributed to a wide variety of causal sources (from genetic mutations and environmental toxins to infractions committed in a previous life or by a relative). In her exquisite and now-renowned depiction of the clash between a small county hospital in California and the refugee Hmong family of a young girl with epilepsy, Anne Fadiman (1998) explains the family’s understanding of the daughter’s first seizure:

When Lia was three months old, her older sister Yer slammed the front door of the Lees’ apartment. A few moments later, Lia’s eyes rolled up, her arms jerked over her head and she fainted. The Lees had little doubt what had happened [to their daughter, Lia]...the noise of the door had been so profoundly frightening that her soul had fled her body and had become lost. They recognized the resulting symptoms as *quag dab peg*, which means ‘the spirit catches you and you fall down.’

(Fadiman, 1998, p. 20)

This description is effective because it portrays the family’s beliefs as issuing from a logical interpretation of available information. Lia’s doctors’, however, had very different explanations for this same event. The dissonance between Lia’s family and her doctors persists and, ultimately leads to Lia’s tragic decline. This story, highlights the importance of closely considering and eliciting the perspectives of others, and being mindful of how these perspectives interact and contrast with our own.
Table 2.1
*Summary of Parents’ Beliefs regarding the Etiology of Disability*

<table>
<thead>
<tr>
<th>Culture</th>
<th>Disability</th>
<th>Attribution</th>
<th>Citation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chinese-American</td>
<td>Unspecified</td>
<td>Punishment for parent’s violation of a religious, moral, or ethical code</td>
<td>Ryan &amp; Smith, 1989</td>
</tr>
<tr>
<td>Sephardic Jewish</td>
<td>Unspecified</td>
<td>Religious or magical causes</td>
<td>Stahl, 1991</td>
</tr>
<tr>
<td>Cultures that believe in reincarnation</td>
<td>Unspecified</td>
<td>Transgression in a past life</td>
<td>Lui, 2005</td>
</tr>
<tr>
<td>African-American, Asian/Pacific Islander, and Latino</td>
<td>Unspecified</td>
<td>Less likely to see personality or familial, or relational factors as causing a child’s disability</td>
<td>Yeh et al., 2004</td>
</tr>
<tr>
<td>Korean-American</td>
<td>Unspecified</td>
<td>Punishment from God</td>
<td>Park &amp; Turnbull, 2001</td>
</tr>
</tbody>
</table>

*Course*

In addition to holding disparate beliefs about the causes of disabilities, families (and professionals) may have diverse beliefs in regard to a condition’s course (see Table 2 for a summary of parental beliefs related to the course of disability). And these beliefs are hypothesized to be correlated with perceptions of educational goals and treatment decisions (Mendell & Novak, 2005). For example, a parent who believes that autism is
Many voices at the table curable “may follow a treatment regimen designed to cure the disorder. If symptoms are not ameliorated, [the parent] may become frustrated and switch or add treatments” (p. 112). On the other hand, a family who believes that the symptoms of autism can be treated but that the condition itself cannot be cured may make “more stable treatment decisions” (p. 112). And finally, families with a fatalist perspective may not set the goal of changing the course of the condition. What is clear from this literature is that a vast array beliefs exist about disabilities. Although scholarship does not articulate well the ways in which educators make sense of disabilities and the extent to which their beliefs are varied, it is easy to imagine the ways in which educators’ beliefs might differ from families lead to misunderstandings in educational planning processes.

Table 2.2
Parents’ Beliefs about the Course of a Child’s Disability

<table>
<thead>
<tr>
<th>Disability</th>
<th>Culture</th>
<th>Belief</th>
<th>Citation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>Latino-American</td>
<td>fatalismo—one cannot alter one’s fate</td>
<td>Flores, Bauchner, &amp; Feinstein, 1999</td>
</tr>
<tr>
<td>Autism</td>
<td>Chinese-American</td>
<td>Autism is temporary. Hope that child will outgrow it.</td>
<td>Ryan &amp; Smith, 1986</td>
</tr>
<tr>
<td>Not specified</td>
<td>Cultures that believe in reincarnation</td>
<td>Disability is temporary in the context of continuing from one life to the next.</td>
<td>(Reiter, Mar’I, &amp; Rosenberg, 1986)</td>
</tr>
</tbody>
</table>
Many voices at the table

No research to date explicitly explores the beliefs of Somali-American parents on disabilities. One study, Kediye, Valeo, and Berman (2009), introduced in chapter 1, discusses the experiences of a group of Somali-Canadian mothers in raising children with autism. The study’s findings provide highly relevant and interesting information about the stress experienced by these mothers as they seek support for the children. A discussion of the mothers’ perceptions of the cause, course, and treatment of autism is, however, outside the scope of the authors’ work.

Somali-American conceptions of health and mental health, however, have been outlined in scholarly literature. While these conversations are not specific to disability, a thoughtful interpretation of their contents can help frame an understanding of disability (and more specifically autism) in the Somali-American context.

In thinking about health and medical care in general, Somali patients are accustomed to a system defined by personal relationships and care. They expect to know and be known by their physician and for the doctor to be able to integrate their symptoms quickly and assign an appropriate treatment regime (Groen, 2009). In contrast, the American medical system requires that doctors see many patients and allots a short reimbursable visit for each one. Doctors rely heavily on the results of diagnostic tests and laboratory analysis and are unlikely to give definitive advice at an initial visit (Groen, 2009).

Brown, Carroll, Fogarty, and Holt (2010) offer an in-depth analysis of misunderstandings between Somali-American women and American doctors in the context of obstetrical interventions. Their findings suggest that in order to provide culturally competent medical care, American doctors need to understand their Somali patients’ fear about routine American medical procedures (e.g., that cesarean sections could result in
Many voices at the table
dearth) and that their practices should provide patients with access to information about
how the American medical system works and should “explicitly incorporate Somali
women’s views in a respectful manner” (Brown, Carroll, Fogarty, & Holt, 2010, p. 225).

Furthermore, many Somali patients have different beliefs on the etiology of disease
and disability than their Western physicians. Traditionally, Somalis believe in a connection
between health and the spiritual realm—that, for example, an illness may be caused by
waddado (spirit possession) (Scuglik, et al, 2007) or as “part of Allah’s destiny” (Pavlish,
Noor, & Brandt, 2010, p. 355). These “discordant health beliefs” have often devolved into
difficult misunderstandings (Pavlish, Noor, & Brandt, 2010, p. 355). The result is that many
Somali refugee patients become confused by and frustrated with their care and are
subsequently less likely to seek medical attention even when it is highly necessary (Groen,
2009).

Mental health the Somali-American context. Such misunderstandings may be
particularly pronounced in the arena of mental health. Whereas Somali patients might be
somewhat comfortable discussing physical concerns with their physicians, they are likely
less willing to discuss concerns related to mental health, which are highly stigmatized in
Somali culture. Somalis may, for example, see individuals’ reactions to traumatic events
(e.g., experiences associated with the Somali civil war) as being purely situational and
“normal”—not something that warrants a label or clinical attention (Boynton et al., 2010;
Ellis et al., 2010). And although many American patients are comfortable seeking mental
health treatment, the majority of Somali families care for their loved ones with mental
illness at home, in part, to avoid the stigma of seeking medical care (Ellis et al., 2010).
Beyond the question of stigma, traditional Somali notions of mental health are simply quite different from corresponding Western notions. As mentioned in chapter 1, for Somalis, the concept of mental health has traditionally been viewed as a strict binary: “sane” versus “insane.” Within this model, the term “insane” is reserved for those who are violent or whose behavior simply cannot be controlled (Ellis, 2010). Although no explicit discussion of these Somali notions exists within special education scholarship, it is interesting to note that autism (and other disabilities, for that matter) does not fit neatly within the “sane”/”insane” binary and that this type of condition, dwelling in a sort of gray area, might challenge traditional Somali categories of mental health.

**Beliefs about Education for Students with Disabilities**

Some studies have found non-U.S.-born families to be impressed by the comprehensiveness of services available (e.g., Bailey et al., 1999, Park & Turnbull, 2001). Others (e.g., Bernier, Mao, & Yen, 2010, Harry, Rueda, & Kalyanpur, 1999) reiterate the importance of understanding families’ particular views and needs in developing appropriate educational goals.

Park and Turnbull’s (2001) qualitative study on the beliefs about and perceptions of the U.S. special education system held by eight sets of Korean parents’ overall satisfaction on many fronts. In fact, some of the parents interviewed had come to, or stayed in, the U.S. expressly so that their children could access U.S. services. Satisfaction was based, first of all, on the parents’ belief that their children were receiving high-quality services and also on the fact that comparably fewer services were available in Korea. They were pleased, in particular, that curricula were tailored to meet the specific needs of individual students. In
addition, parents were impressed when they first attended an IEP meeting by the attention given to their child’s progress by a host of professionals. Korean parents, who are accustomed to treating professionals with respect and deference, were also excited by the U.S. system’s emphasis on parents’ active involvement in children’s educational decisions. Finally, Korean parents, who traditionally interpret disabilities as “a punishment from God,” were happy to learn about the benefits to which they were entitled to help them enrich their child.

Bailey et al.’s (1999) mixed methods study of the perceptions and beliefs of 100 sets of parents of Hispanic (50 Mexican; 50 Puerto Rican) students with disabilities revealed overall awareness of and satisfaction with the services available to their children. Approximately two thirds of parents surveyed were aware of the services available to their children and, on average, parents reported being “moderately satisfied” with the services they received. Factors that led to dissatisfaction with services included: not understanding written or oral communications, not receiving information related to the services available, being sent from one place to another without receiving services, and feeling discriminated against as Latinos.

Harry, Rueda, and Kalyanpur’s (1999) study of seven families of students with disabilities (races and ethnicities included African American, Hispanic, Trinidadian, Palestinian, and Chinese), which relied on both ethnographic and participatory action research (PAR) methods, illustrates the ways in which professionals can provide assistance that is relevant to a particular family’s needs rather than “targeting goals that are normative for the mainstream, but not for the family” (p. 123). The researchers use these results to suggest that professionals must recognize that beliefs about disabilities are
culturally based rather than universal. Also, they conclude that service providers need to account for heterogeneity within culturally diverse groups—to attend only to the skills-based level of the group risks stereotyping individuals according to group traditions.

Bernier, Mao, and Yen's (2010) "Psychopathology, families, and culture: Autism" offers a comprehensive review of literature relating to parents' beliefs about autism spectrum disorders. One of the piece’s most significant contributions is its comprehensive overview of the relationship between cultural background and treatment decisions. The authors make a strong case that “perceptions of treatment are influenced by cultural values” (p. 860). Although this notion had been put forth previously, Bernier, Mao, and Yen provide specific examples and emphasize not only the cultural values held by “diverse” families but also the cultural underpinnings of the American special education system.

In covering this ground, the authors explain that “a high value is placed on individualism in Anglo-American culture, whereas some other cultures have a more collectivist orientation, prioritizing the group over the individual” (p. 861). This contrast may directly influence ideas about what constitutes appropriate educational goals. For example, the behavioral interventions so popular within the American special education system often aim at “fostering independence and self-help skills” (p. 861) while families of various backgrounds may prize skills that allow students to participate in family and group activities.

In drawing out this distinction, Mexican-American families may be keen on having their children learn to be polite and obey authority figures, while Anglo-American parents may prefer for their children to develop independent thinking skills. Autism education programs, in particular, often focus on “recognition and expression of emotion” (p. 861).
Many voices at the table

This focus may not be in line with the belief systems of families from cultures that “value private over public displays of emotion and discourage outward emotional displays” (p. 861).

Beliefs About Collaboration and Educational Decision-Making

As mentioned earlier, the very idea of family-educator collaboration, with its underlying assumptions of a relationship among coequals and the importance of self-advocacy, is grounded in Western ideals (e.g., Jung, 2011, Lo, 2012, Sheehey, 2006). Research shows that some families of students with disabilities strive to “maintain a modest, compliant, and agreeable stance with school professionals in order to nurture good relationships on behalf of their children” (Jung, 2011, p. 22). The preference for amicability and the inclination to avoid conflict result in parents taking a passive role and “entrusting their children’s education to the school professionals” (Jung, 2011, p. 22). In the context of an IEP meeting in particular, this stance can lead to parents viewing an educator’s opinion as final rather than negotiable and can prevent a parent from speaking up even if her perspective is at odds with that of the school.

Sheehey's (2006) qualitative study of the beliefs of rural families of native Hawaiian descent explores, along with other topics, parents’ beliefs about what constitutes involvement in educational decision-making. Among the interesting themes revealed by the study was a tendency by participants to conflate educational decision-making with “frequent informal exchanges of information with teachers”— regardless of the content of those exchanges. This belief, Sheehey explains, is in keeping with the “talk-story discourse style characteristic of Hawaiian communication” (p. 12) and with the centrality of interpersonal relationships within that indigenous community.
Harry’s (1992) ethnographic study of 12 Puerto Rican–American families of children with learning disabilities and mild mental retardation addresses “the challenges of parent-professional interaction in a cross-cultural context” (p. 471). Harry’s data reveal that the expectation by families from traditional Hispanic backgrounds to participate only minimally in their children’s schooling does not reflect, as is popularly believed, a high level of trust in school authorities. Nor does deference to school authorities, as the study reveals, imply parental trust. This lack of trust, according to Harry’s interviews and observations, was grounded in a number of factors. For one thing, the school system in Puerto Rico is defined by highly personal communication. In contrast, the mainland U.S. system—defined by a medical view of disability and intended to be “objective” (p. 489)—seemed “unpersonal and uncaring” (p. 479) to Puerto Rican–American parents. In such a context, parents were relegated to merely giving consent to “experts” rather than acting as full collaborators.

In seeking to understand the cultural dissonance she encounters, Harry considers Hall’s (1977) concept of “high-context/low-context” cultures. In high-context cultures communication involves a wide range of content surrounding a particular piece of information and relies on personal delivery and affect. American law, in contrast, is markedly low-context. American special educators tend to speak clearly and directly, which may be interpreted by families as evidence of coldness or distance (Jung, 2011). And even when the logistical and linguistic barriers to participation have been overcome, research shows that parents and educators may take part in a dynamic that inhibits participation.

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9 This term, preserved from the original study, is no longer used in special education literature.
Many voices at the table

Trainor’s (2010) qualitative study of educators’ expectations of parent participation is framed by critical theoretical perspectives and examines, in particular, the roles of social and cultural capital. The study consists of three focus groups of educators (mainly special educators). Analysis of data from the focus groups indicates educators’ awareness of their responsibility to promote collaboration with families—and that they take this responsibility seriously. Generally speaking, educators reported the belief that immigrant and refugee parents, in particular, face many barriers to authentic collaboration with educators. Educators focused primarily on surface-level barriers (e.g., scheduling constraints, language barriers), neglecting almost entirely the complex interaction among intangible barriers including “diversity, power and status, and poverty” (p. 40).

Characteristics of Autism Educators and their Beliefs about Immigrant Students and Families

A dearth of empirical literature addresses the qualities of and characteristics of American special educators who teach children with autism in the U.S. (Hendricks, 2011). Available research outlines the areas in which teachers report feeling the most comfortable (addressing behavior, individuation etc.) (Hendricks, 2011) and implies that a connection exists between teachers’ cultural backgrounds and their practices/beliefs (Taylor & Sobel, 2001). However, few specific details are presented.

Although special educators’ beliefs about disabilities themselves have not been widely studied, these educators’ perceptions of students and families from diverse backgrounds have received considerable scholarly attention. Empirical research conducted in this arena looked at educators’ stated perceptions and actions as they related to immigrant and racial minority students and families (Aloia, Maxwell & Aloia, 1981, DeMeis
Many voices at the table


In the 1970s and 1980s, in particular, a class of attempts employed hypothetical case studies and manipulated demographic characteristics of students and families in an effort to determine whether educator bias influenced special education referral decisions. Almost universally, these studies found that students’ race was an important factor in teachers’ referral decisions (Tyler, Yzuierdo, Lopez-Reyna, & Flippin, 2004). For example, Zucker and Prieto (1977) found that teachers were more likely to deem a special education placement appropriate for Mexican-American students as compared with peers of European decent.

In recent years, an increased awareness of overrepresentation of minority students in special education has changed the landscape, and more recent studies show more varied findings. Some studies do not indicate an interaction between student race and ethnicity and teacher referral practices (e.g., Bahr, Fuchs, Stecker, & Fuchs, 1991, MacMillan, Gresham, Lopez & Bocian, 1996) while others find that a referral bias is still present (Andrews, Wisniewski, & Mulick, 1997; Sturges & Moore, 2002)

Kalyanpur, Harry, and Skritic’s (2000) study found that educators’ beliefs about participation in special education decision-making processes are reinforced by the American special education system itself, which is underpinned by positivist values that prize scientific processes such as observation and experimentation for arriving at “knowledge.” This orientation naturally gives professionals an edge over parents in the IEP process. At an IEP meeting, for example, educators may support their position by using
Many voices at the table

statistics or graphs of student progress. The result is that parents, who likely have only anecdotal observations, may feel inadequate as participants in the conversation and may shy away from sharing their impressions.

Power Asymmetries

While Friend and Cook’s (2007) notion of collaboration involves interactions among “coequal parties” in the context of special education decision-making, “educators are generally the ones who decide the parameters of the relationship” (Olivos, Gallagher, & Aguilar, 2010, p. 31). Given this assumption, families (particularly those who are not educated and who come from low socioeconomic backgrounds) may not be validated as “legitimate stakeholders” (Olivos, Gallagher, & Aguilar, 2010, p. 31). Special education researchers have proposed several practical suggestions for reducing the power differential between educators and parents. Suggestions include (a) holding meetings at round tables to suggest equal status among participants (Dabkowski, 2002), (b) giving parents access to information prior to IEP meetings (Lytle & Bordin, 2001), (c) meeting with parents one-on-one (i.e., as opposed to in large IEP meetings) (Lo, 2012), and (d) providing parents with documentation in their native language and that matches their educational level (Lo, 2012).

Conclusion

The importance of effective family-educator collaboration in supporting students with disabilities is well established within special education scholarship. And the challenges of achieving true collaboration between American-born special educators and immigrant and refugee families is widely written about as well. This literature review has systematically outlined four of the most widely reported barriers: (a) logistical and language barriers, (b) family beliefs about disabilities and about the education of students with disabilities, (c) beliefs about
Many voices at the table

collaboration and educational decision-making, (d) and educators’ perceptions/stereotypes of immigrant and refugee families.

Within special education scholarship, these topics are clearly articulate and the ways in which they threaten collaboration between families and special educators follows logically. Absent from the literature, however, are studies that examine the ways in which families and educators interact and collaborate in the educational decision-making process and the ways in which both parties’ behaviors are shaped by their perspectives and experiences. Further, the literature tends to view ethno-cultural groups as being monolithic (e.g., Puerto Rican–American parents emphasize collective experiences whereas American educators prioritize independence). An important need exists for studies that look closely at both the similarities and differences among members of the same ethno-cultural group. Also needed are studies that examines, on the same terms, the behaviors and perspectives of educators and family members in the educational planning process. Finally, close analysis is needed of not only impediments to collaboration between immigrant and refugee families and educators, but also examples that highlight elements of the planning process that work well.
CHAPTER III: METHODOLOGY

This study explores the nature of the collaboration between American-born special educators and Somali parents of boys on the autism spectrum in developing educational goals. More precisely, through this research, I aimed to explore participants’ explanatory models of autism and the connections between these and notions of appropriate autism education. The study consisted of a qualitative multiple case studies design across the educational decision-making processes surrounding three Somali-American boys with autism.

Research Questions
1. What is the nature of the collaboration between Somali-American parents and educators in devising educational and treatment goals for children on the autism spectrum?

2. In what ways do Somali-American parents’ explanatory models about autism resemble/differ from those of educators?
   a.) To what extent do parents’ and educators’ explanatory models influence their own notions of appropriate education for students on the autism spectrum?
   b.) How do families’ and educators’ multiple identities and lived experiences interact and influence ideas about educational goals for students with ASDs?

3. How are parents’ and educators’ notions about what constitutes appropriate education for students on the autism spectrum reflected in the outcome of the IEP process (e.g., signed IEP, refusal of special education services, mediation)?
Design of the Study

A qualitative multiple case studies design, as outlined by Yin (2009), was used to explore the nature of the collaboration among Somali families of children with autism and American-born special educators. In designing this study, I established criteria for all critical aspects of the methodology including: (a) identification of setting, participants, and materials, (b) procedures for collecting and analyzing data, and (c) safeguards for maintaining the integrity of the study (e.g., trustworthiness, credibility).

Qualitative Multiple Case Studies Design

In order to understand the nature of the collaboration between educators and Somali-American families of students with autism, I designed a qualitative multiple case studies design of the educational planning process across three Somali-American boys with autism spectrum diagnoses. The case study design allows researchers to derive meaning about complex social phenomena while “retain[ing] the holistic and meaningful characteristics of real-life events” (Yin, 2009, p. 4) and is well suited to addressing research questions that explore the nature of a particular phenomenon (e.g., the educational planning process). In addition, the case study design allows for “multi-perspectival” analyses that will allow me to foreground not only the voice of an actor or group of actors but also the interactions among these actors. As such, the case study design lends itself particularly to studying units of analysis that are “systems of action” (Tellis, 1997), such as the educational decision-making processes central to this study.

The case study design is not yoked to particular types of evidence or epistemology—qualitative, quantitative, and mixed methods case studies are possible. Given the nature of my research questions, I collected qualitative evidence alone and
Many voices at the table
gathered three distinct types of evidence for each of the three cases: (a) in-depth interviews with family members and educators, (b) direct observation (e.g., at home, in classrooms, and at IEP meetings/EI therapy sessions), and (c) analysis of educational and diagnostic documents in students’ files.

Case study research includes both single and multiple case study designs (Yin, 2009). As noted, I conducted a multiple case studies design, which affords “substantial” analytical benefits as compared with single case study designs and allowed me to see both similarities and differences across three carefully selected cases (Yin, 2009, p. 61). In this study, the cases, while not intended to be “direct replications” of one another, were selected to share certain characteristics (e.g., gender, ethnicity, diagnosis), which allowed me to explore the phenomenon (educational decision-making) across cases.

Each of the three distinct sources of evidence (interviews, observations, and documents) offered a unique contribution to the study. Table 3.1 provides a more in-depth description of the types of evidence that will be collected along with a rationale explaining how each type of evidence will contribute to the present study.

Table 3.1
Sources of Evidence Across Cases

<table>
<thead>
<tr>
<th>Type of Evidence</th>
<th>Description</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observations</td>
<td>1. Initial educational observation</td>
<td>Initial (home and school) observations allowed me to form judgments about the students’ functioning across environments and about priorities for</td>
</tr>
<tr>
<td></td>
<td>2. Initial non-educational observation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. IEP team meeting observation</td>
<td></td>
</tr>
</tbody>
</table>

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Many voices at the table

<table>
<thead>
<tr>
<th>Interviews</th>
<th>the students’ educational goals. These judgments informed my interviews and observations at IEP meetings.</th>
<th>Observation at IEP team meetings provided me with insights into negotiations among educators and family members.</th>
<th>Observation at the IEP meeting guided the development of post-meeting interview questions.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-IEP meeting interview with parent</td>
<td>Pre-meeting interviews allowed me to probe teachers’ and parents’ perspectives on the process of developing educational goals, autism itself, and the notion of family-educator collaboration.</td>
<td>Post-meeting interviews allowed me to bring observations from the meeting back to participants to give them the opportunity to explain their thought</td>
<td></td>
</tr>
<tr>
<td>Pre-IEP meeting interview with educator</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immediate post-IEP meeting interview with parent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immediate post-IEP meeting interview with educator</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow-up post-IEP meeting interview with parent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow-up post-IEP meeting interview with educator</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

11 In one case, the pre-IEP meeting parent interview was not audio-recorded for logistical reasons. Copious field notes were taken instead.

12 In one case, the educator was not interviewed prior to the IEP meeting for logistical reasons. In this case, the first interview (immediately following the IEP meeting) was based on the questions from both interview protocols 1 and 2.
Many voices at the table

| Documents | Examples include assessments and diagnostic reports from students’ files, draft IEPs, and final IEPs. | Data collected from documents will be used to support observation and interview data (e.g., a parent’s perception of having influenced the development of the IEP may be supported by the addition of a particular goal to the student’s IEP). |

Each of the three case studies centered on the decision-making processes in relation to setting educational goals for students with autism. Collection of evidence for each of the three cases occurred in a prescribed order to offer as comprehensive as possible a picture of the events at the IEP meetings (e.g., initial observations of students allowed me to form opinions about the students and to deepen my understanding of the proceedings of the IEP meeting). Each piece of data collected contributed to my evolving understanding of the phenomenon at hand. The data collection process for each of the case studies occurred in the following order:
1. Initial observations of the student.
   - *Out-of-School.* Initial observation of the student interacting with parent. Observations lasted between 30 minutes and an hour. Observations of Idris and Aadan took place at home, while Bilal’s observation was at the Somali Development Center (SDC), where his mother worked on weekends and an environment in which he was very comfortable.
   - *At School.* Observations lasted a minimum of 30 minutes and featured the case student in an educational setting. Idris and Bilal were observed in their classrooms while Aadan was observed working with his developmental specialist during an early intervention (El) session.

2. Pre-IEP-meeting interviews with caregiver and educator. Interviews were conducted at school for the educators and at home or another outside-of-school location¹³ for the caregivers.

3. Observation at the IEP meeting. Observation lasted for the duration of the IEP meeting (i.e., 1-3 hours). The educator and caregiver participating in the interview portion of this study were both be present at the meeting.

4. Immediate post-IEP-meeting interviews with caregiver and educator (order of these interviews can vary) were be conducted within one week of the IEP meeting.

5. Follow-up post-IEP-meeting interviews with the caregiver and educator were be conducted between one and two months after the IEP meeting.

¹³ For convenience, one interview was conducted as an Indian restaurant and several others were conducted at mothers’ workplaces.
Many voices at the table

6. Document analysis was conducted across the interview and observation process. I will conduct a final review of all relevant documents once the final interview is completed.

Theoretical Frameworks

Applying qualitative methodologies to studies of the education of students with autism is relatively unusual. Historically, scholarship pertaining to autism spectrum disorders (ASDs) and other developmental disabilities has been closely aligned with the fields of psychology and medicine. As such, research in this area has traditionally been guided by behaviorist and positivist theoretical frameworks and has relied on quantitative methods to investigate its research questions. I argue that these lenses fail to encompass the tremendous diversity of students with autism. ("If you've met one child with autism," the saying goes, “you've met one child with autism.”) Therefore, positivist frames are insufficient in addressing the range of questions related to how educational services are delivered to children with ASDs and particularly for those who are also from immigrant and refugee families.

This study draws on anthropological and sociocultural frameworks and views autism as a phenomenon with not only biological but also social underpinnings (Grinker, 2007). In this regard, I follow a pioneering group of autism researchers (Ochs, Kremer-Sadlik, Sirota & Solomon, 2004; Ochs & Solomon, 2004; Sterponi, 2004; Jegatheesan, 2005; Kremer-Sadlik, 2005; Grinker, 2007; Sirota, 2010) who have examined autism using qualitative methodologies. Four particular theoretical frameworks have guided the development of this research project: (a) intersectionality, (b) phenomenology, (c)
Many voices at the table

explanatory models, and (d) institutional ethnography (IE). These frameworks overlap with and complement one another in giving context to the present study.

*Intersectionality*

Intersectionality, which originated in feminist sociological theory, posits that biological, social, and cultural categories (e.g., race, gender, disability status) are “multiple and interlocking” (Bowleg, 2012, p. 1267) and that discrete forms of oppression shape and are shaped by one another (e.g., Bowleg, 2012; Collins, 2000; Pearson, 2010). My work is not the first to use this paradigm to explore the experiences of individuals in light of both disability status and cultural background. For example, in her autoethnography covering her life with impaired hearing, Pearson (2010) explored the intersections of ethnicity and (dis)ability and articulated a more nuanced description of her own experiences than either disability studies or East Asian studies, or both together, would have allowed.

In viewing the present study through the lens of intersectionality, I suggest that all participants’ perspectives represent complex combinations of experiences and, in doing so, seek to challenge readers to recognize the uniqueness inherent in each family, student, and educator. The intersectionality lens also, makes visible the ways in which various vectors of power intersect with one another, influencing individual’s experiences of power (e.g., Saida articulates quite clearly the extent to which her educational goals for Bilal are influenced by the intersection of his disability, gender, and race—because he is a “black boy” in America, the behavior differences associated with autism are likely to be more problematic for him than they would be for a white girl, for example.)

My intention is to avoid the tendency to see the study’s findings as being generally applicable to specific demographic groups (e.g., Somalis, American-born educators, parents
of children with autism). In exploring the unique combination of identities assumed by each actor, intersectionality supports the understanding of individual participants’ lived experiences. In addition I seek to understand the importance of unequally distributed power within the educational decision-making process and to see the ways in which race, religion, disability status, gender and other dimensions interact with one another and influence power dynamics.

**Phenomenology**

Phenomenology, drawn from the field of philosophy, focuses on the lived experiences of individuals and allows researchers to identify phenomena by exploring how they are perceived by the various actors in a given situation (Paterson & Hughes, 1999). In the case of the present study, a phenomenological perspective will allow me to understand the process of educational goal-setting for Somali students with ASDs by looking at how both parents and teachers understand the process. The phenomenological perspective has been applied to conceptions of disability (e.g., Craig, 2009; Morgan et al., 2010; Murphy, 1987; Landsman, 2008) and to autism in particular (e.g., Sirota, 2010).

Roscigno and Swansen (2011) employed a phenomenological framework to explore the experiences of culturally diverse parents of children with disabilities (traumatic brain injuries, specifically). This study found that “parents’ realities were framed by their child’s injury and its implications” (p. 1422). Not surprisingly, though, this research found that parents’ beliefs were not static or preordained, but rather strongly influenced (both positively and negatively) by interactions with health care providers and members of their communities. In light of these findings, it is important to be cognizant, in applying a phenomenological frame to case studies, that the participants’ worldviews (here, Somali
parents and American-born special educators) are always evolving and shaping one another.

Explanatory Models

The phenomenological perspective informed the work of medical anthropologist Arthur Kleinman (1978) and his notion that individuals hold diverse “explanatory models,” or cognitive processes by which they understand illness and disability. That is to say, individuals may have vastly different beliefs about the etiology, course, and remediation of the same condition. As applied to autism, those with a Western medical orientation will likely see the condition as a lifelong developmental disability caused by an interaction between genetic and environmental factors (Deth et al., 2008).

In striking contrast, others believe that the symptoms associated with autism may be short-lived and that their cause may be related, for example, to a transgression committed in a previous life (e.g., Lui, 2005). The phenomenological framework coupled with the concept of explanatory models have shaped the subfield of cross-cultural psychiatry (Jacob, Bhugra, Lloyd, & Mann, 1998; Patel, 1995; Patel, Gwanzura, Sinugu, Llyod, & Mann, 1995). I argue that this combination of frameworks is equally valuable in understanding disability in cross-cultural contexts, although less of a precedent exists for this application.

Kinavey (2006) employed a phenomenological framework to explore the explanatory models of adolescents born with spina bifida. Findings from this study suggest that individuals’ understanding of their own disabilities are fluid rather than static and are intimately connected to local practices and “larger sociopolitical contexts” (p. 1081). In the context of the present study, the notion of explanatory models will allow me to explore
similarities and differences among American-born educators and Somali-American parents in their perceptions of autism and to see the ways in which these groups’ explanatory models belong to a larger integrated system.

Returning to the notion of intersectionality, we assume that the identities of groups (e.g., American-born special educators, Somali families of children with autism) are not monolithic but instead contain important intragroup variability. Additionally, researchers in special education and medicine have tended to view Western conceptions of autism as a norm against which other viewpoints can be compared. I argue that Kleinman’s work, which can be used to explain the “explanatory models” of all parties involved, is useful in avoiding this tendency.

**Institutional Ethnography (IE)**

The conception of the present study is also information by the sociological method of inquiry called institutional ethnography (e.g., Smith, 2006). IE was originally developed in relation to critical feminism, and, particularly relevant to this study, has been applied to educational contexts (e.g., Nichols & Griffith, 2009; Tummons, 2010). In the case of the present study, the IE framework helps to make explicit the ways in which institutions (e.g., schools and school systems) interact with documents (e.g., IEPs and educational assessments) and individuals (e.g., family members and educators) to shape a process (i.e., educational decision-making).

**Methods**

The research design for this project consisted of a multiple case studies design across three Somali-American boys with diagnoses of autism.

**Participants**
The case unit includes the web of people intimately connected with each of three Somali-American boys with autism. Each case comprised, at a minimum: a boy diagnosed with autism, his mother, and an educator.

*The case student.* Each of the three cases for this study centered on a Somali-American boy with an autism spectrum disorder. The boys ranged in ages at the time of the study, including 2.11 years (early intervention transitioning to preschool), 5.6 (preschool transitioning to kindergarten), and 17.11 (high school transitioning to residential). It is notable that all three IEP meetings included in this study constituted what I will call “a pivotal educational transition.” Although not an intended feature of the study design, this fact led to a study in which the educational decision-making processes across all three cases were particularly involved and “high stakes,” in the sense that the outcomes of each of the meetings had important implications for the students, families, and educators involved (e.g., about a change of status from day- to residential-student, about initial special educational placement [i.e., integrated vs. self-contained classroom])

For an overview of the three boys who participated in this study and their familial contexts, see Figure 3.2. Note that certain similarities exist across all three cases (e.g., all three boys were born in the Diaspora to Somali-born mothers), there are also important differences across cases (e.g., two of the mothers hold Master’s degrees while the third has no formal education.) While an overview of demographic characteristics such as those presented in Table 3.2 can help readers get a rudimentary sense of the participants, I contend that a table like this can be flattening, giving the false impression that people are simply the sum of their component parts. I will, instead, introduce readers to the individuals in each of the cases via narrative descriptions. These are presented in chapter 4.
In these descriptions, I draw on individuals’ descriptions of themselves, their life stories, and my own interactions with them to provide richer and more nuanced portraits.

Table 3.2  
*Family Overview*

<table>
<thead>
<tr>
<th></th>
<th>Case #1</th>
<th>Case #2</th>
<th>Case #3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Student’s Name</strong></td>
<td>Idris (Dris)(^{14})</td>
<td>Bilal</td>
<td>Aadan</td>
</tr>
<tr>
<td><strong>Mother’s Name</strong></td>
<td>Saida</td>
<td>Amina</td>
<td>Nadifa</td>
</tr>
<tr>
<td><strong>Student’s Age at start of study</strong></td>
<td>17.11</td>
<td>5.6</td>
<td>2.11</td>
</tr>
<tr>
<td><strong>Educational Placement</strong></td>
<td>The Hope School (Out-of-district placement)</td>
<td>Leapfrog Preschool (integrated public preschool program)</td>
<td>Big Dipper Early Intervention Program (BDEIP)</td>
</tr>
<tr>
<td><strong>Student’s Grade Level</strong></td>
<td>11(^{th}) grade</td>
<td>Pre-School</td>
<td>Early Intervention</td>
</tr>
<tr>
<td><strong>Family Members at home</strong></td>
<td>Mother</td>
<td>Mother</td>
<td>Mother</td>
</tr>
<tr>
<td></td>
<td>Older Brother</td>
<td></td>
<td>Father</td>
</tr>
<tr>
<td></td>
<td>Cousin</td>
<td></td>
<td>3 older sisters</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 older brothers; 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>with autism diagnoses</td>
</tr>
<tr>
<td><strong>Mother’s Educational Level</strong></td>
<td>Graduate Degree</td>
<td>Graduate Degree</td>
<td>No Formal Education</td>
</tr>
</tbody>
</table>

\(^{14}\) The names of participants and schools in this table are pseudonyms to protect participants’ identities.
Many voices at the table

<table>
<thead>
<tr>
<th>Mother’s Profession</th>
<th>Medical Case Manager</th>
<th>Scientific writer</th>
<th>Stay-at-home-mother</th>
</tr>
</thead>
<tbody>
<tr>
<td>Languages spoken at home</td>
<td>Somali (primary) English</td>
<td>English (primary) Somali</td>
<td>Somali</td>
</tr>
<tr>
<td>Student’s Country of Birth</td>
<td>Sweden</td>
<td>Canada</td>
<td>USA</td>
</tr>
<tr>
<td>Mother’s Country of Birth</td>
<td>Somalia</td>
<td>Somalia</td>
<td>Somalia</td>
</tr>
</tbody>
</table>

**Educators.** For each case study, the primary educator involved with the case-student was identified. The educators had different roles and/or titles (e.g., developmental specialist, lead teacher), and were selected based on the degree to which they participate in the student’s educational planning. For an overview of the demographic characteristics of the educators, see Table 3.3.

Table 3.3
**Educator Demographics**

<table>
<thead>
<tr>
<th>Name</th>
<th>Case #1</th>
<th>Case #2</th>
<th>Case #3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>male</td>
<td>female</td>
<td>female</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>Caucasian</td>
<td>Caucasian</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Languages spoken at home</td>
<td>English</td>
<td>English</td>
<td>English</td>
</tr>
</tbody>
</table>
Many voices at the table

<table>
<thead>
<tr>
<th>Highest Degree</th>
<th>M.Ed (gen. ed)</th>
<th>M.Ed, BCBA (sped)</th>
<th>BA (gen ed/sped)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years of teaching experience</td>
<td>8</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td>Years at current job</td>
<td>4</td>
<td>8</td>
<td>6</td>
</tr>
</tbody>
</table>

*Materials*

I used handheld digital voice recorders to record interviews sessions. In addition to these recordings, I made pencil-and-paper memos and field notes to record my own thoughts and observations that would be missed given the audio recording alone. Semi-structured interview protocols (see appendices) guided interviews.15

*Procedures*

The data-gathering process for the present study included interviews, observations (of students and IEP meetings), and collection of documents.

*Initial observations.* Prior to interviewing parents and educators and to conducting observations at IEP meetings, I observed the case student and the way in which he functions in his environment(s). At a minimum, I observed the student in his educational setting (i.e., early intervention session; at school). For the two school-aged students, I observed a group-based academic period. In addition, I observed each of the students in a non-school setting (i.e., at home for two of the case students and at his mother’s workplace for the third). Each of these initial observations lasted a minimum of 30 minutes, was informal (i.e., not be guided by a formal observation protocol), and allowed me to see the
student and form judgments about particular challenges for the him, along with ideas about what might constitute appropriate goals. (e.g., If I observed the participant attempting but struggling to initiate a conversation with his classmate, I may have viewed “initiating conversations” as an appropriate goal for that student. Notions such as these colored my impressions of what constituted appropriate educational decisions at the IEP meetings I observed.)

I wrote memos during initial observations. These memos served to capture my initial impressions of each child, which in turn informed my perceptions of subsequent interviews and IEP meeting observations (LeCompte & Schensul, 1999). For observations in a Somali-language setting, I was accompanied by a Somali-language interpreter. In the case of at-home observations, my presence presumably changed the home dynamic. For example, one of the Somali families wanted to “host” me, offering me an elaborate meal of sambusas, rice, chicken, and chai, and engaging me reciprocal conversation. All of the families likely altered their interactions to correspond with what they thought I would want to see. Likewise the child(ren) with autism may have been affected by my presence (e.g., over-stimulated, excited, or withdrawn in my presence and may not behave as he would if alone with his family). I was aware of the ways in which observations may differ from everyday life and will be thoughtful about the conclusions that I could (not) draw from these observations.

Interviews. In-depth interviews with caregivers and educators took the form of “guided conversations” as opposed to “structured queries” (Yin, 2009). This format allowed me to pose open-ended questions (e.g., “What is the most important consideration in educating students with autism?” “How should parents and teachers work together to
decide on educational goals for students with autism?” See appendices for interview protocols.) and to elicit interviewees’ perspectives on themes that are central to the research questions. Interviewees also had the opportunity to introduce his or her own insights on the subject at hand. When interviewing Somali family members, I took into consideration the fact that “Somali culture has its own high narrative tradition” (Barnes, and will design interview questions that will allow participants to respond in their poetic oral style rather guiding them to respond in a linear Western narrative style. While American-born interviewees tend to see the interview process as formal, answering questions and prompts directly without volunteering unrequested information.

Interviews were conducted with each boy’s mother and one of his educators. A total of three interviews were conducted per adult—one before the annual IEP review16, one during the week following the IEP meeting, and a final interview between one and two months after the IEP meeting17. In reviewing the data from the IEP-meeting observation, I will selected three “important moments” (e.g., a disagreement about what type of extended school year (ESY) services were appropriate for a given student and why) about which will ask interviewees during follow-up interviews. “Important moments” are instances about which I as the researcher would like to learn more and are defined as moments during the

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16 In one of the three cases, I was not able to attend the student’s IEP meeting because I had been granted IRB approval from the Early Intervention agency but not from the school district. In this case, the series of three interviews centered on an observation of a home-based early intervention session. This allowed me to analyze parent-educator collaboration and educational decision-making during the EI session. In addition, because the student’s IEP meeting coincided (need clarify how closely) with my observations and interviews, I was able to interview both the parent and educator about the educational negotiations at the IEP meeting although I had not witnessed the meeting itself.

17 In one case, for logistical reason, it was not possible to interview the educator in advance of the student’s IEP meeting. In this case, I combined the first and second interview protocols to create a composite first/second interview that I conducted shortly after the student’s IEP meeting.
IEP meeting in which multiple perspectives are represented. Perspectives need not be represented verbally, but might include a discrepancy between something written in the IEP and what is stated. Or an “important moment” could consist of a statement made by a parent and an educators non-verbal response to that statement (e.g., raised eyebrows signifying disagreement). For each case, I used the same set of instances to probe caregivers and educators. These “important moments” are included in interview protocols available in appendix D.

The second post-meeting interviews allowed me to capture additional information about parent and educator perspectives on the educational goals and IEP process once some time had elapsed after the meeting. In some cases, elements of the IEP process had transpired between the initial and follow-up post IEP interviews (e.g., caregivers may receive copy of IEP, new IEP goals may be implemented, a residential placement started). Caregivers and educators were then be able to comment on the educational goals in terms of students’ progress since new goals have been implemented. In the final interviews with educators, I may brought general information about Somali families’ perceptions of autism and autism education and ask the educators to respond to these notions. Likewise, in final interviews with parents, I shared educators’ perspectives so that the parents had the opportunity to respond. (e.g., Some Somali families believe that autism is a temporary condition that can be remediated by traditional healers. Would awareness of this perspective alter how you discuss educational goals with Somali families? If so, how?) In either case, I brought evidence to teachers and parents only as general or representative statements so that neither group could trace a particular sentiment or opinion to an individual participant. In the third case, all interviews and observations were translated by
an interpreter. I transcribed interviews on an on-going basis. The process of transcribing interviews allowed me to begin to form impressions about my data and I wrote memos on my observations throughout the process.

**IEP team meeting observations.** Direct observations took place during an annual IEP meeting for two of the students and observations of parent-educator interactions and interviews shortly following the meeting were use for the third. I did not offer any contributions to the meeting. However, I am aware that my presence at meetings may have changed the nature of participants’ behavior (e.g., school personnel may have taken extra precautions to ensure that they met all legal requirements of the IEP process; some parents may have participated more actively if they believe I value parent participation). I accounted for this principle, known as *reactivity* (e.g., Maxwell, 2004), by minimizing my own presence as much as possible, even as I may not be able to eliminate any impact (see discussion of reactivity toward the end of this chapter).18 During meetings, I collected copious field notes both of verbatim dialogue between parents and educators, and my own impressions of the meetings and the negotiations. I recorded these field notes by hand in a notebook and transcribed them into a computer file immediately following the meetings. Typing the notes while the meeting was still fresh in my mind allowed me to solidify my impressions. Examples of observations that were recorded in field notes included distinctive body language and other visual details. (e.g., Teacher suggests that the student would benefit from opportunities to practice conversation skills with general education peers. Mother nods; father furrows brow and shakes head.) In addition, to these field notes,
I collected any documents that were shared at the meeting (e.g., agenda, draft IEPs, explanations of procedures).

Document analysis. 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 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, level of detail included, and source of assessment (e.g., internal vs. external). The attendance list from the IEP meeting will be collected and may be helpful when I am reading the meeting transcripts.

Data Analysis

A plan for analyzing case study evidence was developed before data collection began (Yin, 2009). In this qualitative research project, data analysis was an ongoing and holistic process. A variety of documents were developed before and during the data collection process. For a list of data analysis documents, see table 3.4.

Table 3.4
Data Analysis Documents

<table>
<thead>
<tr>
<th>Document</th>
<th>Created</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of a priori codes</td>
<td>Before start of data collection</td>
</tr>
<tr>
<td>Code Book</td>
<td>Revised across rounds of data analysis. Included inductive and deductive codes. This list of codes was developed within the Dedoose qualitative data analysis program</td>
</tr>
</tbody>
</table>
In-the-field analysis. The initial “in-the-field analysis” (LeCompte & Schensul, 1999) occurred as I assessed and made decisions about lines of questioning to pursue or details to attend to during an observation or while analyzing a document. In this way, I was generating and testing hypotheses continually (e.g., If I noticed that parents’ comments during an IEP meeting vary from the perspectives they put forth in initial interviews, I used the post-meeting interviews as an opportunity to discuss the observation with the parents; If a teacher made a interesting comment, I asked the parent about the same subject in subsequent interviews). This “recursive process” allowed me to refine questions and make sense of the evidence as well as to shape and nudge the process of data collection—suggesting questions to be asked, highlighting focal points of observations to come.

Once all of the student observations, family/educator interviews, and IEP meeting observations had been conducted, I uploaded all transcripts and field notes into Dedoose, a web-based data analysis program that allowed me to organize and manipulate this large corpus of data. Throughout the data collection process, I met with members of my dissertation committee to discuss the status of the study and to review and modify my data analysis plan as appropriate.

In analyzing the data for the proposed study, I drew on the qualitative data analysis methodologies of theme analysis (Miles & Huberman, 1994, grounded theory, and constant comparative analysis (Charmaz, 2000). In terms of coding themes, I used a hybrid approach including both a priori codes from my theoretical frameworks and inductive codes from the
Many voices at the table

data itself. This combination allowed for as complete as possible an understanding of the themes (Fereday & Muir-Cochrane, 2006).

Applying the constant comparative approach to data coding entails: “(a) comparing different people ..., (b) comparing data from the same individuals with themselves at different points in time, (c) comparing incident with incident, (d) comparing data within a category, and (e) comparing a category with other categories” (Charmaz, 2000, p. 515). Looking at pieces of evidence in these multiple ways allowed me to examine and reexamine themes and to understand well the ways in which different pieces of evidence relate to one another.

A Priori Codes

This study is strongly influenced by certain a priori codes. Because this study centers on the decision-making process that occurs at IEP meetings which is a document-driven process, the IEP document itself introduces some important codes (e.g., parent concerns, academic goals, vision statement). The IEP process is driven by special education law, and generally, the decision-making process that occurs at IEP meetings is driven by the IEP itself. In addition to the domains introduced by the IEP document, my review of the literature has introduced several other domains (e.g., beliefs about disability, conceptions of collaboration). These domains have shaped the interview protocols (see appendices) and the procedures for observations. In the initial round of coding I first applied these a priori codes to my data by marking each time one of these codes was present in an interview transcript, document, field note, or memo.
Many voices at the table

Open Coding

After applying a priori codes, I reviewed my corpus of data in its entirety one time (e.g., interview and observation transcripts, field notes, memos, and documents). I reviewed the interviews and observation transcripts and corresponding memos and field notes in the order that they were collected, but reviewed the documents throughout this process alongside the transcripts they complemented most closely (e.g., I read diagnosis-related documents alongside the initial parent interview in which we discussed the diagnosis process). I coded each transcript or set of field notes in its entirety before moving to the next. This first round of coding allowed me, inductively, to form initial categories and themes (e.g., Glaser & Strauss, 1967). Many of the transcripts that I read introduced new codes and helped me to understand the nature and boundaries of codes found in previous data: what should be included, what excluded.

Axial Coding

After the first phase of coding, I reread all transcripts, memos, and field notes along with the initial codes, and patterns across participants became apparent. This second round of coding allowed me to move from more substantive codes (which were grounded in the data) to more theoretical codes.

Selective Coding

Following the second round of coding, I looked at the codes that I had developed alongside hardcopies of raw transcripts, memos, and field notes to ensure that the codes reflected the raw data. I made repeated passes through my data (both selected passages in Dedoose as well as hard copies of raw transcripts) to look for relationships between my categories and evidence both for and against these categories until the point of saturation
Many voices at the table (i.e., when I no longer found new or different perspectives on the evidence). These repeated readings allowed me to expand and, in some cases, collapse codes. I recursively examined my interpretations by returning to my field notes and memos (LeCompte & Schensul, 1999, Richards, 2005). In this process, I systematically and continuously sought multiple perspectives (Strauss & Corbin, 2000) by considering the different ways each theme is represented in different sources of data (e.g., interview transcript, IEP, observation).

**Memo Writing**

Across the data collection and analysis process, I wrote memos to record thoughts and ideas as they emerged. During data collection, memos included observations that called for further inquiry in an upcoming interview; during data analysis, memos included, among other things, thoughts about codes themselves (e.g., relationships between codes, ideas about what certain codes include). Memos from both the data collection and data analysis processes became pieces of evidence themselves to be assessed during the subsequent phases of data analysis.

**Toward Rigorous Qualitative Research**

Notions of what constitutes high-quality qualitative research differ from their quantitative analogues and even vary across qualitative paradigms and epistemologies (e.g., Lincoln & Guba, 1985; Morrow, 2005; Rubin, 2000). In short, there is no true consensus among researchers as to what constitutes rigor in qualitative research (Rubin, 2000).

According to Lincoln and Guba (1985), the concepts of “validity” and “reliability” used in quantitative paradigms are fundamentally incompatible with the assumptions that underpin qualitative work. In light of this, Lincoln and Guba put forth the term “trustworthiness.” Padgett (1998) builds on Lincoln and Guba’s (1985) work and
Many voices at the table

articulates the following specific threats to “trustworthiness” in qualitative work: (a) researcher biases, and the ways in which these affect questions asked during interviews, interpretations of observations, etc., (b) reactivity (discussed earlier)—the effect of the researchers’ presence in the field, and (c) respondent bias—in relation to participants’ notions of what is socially desirable. In designing this study, I have taken steps to limit the role of these threats.

Positionality—understanding potential sources of bias. In qualitative case study research, it is common practice for a researcher to begin by articulating his or her background. The rationale for this practice is twofold. First, in conducting case study research, being knowledgeable about the subject at hand positions a researcher well to collect and analyze case study data (Yin, 2009). At the same time, however, a researcher’s unique lived experiences often correspond with particular opinions or biases. Articulating background experiences clearly allows the researcher to demonstrate an awareness of potential biases and to understand and/or limit the ways in which these assumptions influence her work. The following description of my own experiences serves both of these purposes:

I am an experienced special education teacher and researcher. I have taught children with ASDs in private and public school settings and have provided home-based consultation and parent trainings to families of children with autism from diverse cultural backgrounds. In these capacities, I have attended dozens of IEP meetings—both collaborative and contentious in tone.

I have also conducted qualitative and quantitative research related to students with disabilities and, in so doing, have gained teacher and student perspectives on educational
goals and decision-making processes for students with disabilities. Based on these teaching and research activities, I am intimately acquainted with the process of developing educational goals for children on the autism spectrum and aware of barriers to seamless collaboration between immigrant and refugee families and special educators.

Qualitative research, however, (like all empirical work), is inherently subjective. The notion of reflexivity simply acknowledges a researcher’s inability to divorce her own theories, perceptions, or values from her research (Maxwell, 1996). Importantly, however, the researcher must be able to reflect upon and grapple with her own perceptions of and reactions to the subject matter she is studying and the individuals who are participating in the research project.

Although biases cannot be eradicated, I know how important it is to be aware of the ways in which my own biography may color my approach to and interpretations of the subject matter at hand. In fact, the very act of writing a statement of positionality forces me to begin the process of developing awareness.

As a U.S.-born white woman and former teacher, my experiences and biases were almost certainly more closely aligned with the participating teachers than with the participating families. I have experienced the many demands on teachers of children with autism spectrum disorders and the pressures associated with developing educational goals for these students and participating in IEP meetings as an educator.

However, as the mother of a child who was born extremely prematurely, I have also participated in developmental assessments and individualized family service plan (IFSP) meetings and participated in developing educational goals as a parent. These experiences have helped me develop a degree of empathy with the stress and disempowerment that
Many voices at the table
parents experience in advocating the interests of vulnerable children. Yet despite the similarities between my experience as a mother of a premature infant and those of the participants in the present study, in other ways my experience is markedly different. Notably, my own efforts to navigate systems are mediated by my professional expertise as a special educator and by my demographic characteristics as an educated, white, upper-middle-class, native-English-speaking woman. My experience also differs from that of the parents who participated in this study because my son’s developmental differences are likely short term. Autism, in contrast, is associated with lifelong effects.

In addition to my experience as a teacher, I have also have experience working with immigrant and refugee populations. I have coordinated services for newly arrived immigrant and refugee families of diverse backgrounds through the International Institute of Boston and have worked with Somali families in particular through Catholic Charities in Lewiston, Maine and the Somali Development Center in Boston. And although the experience of working with refugee families affords some level of understanding, the experience of being a newcomer in a country is quite different.

As a young adult, I lived outside of the United States for a total of four years in France (one year—as a student) and Morocco (three years—as a Peace Corps Volunteer and Fulbright grantee). The experience of living abroad allowed me to experience the challenges of communicating in languages that I do not speak natively (French, Moroccan Arabic, and Tashelheet) and navigating systems (e.g., medical, educational) that were unfamiliar to me. I struggled to rent apartments, open bank accounts, and enroll in university classes. I made many mistakes and breaches of social etiquette. And yet, my experiences of living abroad were buffered by the many advantages I have: financial
security, education, an American passport, and the knowledge that I can leave and go “home” at any point. And so I recognize that my experiences are very different and in almost all ways easier than Somali refugee families who have none of these.

This positionality statement and my attempt to understand my own experiences and perspectives address one of the threats to trustworthiness in qualitative research—*researcher bias*. The following paragraphs cover measures I have taken to limit the effects of two other threats to the integrity of the proposed study—*reactivity* and *respondent bias*.

*Limiting the reactivity and respondent bias.* 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. The present study was designed to allow me to interact with participants over several months (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 lessen the extent to which the researcher’s presence is obtrusive, thus promoting more honest interactions (e.g., Padgett, 1998). I also hoped that by connecting with research participants through well-known social service agencies and via members of the Somali community, I would be able to foster trusting relationships with participants and facilitate candid exchanges.

In addition, by collecting data from multiple sources (observations, interviews, and documents), I was able to use the data analysis strategy of *triangulation*, which means simply using multiple sources of evidence to explore the same phenomenon (Golafshani, 2003). In the present study, for example, I used my own field notes and observations of an
Many voices at the table

IEP meeting in conjunction with interviews with two participants at the meeting, to understand the decision-making processes at the meeting from several vantage points.

In this chapter, I have described the methodology associated with this multiple case study design across the educational decision-making processes associated with three Somali-American boys with autism spectrum disorders. As explained previously, three categories of data were collected for each of the three cases: (a) semi-structured interviews with mothers and educators, (b) observations, and (c) document analysis. At the outset of the study, the intention was to observe the student’s IEP meeting in each of the three cases. However, due to challenges of recruiting Somali-American families who were willing to participate in the study and difficulty gaining access to IEP meetings, I elected to include one case in the study where observation of the IEP meeting was not possible. As discussed, the rationale for including this case was that the demographic characteristics of this particular family offered an apt counterbalance to the other two families. In the following chapter, I introduce readers to each of the three cases in much greater detail.
CHAPTER IV: A STUDY IN THREE CASES

Notes on Recruitment

For any mother discussing life with an autistic child can be cathartic, overwhelming, and deeply personal. As Clara Park Claiborne muses in the introduction to her memoir, *Exiting Nirvana: A Daughter’s Life with Autism* (2001):

“How to begin? In bewilderment, I think—that’s the truest way. That’s where we began all these years ago. That’s where everyone begins when they have autistic children. And even now, when my daughter is past forty...” (3)

For Somali-American mothers, who straddle multiple competing conceptions of disability, the request to discuss something so personal may have been quite off-putting.

From the outset, I recognized that recruiting Somali families of children with autism to participate in this study would be a challenge. As a non-Somali-speaking white woman, I was not exactly well-positioned to earn the trust of families. I did, however, have personal connections with three influential Somali organizations in the area (The Somali Development Center [SDC], African Community and Economic Development Center of New England [ACEDONE], and The Refugee and Immigrant Assistance Center [RIAC]) and I thought that with their support, finding willing participants might not be such a daunting task.

When my Somali contacts at each of these agencies emphasized the extent to which autism is stigmatized within their community and explained that even families they work closely with might not disclose to them the existence of a child with a disability, I began to realize what I had undertaken. I discuss this process of recruiting participants, because I believe that it is important in terms of understanding why each of these three families chose to participate in my study.
Many voices at the table

I recognize, of course, there is no such thing as an average Somali refugee family. But I argue that my participants are unique even in the context of the delineated population—Boston-based Somali refugee families of boys with autism. And likewise, there is no such thing as a perfectly average autism educator. Each of the educators who participated in this study brought with them a unique set of experiences that have shaped their beliefs about autism and education. Selection of the educators who participated in this study was based on the families they were paired with rather than their specific personal attributes.

A trio of Trios—Mothers, Sons, and Teachers

At the center of each of the cases in this study is (a) a Somali-American boy with autism, (b) his mother, and (c) his educator. From these cases, we can learn a lot about how educational decisions are made. Before analyzing the themes that weave through these three cases, it is important for readers to “meet” the participants in each of the cases, to better understand how their personal attributes might factor in the educational decision-making process. For an overview of the three cases, refer back to Table 3.2 (Family Overview) and Table 3.3 (Educator Overview) in Chapter 3. A more textured description of each of the three cases follows. Because each of these cases is distinct, I do not aim to provide comparable information about each in parallel structure. Instead, I share the details about each case that I think are most salient in terms of understanding the educational decision-making that ensued.

Saida, Bilal, and John (Transition to a Residential Program)

When I described my project to Fatima, a Somali social worker at the RIAC, who I had met the previous year at a lecture, she was immediately engaged. “Autism is a huge problem in our community,” she told me. Naima very generously agreed to broach the idea...
Many voices at the table

of participating in my study with a few of her clients—she would inquire delicately, she assured me. But when none of the families would even entertain the idea of participating, Naima had another idea. She called Saida, a former colleague, who was now the medical case manager at a nearby hospital and the mother of an adolescent with autism.

_Saida and Dris_

Saida was eager to learn about my study and invited me to meet her at her office the following day. Trained as a researcher herself, Saida was a self-described proponent of research. When I arrived at the clinic, she snuck me into a small conference room (“only employees are allowed back here.”) and we talked for over an hour—Saida, is a storyteller and at all of our meetings she talked easily. Looking back at the transcripts of our interviews, it was easy to see that Saida drove the conversations. She shared what was important to her, not always related to what my questions asked and not always in an order that felt logical to me. But telling the story of her son Dris’s autism is something she is practiced at and happy to have an audience for. Without much guidance from me, she naturally talked about all of the themes I had hoped to cover.

Rereading the transcripts of her interviews, I am also reminded of Saida’s feistiness and quick sense of humor—always ready to laugh at herself and anyone else. For example, when I interviewed her in her home just after the suspects in the Boston Marathon bombings had been identified, Saida told me, clearly amused, that her phone had been ringing constantly—relatives abroad, American colleagues—all worried about the backlash against her as a Muslim woman living in Boston. “But they have the suspects. Everyone knows it wasn’t me,” she laughed.
Many voices at the table

For the final two interviews I met Saida at her home in an inner-city Boston neighborhood not far from my own. Saida prided herself on her hospitality and was eager to host me, but she was also nervous to invite me to her neighborhood which she seemed to worry might feel unsafe to me. Saida herself had contributed 300 hours “sweat equity”—through Habitat for Humanity—to building the handsome light blue townhouse. The house still felt brand new. It was in pristine condition, which accentuated the other less-well tended buildings on her street—a block of turn-of-the-century brick row houses and worn around the edges white clap-board mosque.

When I arrived the first time, Saida seated me in her living room appointed with a matching love seat and sofa, a large flat screen TV and lots of plants. Although I had explicitly asked her not to fuss when I set up the interview, I found Saida busy in her kitchen preparing for me a large Somali meal—spicy beef samusa, bean croquets, steaming baaris (rice) topped with onions and lima beans, a cup of Chai. The meal presented on an oblong tray was for me alone. Saida is gracefully assertive. Even though I had initiated this meeting, she is my hostess. There is something almost maternal about the interaction.

When Dris was born in 1995, Saida had already been living in the Sweden for several years. She was studying medicine in Stockholm on a prestigious scholarship from the European Community—“at that time, our country, they didn’t have a lot of researchers,” she explained. Saida had fully intended to return to Somalia after her studies, but when the civil war broke out in 1991 she sought and was granted asylum.

Saida had fond memories of the Swedish neighborhood (”very green, very clean”) where she lived with her late husband, a scientist, their first son Abdi, and finally Dris. Just
Many voices at the table behind their house was a “small canal” and a “whole backyard of plants.” At age two Dris’s Swedish daycare provider noticed changes in his behavior and when he was diagnosed with an autism spectrum disorder (ASD) and severe mental retardation (MR)\(^\text{19}\), Saida was “shocked.” “What’s autism?” she asked. Even in her medical training, she had never come across the word. The diagnosis was especially unsettling because up until his second birthday, Saida had felt like Dris was developing typically. He had spoken in both Somali and Swedish.

The diagnosis set Saida into a frenzy of informal research. Swedish colleagues told her that America has more resources for children with disabilities and she and her husband “decided [they] would look everywhere.” Even before they left for the United States, Saida had read about and become interested in the Northeast Autism Center (NAC). She was drawn initially to NAC’s strict emphasis on applied behavior analysis (ABA), which she had read was the gold standard for teaching children with autism.

In the United States, the family settled in an urban neighborhood, which Saida described as “very crowded, very ugly.” Dris spent just a couple of months in a self-contained public school classroom before his teachers suggested that the classroom was not a good fit for him. Saida was initially very happy to enroll him at NAC, where he stayed for nearly a decade. But as time went on, Saida became convinced that the school, which prioritized discrete trial training (DTT) and other seated work, simply was not a good fit for high-energy Dris. Saida had to trust her own gut feeling about the school. Dris, who is non-verbal had limited means of communicating functionally and certainly did not have the skills to offer an opinion about his school. He was able to request preferred items and

\(^\text{19}\) The term MR is no longer used and is considered to be pejorative. I have retained the terminology here, because it is what is used in the Dris’s reports.
activities by “hand-leading” and “gestures” and used a voice output device, but primarily to request snacks.

In her second round of school searching, Saida, accompanied by the out-of-district liaison, toured three more potential placements for Dris. When she visited the Hope school and learned about their emphasis on physical exercise, she knew that it would be the right fit for her ever-sprinting, always-jumping-son.

At the time of this study, Dris had been a day student at the Hope School for over five years. Saida was happy with the progress he was making. Overall he seemed calmer and happier than he ever had. Saida noted that he was not making significant academic progress (“Dris’s not a student” [fieldnotes]). She attributed the slow progress to his inherent ability level rather than to the school’s instruction. The IEP meeting I attended was just before Dris’s eighteenth birthday, and the focus of this meeting, above all else, would be to determine whether or not he would qualify for a residential placement at Hope.

The decision to request a residential placement for Dris was very stressful for Saida. She had believed that parents should take care of their children at home forever. Saida’s siblings, nephew and older son concurred with this sentiment and reminded her of it frequently. But Saida’s perspective had started to shift as she had more contact with other parents at Hope. She met other parents who “…have good jobs. They’re good mothers. They’re very involved.” These mothers were convincing when they described why they had enrolled their children in the residential program at the Hope School. Through conversations with these parents, Saida began to question her original assumptions.
John

Unlike Saida, Dris’s teacher, John, was a focused and linear interviewee. He answered my questions thoroughly and formally (although he warmed up a bit as the interviews went on). He offered much less additional information (but then it should be noted that I interviewed him at school during his planning period. Time was limited.) John grew up in Centerville, a predominantly Irish Catholic suburb, which he described as being fairly homogenous, but not “strictly lily white.” In high school, he “loved history” and imagined himself teaching the subject one day.

After graduating from Boston College, John taught history for a couple of years, for part of the time in the urban and ethnically diverse community of Brockton. John was self-deprecating about his ability as a teacher and was quick to admit that he struggled with classroom management during his time as a general educator. He emphasized to me that he had never intended to become a special educator. He was deeply shaped, it seemed, by being the slightly younger sibling (by 18 months) of a non-verbal brother with autism. When I first asked John if he would like to participate in the study, he warned me that because of this personal experience with autism, he did not feel like he was a “typical” [fieldnotes] autism teacher. John’s brother, who has since passed away, had been a student at the Hope School. John and his parents were deeply connected to the Hope community. John grew up “hanging around” the school and had his first job as a dishwasher there while his brother was still a student. But in spite of his early experiences and even after 8 years of teaching, John maintained that special education was not his “number one choice” and explained that having had a brother with autism, that maybe he was “autismed out.”
Talking to John, it was clear that in spite of his insecurities about being a special educator without formal training in special education, he was a committed and compassionate teacher. In particular, as a family member of an individual with autism, he connected easily with parents. When I spoke about Saida, John conveyed deep respect and empathy for the difficult decision she was making (i.e., enrolling Dris in a residential program) and for her persistent and graceful advocacy on Dris’s behalf.

Amina, Bilal, and Katherine (A Transition to Kindergarten)

I met Amina and Bilal through Abdi, the head of the SDC where Amina worked part time as a bookkeeper and I volunteered as an English teacher.

Amina and Bilal

When I first met with Amina to tell her about my research I immediately noticed the relationship between this mother and her five-year-old son with autism. Their closeness, Amina speculated, had something to do with the fact that the two of them were a family unto themselves—a single mother and an only child with no extended family in the area. Bilal was talkative and funny and it was hard to believe that only two years earlier he had been completely non-verbal. Amina and Bilal were constantly joking around and playing and as Amina said, he is “pretty social” for a kid with autism. When he talked, I noticed that he inserted certain scripted phrases (echolalia) and that his prosody was a bit unusual, but he was undeniably engaging and communicative.

Amina’s family immigrated to Toronto from Somalia when she was in sixth grade. Her mother’s side of the family was influential (her maternal grandfather was an ambassador) and her father was a “smart hardworking guy,” who “definitely married up.” Back in Mogadishu, the family compound had included several buildings, one expressly for
Many voices at the table

entertaining and another for housing the “help” (e.g., nannies, chefs, drivers). Amina had vivid memories of childhood travels— to Kuwait, Kenya, and London, for example. As a parent, she hopes to provide Bilal with similar opportunities— “kids remember [travel] so much more than toys or games.”

The shift from being elite almost-royalty to “Somali refugees” was a big one— especially for Amina’s mother, who left “everything behind.” One thing that Amina’s parents were not willing to give up was education for their six children. They offered to pay “whatever it takes for tutors” but they expected their children to get into college and to pay the tuition themselves.

Amina went to college and then enrolled in a doctoral program in chemistry. While in graduate school she met her future husband who had grown up in Minneapolis, but was originally from Somalia as well. Amina’s parents were very pleased. But Amina soon began to resent her husband, and in particular his lack of ambition. Shortly after Bilal was born in 2007 the couple separated and Amina moved to Massachusetts. The first time that Amina remembers noticing that there was something different about Bilal’s development was when he was “a little over two” and she had driven to Cape Cod to visit a friend with a similar aged child. On the “long drive home, I was just like ‘oh my God,’ something’s wrong, something’s wrong. Like something is wrong” (emphasis hers).

During the period of Amina’s separation and divorce Bilal lived with his maternal grandparents for the better part of a year. His grandparents, having started to realize that something was different about his development responded by keeping him at home, away from public scrutiny. When Amina went to Toronto to take him back to live in Boston with her, she was “furious” to realize that Bilal “didn’t even know what a raindrop on a car
sounded like.” Interestingly, Amina believes that her own brother, now an adult—engaged to be married and working full time—could be diagnosed with high functioning autism, and that her mother has always been in denial of this fact. Her mother’s response, Amina explained, was “very typical” of that generation—“her sisters would have done the same thing.” Amina is adamant though, in her reaction against this perspective. “I don’t know if you’ve noticed, but I bring Bilal pretty much everywhere,” Amina said laughing. “He’s like a little purse.”

Amina was an impressive woman, not just as a mother. During the time that she was participating in this study, she also started a new job as a scientific writer, trained to run a marathon, and was preparing to take the LSAT so that she could go back to school to be a lawyer (She would only go, she told me, if she got into Harvard, Columbia, or NYU—an important commentary on her understanding of and ability to navigate a system defined by cultural capital.)

When I met them, Bilal was finishing up his final year of preschool. Amina, a self-described urban dweller, had moved to Middleton—30 miles outside of the city—because she felt like the schools would be good for Bilal. And so far, after almost three years in the public preschool program, she was very happy overall. His IEP meeting that year was an important one, because it was both his three-year re-evaluation and kindergarten transition meeting.

Katherine

Amina spoke very highly of Bilal’s teacher Katherine. “You’re going to love her,” she told me. I met with Katherine at her office at the Leapfrog Preschool—a cozy public preschool with just a few classrooms. Like John, Katherine has grown up in a
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predominantly white middle class suburb of Boston and had studied education at Boston College (BC). (Although I also study education at BC, I did not overlap with either of the teachers in this study).

In contrast to John, Katherine had long known that she wanted to be a special educator. In high school, she had volunteered in summer programs for students with disabilities and while at BC, she had worked with students with profound and multiple disabilities at the Campus School. Like John, she also had fears about her ability to manage an entire classroom and envisioned, as an alternative, a career in early intervention (EI) where she could work closely with individual students and their families.

Her first formal job in education was as an “ABA technician” in a public school system. This job confirmed in her the desire to pursue a career in special education. She went on to get a graduate degree at Lesley University and then to become a board certified behavior analyst (BCBA). Katherine emphasized the ways in which being a parent (she had a toddler and a preschooler at the time of my interviews) had changed her perspective on working with her students’ parents. “I’m more hesitant. They know their child best.” And she described having tremendous respect for Amina and all that she does for Bilal.

Listening to Amina describe at the IEP meeting how she accompanies Bilal on all of his play dates to facilitate his success, Katherine seemed guilty to realize how much easier her own experience as a mother of typically developing children has been. She was effusive in her praise of Amina’s efforts and accomplishments in raising Bilal.

Nadifa, Aadan, and Kim  (A Transition from EI to Preschool)

I was introduced to Nadifa originally by Halima, a social worker at RIAC. When I arrived at the Farhan household, it was immediately clear that their lifestyle was very
Many voices at the table

different from the other two families. They had far less capital—financial, economic, educational or otherwise. The family lived in temporary housing: an apartment of maybe a thousand square feet in a four family white clapboard building right alongside the train tracks. The building itself was in poor repair and when I visited an upstairs neighbor on house arrest (as related to me by Halima) often lingered on the front porch. Even though the dwelling was far from spacious or comfortable, the inside of the apartment was clean and pleasant and the air was thick with bhor (incense). It was sparsely furnished and the walls were drab and grayish but almost entirely covered with cheerful batik wall hangings.

On my first visit, I met Nadifa’s husband, Abdi. He was sitting on a futon on the floor of the family’s living room wearing a tee shirt and a sarong around his waist. We exchanged greetings and shook hands but not much more. Shortly after I arrived he went out carrying his bike from the living room where it had been stored. During my subsequent visits when I came to observe EI sessions, only Nadifa and the two youngest children were home. Because, on these occasions, Nadifa was the one interacting with the developmental specialist and other service providers, I considered her to be the “primary” decision-maker in terms of EI. Because my communication with Nadifa was limited, I do not have a full sense of how educational decisions were actually made within the household. I know only what I observed during the EI sessions and what she shared with me about her thinking and the decision-making process.

Nadifa grew up in rural Somalia, where she, like most girls, did not receive any formal education. For me, it was much more difficult to forge a relationship with Nadifa. Whereas Saida and Amina talked openly to me almost immediately, Nadifa did not. For the interviews, Halima served as an interpreter. And I found that the process of interpretation
also seemed to impede the flow of conversation. Reading through the transcripts of my interviews with Nadifa, I notice that he responses are quite short—often just a couple of words or phrases.

Nadifa and Aadan

Nadifa and her family migrated to the Boston area via a refugee camp in Kenya where she and her husband had their first four children. After being resettled in temporary housing in a middle-sized working class city, Nadifa and her husband had three more children—all boys, and all eventually diagnosed with developmental disabilities.

Mohammed was the first of her three children born in the United States. From the beginning, Nadifa noticed that he was developing differently from her older children. “He didn’t cry and he would not cry for hunger.” So Nadifa, not knowing what else to do, would just put him in her lap “and just feed him.” She had never—not in Somalia, not in Kenya, and not since arriving in the U.S.—seen a child who acted like Mohammed. Nadifa brought Mohammed to the pediatrician repeatedly, but the doctor kept “insisting” that nothing was wrong. And because he was not diagnosed, he never received EI or preschool special education services. He did not begin school until age six and was placed immediately in a substantially separate elementary school classroom.

Nadifa’s youngest child, Aadan, is at the center of this case. He was approaching his third birthday when I met the family. He was the only one of the three boys to have received EI services. Halima, a social worker who had been introduced to the family by Nadifa’s mother-in-law, had helped the family to get appointments with neurologists and other specialists, which ultimately helped them gain access to home- and school-based educational services. In contrast to his two older brothers, Aadan was less profoundly
affected by autism. While his two brothers are non-verbal, Aadan “says small words...he plays...he cries.”

Nadifa “never noticed that he was actually sick.” It was Halima, who suggested getting him evaluated with his two brothers. When I first met him, he had been receiving EI for about six months and he was able to play with puzzles and toys. He had clear preferences, too, and could sign “more” when he wanted to keep playing with the farm animals, for example rather than moving on to a shape sorter. At the time of the study, Aadan was transitioning from EI to special education preschool services. While both of his brothers had been placed in a substantially separate magnet program for students with developmental disabilities, Aadan was slated to begin in an integrated preschool classroom in his neighborhood school.

Kim

Like the other two educators in this study, Kim grew up in a middleclass Massachusetts suburb. As a pre-teen and teenager, she spent a lot of time with younger children in the neighborhood—“I guess I sort of always like to help out the kids who needed help.” And from an early age, she envisioned herself as a teacher. But she “had a really bad experience” in her student teaching (she was certified in both elementary and early childhood education). The teachers she was paired with “were just miserable and handing out worksheets all the time.” This experience changed Kim’s career trajectory, at least temporarily. After college, she worked at Fidelity Investments for five years.

It was not until after she had had her own three children that she decided to return to the field of education. Working in EI for the past six years, Kim liked working in families’ homes, especially because she was working in an ethnically diverse community and she
was able to work with a range of types of families. And although Kim did not have formal training in autism, she was drawn to the most challenging children, and pretty soon the agency started to assign the autism cases to her. As an EI therapist, Kim felt that she was in a good position to develop relationships with families. She would often attend students' IEP meetings even though she was paid per diem and the meetings were not included in her paid work.

In this role, Kim felt that she could advocate for the students and families she had gotten to know so well. With many families, Aadan’s included, there was a language barrier between Kim (she is a monolingual English speaker) and the families (many of them are newly arrived immigrants or refugees with limited English proficiency). This language barrier was challenging to the EI model, which emphasizes therapists modeling strategies for parents to try. And Kim also wondered what roles parents felt like they should have during the EI sessions. “I don’t know that the right thing to do is...to tell the mom to sit on the floor and play with her son.” And especially in Nadifa’s case, with seven children to take care of, Kim wondered whether or not the ideal of parent participation is “really a feasible thing.”

This chapter has offered an introduction to each of the family members and educators affiliated with each of the three cases in this study with an eye to the details of each context and sets of experiences that may influence the educational decision-making process. In Chapter 5, instead of looking at each of the cases as its own entity, themes and sub-themes are analyzed across cases, allowing readers to see similarities and differences and to better understand the educational decision making process.
CHAPTER V: RESULTS OF THE STUDY

Results of this study highlight above all, the tremendous variability in how educators and Somali-American mothers of students with autism interact in the context of making educational decisions. In seeking to understand this variability, I analyzed educational decision-making across three distinct phases: (1) pre-meeting activities interactions, (2) family/educator interactions at IEP meetings, and (3) post-meeting decisions and the outcome of the IEP.

As outlined in Chapter 4, the three cases examined in this study differ on several dimensions, from the type of school agency (i.e., early intervention [EI] agency, public preschool, private out-of-district placement), to the nature of the student’s autism (i.e., from high-functioning to classic; highly verbal to non-verbal) and the parents’ educational level (i.e., from no formal education to graduate degree) among many other variables. Broadly speaking, across cases and phases, the educational decision-making process can be understood in terms of institution-level factors (e.g., school policies and culture) and individual attributes (e.g., family member and educator beliefs about collaboration). On a more fine-grained level, individual themes representing beliefs, actions, and interactions among various participants (e.g., mothers, teachers, administrators, and special education advocates) are differentially important across cases and phases of educational decision-making. In the next three sections, I examine the educational decision making process across three phases (i.e., before, during, and after the IEP meeting). Within each of these temporal categories, I discuss the primary themes uncovered by my analyses.
Phase I: Before the IEP Meeting

Research regarding educational decision-making for students with disabilities typically addresses negotiations that occur during IEP meetings and the legally binding decisions that follow (e.g., entitlement to particular direct and consultative services, partial rejection of goals or services) (e.g., Lo, 2012, Mueller, 2005). Findings from the present study emphasize the on-going ways in which educators and family members interact before the IEP meeting itself. The mothers and educators in all three cases discussed the ways in which they communicate with one another and their comments as well as my own observations and analysis point to the conclusion that these interactions influence educational decision-making in significant ways.

The nature of the interactions prior to the formal IEP development process can be understood in terms of: (a) the institutional context (e.g., the explicit policies and implicit norms of schools and agencies), (b) language and other logistical factors, and (c) family member and educator beliefs (about, e.g., educational collaboration, the causes of autism). The formal IEP development process begins before the IEP meeting itself. Therefore, in conceptualizing the themes that influence the educational decision-making process in the pre-IEP meeting phase, it is important to consider the roles of educators and family members in the development of draft IEPs.

The Institutional Context

Schools and EI agencies have philosophical orientations and policies that shape the nature of interactions between family members and educators. Some schools have an “open-door” policy with parents bringing students directly to classrooms and routinely volunteering at school events; others do not. All three institutions in this study have
specific policies regarding family member-educator communication. Besides formal rules and policies, a particular institutional culture(s) permeates each school or organization. Organizational culture informs interaction between family members and educators so subtly that oftentimes, individuals are oblivious to its influence. Nevertheless, it is important to remember that organizational culture is an important backdrop against which individual relationships develop.

*Institutional Culture and Family Member-Educator Communication*

The incidental interactions between family members and educators that are not seen as a formal component of the educational program (e.g., casual conversation at pick-up or drop-off, interactions while a parent is chaperoning a fieldtrip, volunteering in class or attending a performance) can be instrumental in determining the nature of parent-educator relationships. Unlike formally sanctioned interactions, these incidental encounters are shaped by school culture rather than by official policy. Findings from this study indicate that parents who are new to a school or organization observe the actions of veteran parents and take cues from the educators, who themselves (consciously or not) often subscribe to the institutional culture (e.g., Saida [mother, case 1] who fervently believed that parents should care for children with disabilities at home was persuaded, by parents she met through the school’s parent teacher association (PTA) to pursue a residential placement for Dris).

At a school where students, parents, educators and other personnel interact intensively, the culture is both visible and robust. In contrast, the culture at an EI agency is diffuse. Therapists have a brief orientation followed by a period of “shadowing” an experienced provider. Therefore, the transmission of institutional culture from one
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generation of service providers to the next exists only minimally. The influence of school culture on educational decision-making was seen across the following domains (a) parent involvement in school activities, (b) interaction among parents in the school setting, and (c) interactions among parents and educators in the EI context.

*Parent involvement in school activities.* Opportunities for parents to participate in school events can serve as a natural means for family members and educators to establish rapport with one another. Both John [teacher case 1]—who had been a Hope family member prior to being employed at the school—and Saida articulated the degree to which the Hope School encourages parent involvement. Parents are consistently invited to activities such as performances, athletic events (e.g., running races), and social events (e.g., prom). Saida joked that she had probably used “like two hundred dollars in gas” going back and forth between her house and the school during the first two weeks that Dris was “a resident.” Both also talked about the strong role of the school’s PTA, which serves as a support for parents and even siblings.

At Bilal’s [student, case 2] school, Leapfrog Preschool, I observed parents and younger siblings routinely lingering in the foyer and hallway dropping off or picking up students, and chatting with teachers. Amina [mother, case 2], a chemist by training, often volunteered in Bilal’s class on Thursday mornings demonstrating science experiments (e.g., “elephant toothpaste, a volcano, coke and mentos” [Amina]). Opportunities like these allowed for informal face-to-face interactions between parents and teachers. At these times, the mothers and teachers had the chance to interact on a personal level without the expectation of formal conversations about student progress.
Many voices at the table

Both Saida and John and Amina and Katherine [teacher, case 2] knew details about each other’s families. In the moments before Bilal’s IEP meeting officially began, for example, I observed an exchange between Amina and a couple of Bilal’s educators (i.e., his preschool teacher, speech therapist, and OT). Amina and Bilal had just returned from a family wedding in Toronto, and as Amina showed the teachers pictures of the event, it was clear that the teachers were interested in and knowledgeable about Bilal’s life outside of school (e.g., they knew the names of extended family members, had heard anecdotes from the trip). Observations of interactions between these mother-teacher dyads revealed that the intimacy established over the course of their relationships extended into the formal realm (i.e., IEP meetings).

Interaction among parents in the school setting. Parental involvement in school activities serves as a mechanism for parents to be acquainted with not only school staff, but also with other parents. Getting to know the parents of other students with similar disabilities can be a powerful experience and can shape beliefs and educational decision-making. In fact, research suggests that parent support groups can instrumental in relieving stress and improving outcomes in parents of students with autism (e.g., Mandell & Salzer, 2007). Saida, as mentioned previously, had long believed that children like Dris should be taken care of at home by their parents. Her family members (son, nephew, and brothers) shared this belief. The idea of a residential placement was foreign to Saida and her family. It challenged the notion of collectivity and that families should take care of each other (“We [Somalis] are family-based. Family is number one for me. We are not individualized, you know?” [Saida]). When Saida became active in the parent teacher association (PTA) at the Hope School, this belief was challenged. She got to know the mothers of other Hope
Many voices at the table

students, who reportedly urged her: “Saida, why don’t you give [residential] a try.” In contrast to Saida’s preconceptions of parents who would enroll their children in residential programs, these mothers: “...have good jobs. They're good mothers. They're very involved” [Saida]. Saida’s perception of these mothers, as she got to know them, clearly challenged her previous conceptions of what types of mothers would enroll their sons in residential programs.

Over time, Saida started to see a residential setting as an opportunity for Dris. Saida came to believe that being in a setting with other teenagers like himself would foster independence in Dris, allowing him to participate in a broader range of activities. “And I say I think I’m helping him. So I think I’m helping him and I want him to have at least some structure” (Saida). Saida’s newfound emphasis on independence is notably in keeping with the value on independence, which undergirds the American special education system (e.g., *IEP Process Guide*, 2001), and prizes self-care and adaptive daily living (ADL) skills from a young age. This orientation contrasts with the communal perspective on raising children with disabilities which is valued within traditional Somali culture and emphasizes the familial care-taking context rather than the particular skills a student should be taught (e.g., Kediye, Valeo, & Berman, 2009).

Once Saida had decided to make a bid for a residential placement for Dris, it was through Hope parents that she found a special education advocate to support her at the IEP meeting and beyond. (The role of special education advocates in the special education-decision-making-process will be discussed later in this chapter.) Parents of students with disabilities often feel a natural connection with other parents whose children also have
Many voices at the table

disabilities. Therefore, parent’s views on their children’s education may be shaped more or differently by interactions with other parents as opposed to with educators.

*Interactions among parents in the EI context.* The EI context inherently provides fewer opportunities for parent-to-parent contact than a school setting does. However, variability exists in terms of the contact that EI parents get. For example, The Big Dipper Early Intervention Program [BDEIP], like many agencies offers a variety of groups in addition to the one-on-one therapies. Intermittently during this study, Aadan [student, Case 3] participated in a weekly drop-off toddler group. Because Aadan was provided with transportation to the group and Nadifa [mother, Case, 3] did not drop him off or pick him up she did not have access to the ancillary benefit of the group—interacting with other parents of children with disabilities. When my own son was in an EI toddler group, I accompanied him to the group and enjoyed the opportunity to observe him through the one-way-mirror while chatting with the parents of his classmates. I discussed educational decisions I was thinking about with the other parents in the group (e.g., preschool options, questions about developmental milestones).

There are a host of reasons which likely explain why I accompanied my son to his toddler group while Nadifa did not: I had my own transportation, Nadifa did not; Nadifa had other children at home, I did not. And, notably, even if Nadifa had accompanied Aadan to the groups it is unlikely she would have found another Somali-speaking parent to talk to. This example shows the confluence of factors that impact the degree to which parents interact with educators and other parents in the EI setting and more broadly, the ways in which inclusion/exclusion from informal parent networks are established at the very outset of a child’s education. The intersectionality framework is helpful in illustrating the
Many voices at the table

ways in which multiple intersecting identities allow or deny parents to gain access to support networks. As mentioned previously, Saida was very much connected to the Hope PTA. In this case, although Saida and Nadifa are both Somali refugees, the differences between them—facility in English, financial capital (e.g., personal transportation), class, and education status—intersect with ethnicity and contribute to two very different experiences. Namely, Saida is connected with her son’s school and with many parents of disabilities while Nadifa remains isolated.

*Official Parameters for Communication and the Family-Educator Relationship*

One of the most fundamental ways in which institutional policy can influence parent-educator interactions is by establishing expectations for the nature and frequency of communication. All three of the organizations in this study required educators to contact parents with a minimum frequency and type of contact.

These in-built points of contact were designed to serve a range of functions (e.g., facilitate discussions of educational progress, prompt parents to carryover educational activities at home, and communicate logistical information). Specific forms of communication are associated with each of the three institutions: (a) home logs [Hope School], (b) monthly clinic meetings [Leapfrog Preschool] and (c) weekly session notes [BDEIP]. The descriptions of each of these forms of communication highlights inherent advantages and disadvantages and makes explicit the relationship between school policies and relationship development in the context of individual educators and family members.

*Daily home logs (Hope School).* The daily home logs used for communication between teachers and the families of day students at the Hope School served as a quick and informal means of communication. Topics discussed ranged from student
progress/performance to logistics, and led to casual conversations. The degree to which and ways in which family member/educator dyads used the home log structure depended on the communication tendencies of the two parties. John commented that some of the parents of the students in his class were much more likely to use the home logs than others. Some families, because of language barriers, were limited in their ability to access this form of written communication. John recalled, for example, one family in which typically developing siblings assisted parents in corresponding with teachers via the home log.

At the start of this study, when Dris was still a day student, John and Saida wrote back-and-forth on a daily basis. Although the content of these exchanges varied, the tone of the notes was friendly, sometimes humorous. Saida recounted an exchange that she had had the previous year with Dris’s former teacher. One day Dris came home with a baseball cap covering a half-finished haircut. His then-teacher wrote a quick friendly note joking about the “new look” and promising to complete the cut the following day.

In my own tenure as a special educator, there were several families with whom I developed close relationships through the medium of home logs. Much like Saida and John, these families and I tickled each other with funny and telling anecdotes. I remember looking forward to reading these notes each morning and in some cases the information (about, e.g., a sleepless night, or an uneaten breakfast) helped me structure the school day to promote student success. Much more often, families wrote intermittently if at all.

Quick and informal forms of communication such as daily home logs can make visible parents’ and educators’ unique personalities and allow players to get to know one another in a low stakes context (i.e., without the pressure of discussing weighty topics like a student’s educational progress or behavioral challenges). On the other hand, teachers and
educators alike are required to write quick notes in the midst of busy days. There is little
time for detailed explanations or formal discussion of educational planning. Therefore,
home logs, if used as the sole or primary means of communication can fall short of
establishing substantive conversations between educators and family members. (Notably,
the Hope school also offered parents the option of phone calls to complement or replace
daily home logs.)

*Monthly clinic meetings (Leapfrog Preschool).* The Leapfrog Preschool provided a
structure for parents and educators to meet in a face-to-face format each month. These
“clinics” provided a dedicated time for dyads to sit down together for an hour each month
to discuss student progress and broad educational concerns. Katherine commented that
although the focus of these meetings was generally not on the “[IEP] document itself” the
clinics are a time for either family members or teachers to raise “concerns” about a
student’s progress. Amina explained the process:

So we go over the goals and we go over what has Bilal done in a month
but sometimes a month is too long for me so I’m already talking to
them almost every week and if there are certain things that I notice, I
tell them about it. And if there’s certain things that they notice they
tell me about it.

Some family members take a more active role in this process than others, Katherine
explained. Amina, for example, is “fantastic” at asking questions about what she could be
doing to support Bilal’s learning at school. Katherine explained that Amina’s level of
engagement in this clinic is exceptional. Some parents, for example, only want to come to
the clinic meetings “if something is wrong.”

Though the home log and clinic meetings are very different in nature, each structure
is used to different extents by different parent-educator pairs. The home log relies on quick,
Many voices at the table

frequent communication while the clinic meeting’s is based on less frequent but in-depth communication. In the case of parents who do not understand the special education process well, it is easy to imagine that longer face-to-face meetings might promote increased understanding. In addition, face-to-face communication can be a richer way of communicating information than verbal or written communication alone: parents and teachers can read one another’s body language, facial expressions, and gestures resulting in fuller and more authentic understanding. On the other hand, for parents with rigid job schedules, frequent in-person meetings might be stressful or even impossible to schedule.

_Session notes (Big Dipper Early Intervention Program (BDEIP))._ In the Massachusetts statewide EI program, family members are expected to be active participants in every aspect of service delivery—from creating the individual family support plan (IFSP), to learning strategies during weekly therapy sessions, and even participating in program-level decisions (Massachusetts Executive Office of Health and Human Services, 2014). One specific structure designed to prompt parent-educator communication is the “session note.”

At the end of each weekly session, Kim used a template to record what she had worked on during the session and to provide suggestions as to what Nadifa should carryover in the coming week. In my experience as an educator and as a parent of a child receiving EI services, it is clear to me that the goal of this structure is to establish a shared understanding between parent and educator. Oftentimes, it is viewed as a sort of contract with both parties literally signing off on the content and agreeing to a set of “next steps.”

In the case of Kim and Nadifa, the exchange of the session note was no more than a rote exercise. Although the agency had a specific requirement for family-educator communication and although Kim dutifully wrote session notes following each session, the
notes failed to spark authentic communication. For one thing, the session note (like the daily home log) is a written form of communication. For a mother like Nadifa, who is not literate in English (or any other language, including Somali), a note summarizing the EI session simply is not helpful.

Language and Other Logistical Factors

Language barriers are identified as one of the most salient determinants of family-educator communication (e.g., Al-Hassan & Gardner, 2002). Language is differentially important across this set of three cases. To begin, all three of the educators are monolingual English speakers. Saida and Amina are both impressively multilingual and multi-literate (Amina speaks: Arabic, Somali, and English; Saida speaks all of these plus Swedish), and fluent English speakers (they each have professional jobs that require English proficiency). As mentioned previously, Nadifa is a monolingual Somali speaker and is not literate in any language.

The language barrier between Nadifa and Kim [developmental specialist, case 3] might seem surmountable. To begin with, the EI agency compensated Halima, a bilingual (Somali-English) social worker to interpret the weekly EI sessions. The perception that interpreters have an “allegiance” to the school district has been identified as a barrier to open family-educator communication (e.g., Jung, 2011). This case does not fit that pattern. Halima was affiliated with Nadifa and her family prior to the inception of EI services. In fact, Halima navigated the EI system to help the family get services and arranged to insure that appropriate interpretation services were provided (the EI agency elected to hire Halima herself as the interpreter).
Many voices at the table

Nadifa’s involvement in the EI sessions varied considerably across the three sessions that I observed. At one session, for example, she and Halima sat on folding chairs at the threshold of the “therapy room”—a small unfurnished room off of the kitchen where EI sessions took place. Nadifa primarily watched the session, but participated actively in several moments (e.g., practicing signing “more” to Aadan).

During the other two sessions I observed, Nadifa explained to me that she needed Halima’s help for “going over bills.” With seven children (three of whom have autism spectrum diagnoses) and byzantine social service systems to navigate, the demands on Nadifa’s time were urgent.

During one of my observations of Aadan’s EI sessions, Nadifa received a letter in the mail from DCF announcing a home visit the following week. This investigation had been triggered by a 51A20 filed by her doctor’s receptionist who was concerned about Nadifa’s ability to manage her three autistic sons during an extended wait in the office waiting room. Halima and Nadifa spent most of the time during Aadan’s session that week trying to piece together what had happened (Halima had been at the doctor’s office as well) and to devise a plan for the coming home visit. Halima’s professional opinion was that the neglect claim was absolutely preposterous and having seen Nadifa gracefully navigate the needs of her three (very needy) children at home, I concurred. This example is an aside in the context of family member/educator collaboration, but I share it to the end of helping readers understand the very stressful demands often present in families’ lives. Without knowing these details, it can sometimes be difficult to understand parents’ priorities. Stated another way, it was not hard to understand Nadifa’s decision to prioritize the single hour a week

20 Section 51 A of Massachusetts General Law requires mandated reports to file a claim when abuse or neglect is suspected.
she during which she had access to a Somali-speaking social worker for activities other than understanding the intricacies of Aadan’s EI sessions. It is important to remember that the American special education ideal of parent involvement in educational decisions, while noble, may be a luxury inaccessible to many families.

*Language barriers and telephone communication.* Phone and other contact outside of the weekly sessions is another area that can be compromised by a language barrier—after all, there are almost never on-call interpreters at agencies or schools. As mentioned previously, intermittently during this study, Aadan attended a weekly toddler group in addition to his EI sessions. Because he took a bus to toddler group, these sessions did not occasion informal contact between family members and educators. One week, because Aadan had been struggling so much at toddler group (i.e., the teachers were only able to calm him by swaddling him in a blanket), Kim proposed that he take a break from attending the weekly group. There was, however, a miscommunication with the transportation company and the bus came to pick Aadan up in err. Nadifa, not being able to communicate with the driver and not knowing what else to do put Aadan on the bus although it was not her original intention. This instance of miscommunication caused Kim to reflect on the degree of trust that it takes to send such a young child on the bus alone, no questions asked.

And I often think, like gosh, imagine putting your non-verbal two-year-old on a bus. And then seeing him three hours later. You don’t know that they got there.

Kim explained that parents “absolutely could” call to confirm that a child had arrived safely at group. Kim was generally very sensitive to the challenges faced by the families with whom she worked. In this comment, however, I sensed that Kim’s emotional reaction overrode her awareness of the barriers associated with being a non-English speaker and being new to these complex systems of service provision.
Many voices at the table

From my perspective, Nadifa actually did not have the ability to call the EI agency. They did not have Somali interpreters available to respond to calls nor were Nadifa’s older English-speaking children available during the school day when she was sending Aadan off to toddler group. What Kim perceived as Nadifa’s high level of “trust” might have in fact, illustrated her lack of options. In contrast to the other dyads in this study (i.e., John & Saida, Katherine & Amina), Kim and Nadifa had very little information about the ways in which the other made sense of the world. They did not have the luxury of chatting with one another.

These examples illustrate the many ways in which a language barrier can limit communication—from eliminating the option of impromptu interactions (an interpreter would need to have been in place in advance) to decreasing the intimacy of conversations—because every word is filtered through an interpreter. Although language is often the most obvious barrier in the context of culturally and linguistically diverse families, I contend that family members’ and educators’ divergent values and beliefs (e.g., Jung, 2011) represent an even more significant barrier.

Family Member and Educator Beliefs

All educators and family members affected by autism have certain beliefs related to the condition (about, e.g., the cause and course of autism, the nature of family-educator collaboration). The degree to which family members’ and educators’ beliefs are (dis)similar has important implications in terms of the ways in which they negotiate educational decisions together.
Beliefs about the nature of family involvement.

In the American context, collaboration is envisioned as being a “cornerstone” (e.g., Harry, 2008; Olivos, Friend & Cook, 2007, Gallagher & Aguilar, 2010) of the special education decision-making process. In this arena, parents are conceived of as the bearers of important information about their children. Their input is valued. Based on my experience as an instructor in teacher preparation programs, it is clear that pre-service special educators are imbued with a sense of urgency about involving parents. Children will learn better if their parents’ input is taken into consideration, they are taught to believe.

What happens, then, when parents, themselves, do not believe that their children’s education hinges on their own participation? Katherine explained that she finds it to be “very challenging, super challenging” when parents do not see themselves as being active participants in the educational decision-making process. “Some families,” she continued, “are surprised when we expect them to be their child’s primary educator, you know as the role of the parent.” Katherine’s perception was that these parents believe: “[the teacher’s] job is to teach my children and I [the parent] just provide for them.”

Katherine concluded that when a discrepancy exists, often “it is a cultural piece and sometimes it is a socio-economic piece.” In an imagined conversation with hypothetical uninvolved immigrant parents, she fantasized about saying: “Well, no, that’s your job. That’s what you signed up for; that’s what we all signed up for when we choose to have children.”

The perspective articulated here by Katherine, is closely aligned with the values that underpin the American special education system. The structure of IEP meetings as well as the IEP document is founded on the notion that family members should be actively
involved in the special education process. This notion relies on the assumption that family members have both the desire and ability (not always the case given the inflexible nature of many entry-level jobs, lack of transportation etc.) to be involved in educational decision-making processes. The fact that Katherine’s (middle/upper-class) perspective is so neatly aligned with the institutional values function to exclude family members whose perspectives are not in alignment with the dominant view.

Returning to the case of Nadifa and Kim, it seems that Nadifa’s level of participation in the EI sessions probably had as much to do with her beliefs about parental participation in education as it did with the language and logistical barriers outlined previously.

Nadifa asserted that understanding the content of the EI sessions was not particularly important for her. When I asked if she would like the interpreter to translate what Kim was saying to Aadan, she answered tersely “No.” She explained to me that she knows Aadan is “learning something” and believes she does not need to go through each session “step-by-step.”

Kim commented on the variability in Nadifa’s participation in the sessions, “Sometimes [Nadifa] doesn’t come in.” Kim hypothesized that Nadifa’s minimal participation in the EI sessions was related to her notions about parent/educator roles: “She’s like ‘Oh, the teacher's here, the teacher’s gonna teach him.’”

Nadifa’s (apparent) sentiments contrast sharply with the beliefs of both Saida and Amina who saw themselves not only as players in making decisions about their children’s education, but as their children’s primary advocates. Amina and Saida both envisioned the role of a parent in a child’s education as essentially boundless. They were involved in finding appropriate placements and objecting when the found a placement or an aspect of a
Many voices at the table

placement to be inappropriate or insufficient. They sought extracurricular activities to complement what their sons were learning in school and saw themselves as “teachers” in the home environment. In fact, in spite of all that she was doing, Amina reported “always feeling inadequate...because I always feel like I am not fighting enough for him [Bilal].”

Beliefs about how vocal a parent should be.

Because Nadifa was not actively involved in her son’s EI sessions, it might be easy to assume that she did not have strong opinions about his education. Not so. In fact, there were things about Aadan’s EI sessions that bothered Nadifa.

For example, because Aadan had a diagnosis of pervasive developmental delay (PDD) he was entitled to supplemental ABA services. The Northeast Autism Center [NAC] had come out to her house to do an initial intake and assessment. The ABA services would have been delivered three or four times per week instead of the once or twice per week basic sessions. The services that Aadan was entitled to based on his PDD diagnosis would have constituted approximately four times as many hours of total EI services, as compared to the basic level of services.

For logistical reasons, the services were significantly delayed (delivery ultimately started only a couple of weeks before Aadan’s third birthday the end of his entitlement to early intervention). During this gap, Nadifa reported to me in an interview that she was frustrated about the lack of additional services. However, she did not express this frustration to Kim nor to NAC directly. Once the ABA services were in effect (albeit briefly), Nadifa reported that the services were “very helpful—more than the early intervention” vindicating her initial desire for the services to commence and showing that Nadifa’s lack of communication with Kim belied her awareness of and opinions about Aadan’s education.
Although Kim, herself, worried that the delay in service delivery would adversely affect Aadan, she (incorrectly) assumed Nadifa was nonplused by the lag. Based on other comments that Nadifa made, we might extrapolate that Nadifa did not mention her concern because she did not feel that advocating for Aadan (or confronting the system) was her role. And in fairness, perhaps she had (correctly) surmised that Kim was already at work to remedy the situation.

Another example in which Nadifa had clear, though unvoiced, opinions about Aadan’s service delivery was related to his basic EI services. In addition to receiving EI services from Kim (his developmental specialist), he also received occupational therapy (OT). Some weeks the therapists came at separate times. But once or twice per month they came together. When and why they came separately or together was entirely mysterious to Nadifa. Although she preferred for them to come at separate times because she felt like Aadan benefitted from the increased intervention time, she never asked the therapists why they sometimes came together or what their schedule was. I later learned from Kim that the overlap sessions were intended to allow the therapists to collaborate and model interventions for one another. This miscommunication is important in that it shows that even something seemingly as simple as scheduling EI sessions can be misconstrued.

Both Kim and Nadifa expressed the intention of being deferential to the other. Kim felt that this deference was especially important in the context of working in someone else’s house, “I don’t want to step on her toes and be constantly telling her what to do,” she explained. Likewise, Kim perceived Nadifa’s deference in the fact that she was very “trusting” of the EI process—it seemed like she felt like “Oh, they’re in my home and they’re here to help.” And for the most part, Nadifa was very grateful for all of the services that she
had received. She described having “prayed” for people to come help her, and she considered having a developmental specialist, ABA-provider, OT, and social worker as evidence of answered prayers. I argue that this double-sided deference was one of the factors that impeded true communication between Nadifa and Kim. Nadifa expressed gratitude for the services her son was receiving without voicing her critical analysis of the service delivery and Kim, in an effort to be unobtrusive did not push Nadifa for her opinions. As I will discuss in greater detail in chapter 6, I propose that educators would benefit from understanding how to ask targeted and disarming questions that allow them to ascertain what is truly important to family members without falling back on assumptions based on (often limited) knowledge of various cultural groups. The three cases in this study, therefore, illustrate well the degree to which families may hold divergent views on educational participation even within the context of a particular population—Somali-American families of boys with autism. It is important for educators not to make presumptions about a given family’s beliefs about special education participation.

Beliefs About the Causes of Autism

In my interviews, I asked each of the mothers and teachers what they believe to be the cause of autism. Participants’ responses to these questions are summarized in Table 5.1. I present teachers’ and mothers’ beliefs about autism because explanatory models about the cause and the course of autism can have important implications in terms of educational priorities for a student with autism. It is notable here that all three of the teachers but only one mother espouse the belief that autism is caused by the confluence of multiple factors—primarily an interaction between genetic predisposition and environmental triggers. This
Many voices at the table

set of explanations closely mirrors contemporary scientific perspectives on the matter—that autism is a biologically based disorder with both genetic factors (i.e., deletions, mutations, and copy number variants) and environmental factors (e.g., prenatal exposure to valproic acid, maternal rubella infection) (Landrigran, 2010).

Table 5.1.
Beliefs about the Causes of Autism

<table>
<thead>
<tr>
<th>Case 1</th>
<th>Mother</th>
<th>Teacher</th>
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<tbody>
<tr>
<td></td>
<td>Saida</td>
<td>John</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.) Vaccine Hypothesis</td>
<td></td>
<td>1.) The vaccine hypothesis</td>
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<tr>
<td></td>
<td>I believe 100% my son’s problem is from the Mercury in the MMR. I believe that. My son. He was perfect before he took that. I don’t care if they say it’s not true. I don’t care what they believe. This is my own research.</td>
<td>2.) Changes in diagnostic criteria.</td>
</tr>
<tr>
<td>2.)</td>
<td></td>
<td>3.) Biological/genetic factors. Some people, physically, neurologically, are more susceptible.</td>
</tr>
<tr>
<td>3.) Prenatal Environment</td>
<td></td>
<td>4.) Environmental factors</td>
</tr>
<tr>
<td></td>
<td>I think that it happens in the womb and I think I had a very stressful pregnancy because my marriage wasn’t going well. And I was working a lot. I was working two jobs, long hours and I didn’t have the emotional support that I needed.</td>
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<tr>
<th>Case 2</th>
<th>Amina</th>
<th>Katherine</th>
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<tbody>
<tr>
<td></td>
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<td></td>
</tr>
<tr>
<td>1.) Biological/genetic factors</td>
<td></td>
<td>1.) Genetic/Biological Factors</td>
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<tr>
<td>2.) Environmental factors</td>
<td></td>
<td>2.) Environmental Factors</td>
</tr>
<tr>
<td>3.) Prenatal Environment</td>
<td></td>
<td>3.) Changes in Diagnostic Criteria: I know one [doctor] that she would over-diagnosis ...so a child can get services</td>
</tr>
</tbody>
</table>
Many voices at the table

<table>
<thead>
<tr>
<th>Case 3</th>
<th>Nadifa</th>
<th>Kim</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.) Religious explanation: <em>God given.</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.) Environmental Factors</td>
<td></td>
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</tbody>
</table>

Though not an explanation for the cause of autism, strictly speaking, two of the teachers responded to my question about the causes of autism with the (commonly accepted) notion that changing diagnostic practices are at least partly responsible for the increase in autism diagnoses in recent years. This finding is important in the sense that it reminds readers of an on-going confusion about whether or not there is a rise in the actual number of cases of autism (i.e., incidence and prevalence) or simply in the diagnosis of the condition (e.g., Grinker, 2007). Likewise, although there is data to suggest that autism has been disproportionately diagnosed among Somali refugee children, it is unclear whether or not there is actually a high incidence or whether something about this particular subset of the population eludes accurate diagnosis (McNeil, 2013).

I propose that explanatory models of the causes of autism can serve as a proxy for degree to which mother’s and teachers’ ideas about autism resemble one another more broadly. It is notable, then, that each of the three cases in this study is matched/unmatched on this facet to a different degree. At one extreme, Amina and Katherine essentially agree: they both cite the interaction between genetic and environmental factors. On the flipside, there is no overlap between Nadifa and Kim’s understandings. Nadifa believes that it was “God’s will” that three of her children are affected by autism; Kim does not share this belief.

John and Saida fall somewhere between the other two dyads on this metric. Specifically, John, like the other two teachers, reported the belief that autism is caused by
the interaction between biological and environmental factors. In his explanation, he stressed the fact that his own parents subscribe to the vaccine hypothesis and that although he knows that this hypothesis has been disproven, it still resonates with him in making sense of the onset of his brother’s autism.

Saida states her support of the vaccine hypothesis much more strongly than John. Like John, she is aware that vaccine hypothesis has been discredited. However, having watched Dris’s language skills deteriorate (remember: at age two, Dris was “speaking” and understanding both Somali and Swedish) after he received the MMR vaccine, she simply cannot help but believe that the vaccine was a factor—the primary factor—in her son’s condition (“I believe it [the vaccine hypothesis]”). Saida’s belief in the primacy of the vaccine precipitating her son’s autism is substantiated by the fact that his family does not have any history of autism or other developmental disabilities and the fact that she has taken him to a genetic specialist and he has no genetic markers for autism (field notes). Perhaps because John has an immediate family member with autism, his explanation is laced with the emotional/personal quality of living intimately with the condition. Again, I establish the level of (dis)agreement about the etiology of autism as a backdrop for future discussions of the ease with which each of these mother/educators dyad’s relate to one another.

Beliefs About Respecting “Culture”

Working intimately with people from different cultural backgrounds and whose lived experiences are different from one’s own presents an array of challenges. In my own experience of teaching immigrant students with autism, I found one of the greatest challenges to be balancing the desire to be respectful of a family’s “culture” without
compromising my own beliefs about what is in a student's best interests. This tension existed, to varying extents, across all three cases in this study. It is illustrated particularly clearly in the case of Katherine and Amina.

Amina believing strongly in the benefits of intervention, worked tirelessly with Bilal in the hopes of developing his skills and ensuring that he know how to behave appropriately. She worked with him herself, teaching him academic and independent living skills at home and had enrolled him in various therapies and extracurricular activities throughout the week (e.g., swimming lessons, private speech therapy). In the past two-and-a-half years since Bilal was diagnosed with autism, he had made tremendous gains across domains.

Katherine articulated the perspective that Amina “pushes” Bilal and holds him “to a higher standard” (Katherine) than do most parents of children with autism: “she uses every minute of her day to work him.” Katherine countered: “he needs to play with blocks when he gets home. Like, he needs down time. He needs to run around and to have an opportunity just to laugh and be silly” (Katherine). Katherine attributed her perspective on Bilal’s education to the way she herself was “raised.”

The needs of students with autism are complex and ideas about how to educate and raise a child with autism are many. It is, therefore, not surprising that a mother and a teacher would have slightly different opinions. In fact, Katherine and Amina had similar ideas about most aspects of Bilal’s education.

Arguably more interesting is the fact that Katherine conceived of this discrepancy as a “cultural difference” (i.e., “that’s how she [Amina] was raised”). As an outsider to this mother-teacher dyad, I am not convinced that Amina’s perspectives on Bilal constitute a
“cultural difference.” I wonder, for example, if we would see this same behavior across Somali mothers or Somali refugee mothers.

Amina, is a very driven woman by any “cultural” standard. As a full-time working mother of a child with a disability, during the course of the study she also trained for a marathon, prepared for the LSAT, and volunteered regularly in her son’s preschool class. It is conceivable that her ideas about Bilal’s education had more to do with her temperament than with her “cultural background”?

Amina offered her own commentary regarding her expectations for Bilal. She explained: “I’m not gonna be here for as long as he lives...He only has me so if I don’t push him, and if I don’t have high expectations for him within reason, within reason, ... I’m failing as a parent is the way I see it” (Amina). This explanation weaves together Amina’s characteristic balance of optimism and realism. Although Amina did not discuss her perspective as being “cultural” per se, she did see a connection with her own upbringing (i.e., “my parents definitely had high expectations for me”).

In addition, Amina discussed the importance of racial stereotypes in shaping her educational priorities for Bilal:

He [Bilal]’s a black man in America, so I’m doing a disservice to him if I don’t push him...and it would be naïve of me to think the world is fair. The world is not fair.

This idea of the interaction between racial stereotypes and the behaviors associated with autism was not something that Katherine mentioned in any of her interviews. As a white woman teaching in a predominantly white community, her thinking about educational planning seemed to be essentially “colorblind.” That is to say, in her educational decision-making, Katherine viewed Bilal as a student with autism, but not as a member of a
particular racial or ethnic group. Although Katherine’s perspective may appear innocuous at first glance and though she was undoubtedly well-intentioned, colorblindness such as this is grounded in white centrality and serves to marginalize anyone who is not white. In a practical sense, Katherine’s stance may have disadvantaged Bilal by failing to acknowledge the ways in which race, gender, and disability (in this case) interact with one another threatening to disempower him and students like him. As a black boy who engages in behaviors associated with autism, he is particularly likely to excluded from the larger social context. As suggested by Crenshaw (e.g., 1991), by subscribing to a single axis approach (e.g., focusing on disability alone) Katherine obscures the particular nature and magnitude of the subordination that Bilal is likely to face outside of the school context.

Katherine’s educational planning does not take into account a holistic view of Bilal’s learning needs. We might posit that Amina’s steadfast determination to teach Bilal behave appropriately is accentuated by the system’s (or his teacher’s) incomplete understanding of his unique educational needs. A secondary consequence of this scenario is that Amina, perceives that school officials find her advocacy on behalf of her son off-putting (e.g., worrying that they think “here comes the bitch on heels” when they see her). In essence, Amina’s relationship with school personnel is threatened by the fact that she is sensitive to the intersecting aspects of her son’s identity while the school is oblivious to them.

As a point of comparison, Saida also mentioned Dris’ race in the context of his education on several occasions (e.g., “And he was the only black one. And they are all boys and almost all the same age. Six white kids and my son”). John, like Katherine, never once mentioned race as a consideration in Dris’ education.
I delve into this example of a difference of framework between teacher and mother in part because I think that it illustrates well the complex and intersecting factors that influence how individuals arrive at educational priorities for their children or pupils on the autism spectrum.

The other reason that I draw on this particular example is because in the context of educational-decision-making for culturally and linguistically diverse students on the autism spectrum individual’s perceptions of the role of culture is a topic worthy of analysis. More specifically, in this case, Katherine believed that the difference of opinion between herself and Amina was a matter of “culture.” I posit that in this case, culture is used as an overly amorphous construct and that Katherine’s emphasis on it impedes interaction rather than supports open communication. As I stated previously, this perception may or may not be “true” in some objective way. The truth of the matter, I contend, is far less interesting than Katherine’s perception.

During a conversation about Amina’s expectations for Bilal, for example, Katherine explained “I don’t know enough about the [Somali] culture,” implying that she did not feel like she had enough information to avoid making culturally insensitive recommendations. In another interview, Katherine explained how helpful it is when a school district has personnel from the same cultural background as a family:

Here in Southville, we have a lot of Indian families and our OT is also from India, so she’ll come in and be like that’s a Northern Indian thing, that’s a Southern Indian...so that’s nice.

I argue that Katherine’s desire to be culturally sensitive caused her to take a more “hands off” approach than she would have if Amina had been an American-born white mother. If Katherine perceived Amina to be more culturally similar to herself, Katherine
Many voices at the table

might have felt more confident about asserting her professional opinion, thereby challenging Amina’s beliefs. In fact, if we think not about ethnicity or race but about class we might note that they are in fact quite similar to one another.

Conversely, she might have felt more steadfast in her opinion that Amina’s perspective was culturally or religiously sanctioned and therefore not fair game to challenge. I make no judgment as to whether a more assertive versus a more sensitive approach on the teachers part would have been better or worse. I present this example simply to illustrate the role of (perceived) culture in determining the degree to which teachers feel entitled to assert their own opinions and the extent to which they are cognizant of their own lack of knowledge, over the course of the educational decision-making process.

*Initial IEP Planning*

On-going interactions between family members and educators (both formal and informal) inform the process by which IEPs are developed and more formal educational decisions made. Once a date has been selected for a student’s IEP meeting, the planning process becomes a bit more targeted. Family/educator conversations move toward a more pointed discussion of the content of the IEP. Discussions often center on students’ progress toward meeting current IEP goals, the ways in which the environment for the coming school year will affect the student’s learning (e.g., kindergarten classroom vs. preschool), and what goals the parent and educator would like to see the child working toward over the course of the upcoming year. In this context the legal context and the IEP document itself becomes important in determining how the process unfolds. Writing a draft IEP is a complicated and collaborative process that generally takes place over the span of several
weeks to a couple of months. Although the ways in which various people contribute to the process varies from one school to the next, from educator to educator and family to family, certain standard practices exist.

The Teacher’s Role in Developing an IEP Draft

In this study, educators emphasized the ways in which drafting an IEP crystallizes the “whole educational process” (John). John described the mechanism aptly as a “reevaluation” and explained that it clarifies for him “what is really important to work on.” In a similar vein, Katherine explained that the beauty of an IEP is that it captures a team’s really individualized and personal knowledge of what “makes a child tick” and ideally the resulting IEP is a document that conveys important information to other educators and remains in a child’s record.

Generally speaking, there is one “primary” educator who takes the lead role in writing an IEP. In the case of a self-contained class, like Dris’s, the primary teacher is generally the lead author, whereas for a student like Bilal, who is included in a general education classroom, the responsibility is often shared between the general education classroom teacher and a special education teacher. And because students with autism often receive services from a variety specialists and therapists (e.g., occupational therapist [OT], physical therapist [PT], speech and language pathologist [SLP], board certified behavior analyst [BCBA]), the work of writing an IEP gets “very much divided up” (John).

Although the division of labor may seem neat, it can in fact become quite complicated. For example, for a student with significant disabilities, like Dris, ELA and communication goals might be very similar and require collaboration between an SLP and
Many voices at the table

classroom teacher. Therefore on-going communication between members of a team is critical.

When asked about the IEP-writing-process, all three of the educators in this study focused first on the process of writing goals. (Interestingly, as the analysis of the IEP meeting itself reveals, these goals can be a relatively minor focus at the actual meeting). The educators talked, for example, about what they do when they are having trouble deciding on a goal in a particular area for a given student: I ask for advice from “teachers who have had similar students.” [John] It is notable that John’s first inclination was to check with another teacher rather than soliciting information directly from a students’ parents.

Educators also rely on input from students’ families in deciding on appropriate goals. John explained that when he is in frequent contact with a family, he know what their top priorities are and will design goals are these areas (e.g., if “safety” is a parent priority, he will “make sure” to address it in the student’s goals [e.g., teaching the student his home or school address, or to show an identification card when asked for personal information]). And Katherine explained that in addition to informally soliciting parents’ concerns at the monthly clinic meetings, the school also formally sends out “a letter” to ask parents for their “concerns” and “vision statement” in advance of an IEP meeting.

It is notable that the educators devoted relatively little time to discussing the role of assessments in determining appropriate IEP goals. For example, when I asked John explicitly about this topic, he explained:

Yeah, uh, we do keep sort of logs, but we’re not as um, we use a much high percentage of anecdotal evidence um and sort of qualitative evidence over quantitative and I know for some school districts that can be an issue, so our IEP and some of the goals often look a little bit different than other schools.
Absent from this discussion is any description of a particular assessment or explanation of how assessment data might inform educational goals. Neither Katherine nor Kim made any mention of the use of assessment data in devising educational goals either.

Teachers take a lead role in the IEP writing process. The choices they make, in terms of prioritizing certain educational goals over others is influenced by a variety of factors including: their own knowledge of the student, consultation with colleagues, and their perceptions of the family’s priorities for the student.

*The Family Role in Developing a Draft IEP*

One of the ways in which parents are asked to prepare for the meeting is by developing or contributing to the development of a “vision statement.” According to the *IEP Process Guide* (2001) developed by the Massachusetts Department of Elementary and Secondary Education (MADESE), the rationale for this portion of the IEP is:

> The vision statement focuses the Team on the future of the student. The Team steps back from the here and now to take a broader, long-range perspective as it looks to where this student is headed in the future. Developing the vision statement helps the Team balance between the immediate concerns and the hopes and dreams for the future. Teams must remember the ultimate goal for all students with disabilities is independence and productive lives.

> Note that this statement states explicitly that the “ultimate goal for all students with disabilities is independence and productive lives.” Therefore, the role that parents play is contributing in a more nuanced way how they would like to see their child supported in terms of developing “independence” and becoming “productive.” But, the question of whether or not this broad goal applies to a given student is not technically open to be decided by an individual family or even an IEP Team. From an American perspective, the
idea of fostering independence may seem like a given. It is important, however, to remember that educational priorities for students truly are culturally determined.

Parents are also asked to contribute to decisions about a student’s educational goals in a variety of ways. And like other aspects of the family-educator collaboration process, the ways in which parents contribute to a student’s IEP are shaped significantly by the parameters of the document. Kim, illustrated this phenomenon well in talking specifically about changes in the IFSP document. As compared with IEPs, IFSPs are designed to be less technical and more family-accessible. Kim described the new format for IFSP goals as “more simplistic” and explained that this makes it “easy” for families to contribute. A family can say, simply “I just want them to talk” and that can be used as a goal, without requiring the provider to translate the goal into technical jargon. Even with these liberal parameters, Kim explained, some families (Aadan’s included) still do not know where to begin (i.e., “They just have no idea and they just want you to write it”).

In this pre-meeting IEP development process, certainly, the document and the process themselves guide educators in soliciting input from family members. However, in dyads where family members and educators already know one another well before the IEP development process begins, the discussion of priorities can be more fluid. For example, as mentioned previously, John explained that when he knows that a family is concerned about a particular area (e.g., safety) he will automatically focus on that area in one or more of his IEP goals—even if the parent does not mention it explicitly in the IEP development process. This type of personal knowledge also influences the ways in which educational decisions are made at the IEP meeting itself.
Phase II: Educational Decision-Making at the IEP Meeting

At the heart of the educational decision-making process for students with disabilities is the IEP meeting itself. Whereas the collective educational-decision-making process that happens outside of the IEP meeting is long and amorphous, the IEP meeting is highly structured and relatively short (the meetings in this study, for example, ranged in length from one to three hours). The decisions made at IEP meetings, however, are disproportionately important compared with their relatively short length.

The IEP meeting is a complex event. The nature of discussions at an IEP meeting are influenced by a variety of intersecting and interlocking factors. Observations of the student’s IEP meetings revealed important insights about how educational negotiations are enacted. Specifically, at each IEP meeting I identified three “important moments.”

As outlined in chapter 3, “Important moments” are instances about which I, as the researcher, wanted to learn more and are defined as moments during the IEP meeting in which multiple divergent perspectives are represented. Perspectives need not be represented verbally, but might include a discrepancy between something written in the IEP and what is stated. Or an “important moment” could consist of a statement made by a parent and an educator’s non-verbal response to that statement (e.g., raised eyebrows signifying disagreement). For each case, I used the same set of instances to probe caregivers and educators. For examples of important moments, see Appendix A. This process allowed for a multi-perspectival analysis of discrete moments in the educational

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21 As mentioned previously, I was unable to attend Aadan’s IEP meeting due to lack of permission from the school district. Where applicable, I comment on his IEP meeting based on information gathered about the meeting from educator- and parent-perspective. Overall, in discussing the negotiations that happen at IEP meeting, I focus on Dris and Bilal’s meetings.
Many voices at the table
decision-making process and afforded insights into various participants’ recall of particular
instances. Taken together, my IEP meeting observations, participant interviews, and
documents provided during the meetings (e.g., evaluations, draft IEPs, agendas) reveal the
ways in which educational decisions are made in the context of IEP meetings.

Findings in this section are organized around the factors that influence the decision
making process: from the IEP document and the structure of the meeting to the various
stakeholders. The skeleton of an IEP meeting is determined by both the IEP document,
which crystallizes important aspects of special education law, as well as school-level
practices and organizing principals. That is to say, although all IEP meetings cover roughly
the same components they do so in a variety of ways. And just as a schools’ culture affects
the ways in which parents and educators interact, the tone of IEP meetings (e.g., from
casual to formal) varies from one school to the next. These structural aspects are animated
by the particular participants at a given IEP meeting (e.g., family members, educators,
special education advocates, sending district personnel [in the case of an out-of-district
placement]).

_Institutional Culture: The Structure of the IEP Meeting_

The IEP meeting is, by its nature, a very formal activity. The IEP team can consist of
as few as four or five people or as many as twenty. (Dris’s meeting, the largest in this study,
included 16 people.) Parents and teachers across all three cases emphasized the extent to
which these meetings are stressful. Saida told me that she had taken the entire day off from
work, because she knew that she’d need the time to unwind and de-stress post-meeting.
Teachers discussed the ways in which they and their schools try to make the meeting
accessible for parents.
Many voices at the table

Organizational Tools

Research suggests that schools can implement certain practices (e.g., providing an agenda, proving a comfortable space, offering participants water) to promote collaboration and reduce familial stress in relation to IEP meetings (e.g., Mueller, 2005). These practices are particularly important for families who are new to this country (e.g., Lo, 2012) new to the special education process, or both. But even veterans of the IEP process may benefit from support. For example, having three children with IEPs, Aadan’s family attended three IEP meetings in the course of just a couple of months. In spite of this, the family was still confounded by components of the process at Aadan’s meeting which was their last of the year. Likewise, although Saida had attended more than a dozen IEP meetings for Dris, she reported finding his meeting in the year of the study to be stressful.

The agenda. According to Mueller (2005), a well-constructed agenda for an IEP meeting can be instrumental in preventing conflict between families and school. Effective agendas should meet three criteria (a) be “clearly linked with the IEP,” (b) provide “room for group discussion,” and (c) be “posted in the room for all members to view” (Mueller, 2005, p. 64). Bilal’s meeting, a 3-year-re-evaluation combined with a kindergarten transition meeting, was both particularly complicated and quite well scaffolded. A printed copy of the agenda at Bilal’s meeting was provided to each member of the IEP team (see figure 5.1).

Figure 5.1: IEP Meeting Agenda

TEAM Meeting Agenda
3-Year Re-Evaluation Team Meeting

Kindergarten Transition

Date: Wednesday, May 15th, 2013—9:00 – 11:00

Student: Bilal F.

Parent Input is encouraged and welcome throughout the meeting.

Introductions, Review Agenda

Review Evaluations

IEP Development

1. Parent Concerns, Strengths, Team Vision

2. Present Levels of Educational Performance (PLEP A)

3. Goals, Services, Placement

The agenda provided at Bilal’s meeting meets the criteria for an effective agenda as outlined by Mueller (2005). In addition, several components of this particular agenda stand out. First, there is a written statement reiterating that parent input is “encouraged” and “welcome throughout the meeting.” In addition, the agenda itself designates a time to “review” the agenda at the start of the meeting. In this way, the pertinent information is provided to parents in multiple modes (i.e., written, verbal), increasing the chances of authentic comprehension, especially for parents who are not native English speakers. Finally, the category labeled “IEP development” indicates that the document will be developed collaboratively at the meeting rather than just rubber-stamping a pre-created version.
Personalizing the meeting. Aside from the agenda, Bilal’s meeting included several other best practices for promoting parent-teacher collaboration. As suggested in the MADESE process guide, index cards and sharpies were provided so that each person could create a name sign (http://www.doe.mass.edu/sped/iep/proguide.pdf). This allowed meeting participants to address one another by name. As the agenda indicates, Bilal’s meeting began with introductions. Bilal’s meeting was also aligned with the MADESE process guide recommendations in this regard: participants were introduced by name rather than role (e.g., Amina was introduced by her first name rather than as “mom.”)

In addition, within the “introductions” section of the meeting, the director, Lisa (who served as the meeting facilitator) shared several personal and specific anecdotes about Bilal. The IEP document is chock-full of acronyms and jargon (e.g., PLEP-A, service-delivery grid) which can make a meeting feel dry or serious if there are not colorful descriptions of a student to counterbalance.

Dris’s meeting differed on several dimensions. Name signs were not used, and Saida was introduced as “mom” rather than by name. Several of the evaluators shared anecdotes of Dris’s behavior during the evaluations, but neither of the people who knew Dris best (his teacher John, or his mother, Saida) shared any stories during the meetings. IEP meetings are inherently formal. However, if schools are intentional about the structure of an IEP meeting (e.g., allowing times to share anecdotes, calling family members by name), it is possible to create a more intimate atmosphere, which can, in turn, affect the nature of the educational decision-making process.

Time allotted. The amount of time that a school sets aside for the meeting can have important implications for the tone of the meeting. Bilal’s meeting, according to the agenda,
Many voices at the table

was scheduled for two hours (i.e., 9-11 am). In fact, the meeting lasted more than three hours, ending a few minutes after noon. The amount of time assigned for a meeting may appear to be a mere detail. I contend, however, that scheduling a longer meeting can send the message that a school views the IEP meeting as a valuable structure with enough time to hash out important decisions. Furthermore, because there are numerous items that an IEP Team is required to cover: the personalization (sharing of anecdotes, etc.) is often lost in a shorter meeting.

Dris’s meeting, for example, was scheduled for one hour, in spite of the fact the decision to be made (i.e., residential placement) was quite weighty. The result was a quick-paced meeting with few opportunities for pleasantries or digressions. Decisions and negotiations were fast-paced, and Saida, who hardly participated at all, was essentially excluded from the jargon filled conversations. At several points during the meeting, school personnel turned to her (apparently responding to the fact that she looked confused) and explained, that these were just “business” discussions seemingly implying that her participation was neither required nor invited (field notes).

In my other meetings with Saida, I had consistently observed Saida to be outspoken and confident. In my first meeting, at the hospital where she worked, I saw her assertiveness as she interacted with her co-workers and defiantly snuck me into a hospital meeting room where only personnel were permitted. I argue, thus that Saida silence and exclusion from her son’s IEP meeting is particularly noteworthy.

At the IEP meeting, I argue that multiple facets of Saida’s identity intersected to truly disempower her (e.g., Crenshaw, 1991). First, she is visibly different than the other fifteen members of the IEP Team. All of the other members of the team are American-born,
and most are white (two of the BPS representatives are African American women and one administrator from Hope is Asian). And although Saida’s English is excellent, she has an accent and her receptive understanding is likely challenged by the fast pace of the conversation and by the use of technical jargon. In addition, everyone else in the room has professional training in some aspect of special education. The fact that Saida’s contributions to the meeting are neither expected nor welcome can be seen in team members asides that they’re just discussing “business” and in the fact that her concerns and visions for Dris are presented by professionals. The feeling is that Saida’s true participation would cost them valuable time and simply is not worth the investment.

A side by side comparison of the structural features of Bilal and Dris’s meetings observed in this study (see Table 5.2) reveals several important differences between the two (e.g., Bilal’s meeting was more than three times as long as Dris’s meeting, Bilal’s meeting included a written agenda and in-depth descriptions of special education terminology; Dris’s did not).

Table 5.2

*Side-by-Side Comparison of IEP Meeting Characteristics*

<table>
<thead>
<tr>
<th></th>
<th>Dris’s Meeting</th>
<th>Bilal’s Meeting</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Length</strong></td>
<td>1 hour</td>
<td>3 hours</td>
</tr>
<tr>
<td><strong>Use of Names</strong></td>
<td>Saida is referred to as “mom” throughout the meeting.</td>
<td>Everyone is addressed by first name. Name tents provided by school to facilitate this process. Each member of team is provided with individual copy of agenda.</td>
</tr>
<tr>
<td><strong>Agenda</strong></td>
<td>Agenda not provided.</td>
<td></td>
</tr>
</tbody>
</table>
Many voices at the table

<table>
<thead>
<tr>
<th>Physical space.</th>
<th>Number of participants</th>
<th>Explanations provided to parent.</th>
</tr>
</thead>
</table>
| Conference room with rectangular table. | 16 | Thorough Explanations are provided to Amina when technical terms (e.g., accommodation vs. modification; executive functioning are used).

Notably, both Amina and her special education advocate participated frequently during Bilal’s IEP meeting, while Saida and her advocate were virtually silent throughout Dris’s meetings. I suggest that the structural factors outlined in Table 5.2 contributed to this difference in family member communication. However, other factors related to the individual participants likely also contributed to this discrepancy. Those factors will be discussed later in this chapter.

*The Draft IEP*

The IEP meeting is a very document-driven event. Therefore, while each school has some discretion in terms of how an IEP meeting is structured, as discussed previously, IEP meetings across schools share many common features. To start, each meeting centers on a draft IEP. Returning to the agenda from Bilal’s meeting (Figure 5.1), all of the items under IEP development are components of the IEP document itself.

Theoretically, the meeting is envisioned as a place where educational decisions are actually hashed out. In practice, however, the meeting itself can feel very much like a formality, with the goal of approving a pre-written document. This is in part because a lot of the leg work in creating an IEP is done well before the meeting date. Creating an IEP
from scratch would be a far-too-time-consuming and messy process to happen in a
committee meeting. Drafting IEP goals is an involved process that entails soliciting input
from students’ families. And when teachers are stuck trying to determine appropriate goals,
they confer with other teachers and specialists: “I’ll often ask teachers who have had
similar students” [John] and review information that they have about that particular
student: “I’ll look back obviously in past IEPs and see what some of the goals they have
worked on before” [John].

*Parent Concerns.* One of the first sections of the IEP document (preceded only by
student and family demographic information) is “Parent and/or Student Concerns.” At
Bilal’s meeting, Lisa explained, “So the IEP has eight parts and the first part is parent
concerns.” As mentioned previously, parent concerns were formally solicited before the IEP
meeting. In Dris’s IEP, the statement begins “Ms. Yusuf has many concerns regarding Dris’s
well being.” However, the entire remainder of the concern statement focuses on the
difficulty of keeping Dris safe and engaged at home. For example, “His [Dris’s] access to the
community is limited as mom is fearful to take him out alone.” Note that this concern is
expressed in the third person even though it is theoretically Saida’s own statement. At the
meeting, likewise, Siada’s concerns were presented by other Team members. She did not
articulate them herself. Saida’s desire to enroll Dris in the Hope residential program is the
focal point of the meeting. In contrast, the safety concerns are not explicitly addressed in
the IEP goals.

At Bilal’s meeting, Lisa, the preschool director began “Talk to me about your
concerns, Amina.” At this point, Amina, takes out a piece of paper where she has written up
her concerns and she reads them directly. While she is speaking, Lisa types the concerns up
Many voices at the table on her computer, but she also asks, Amina to “send [her] a copy” so she “doesn’t miss anything” [fieldnotes]. This emphasizes the school’s desire to accurately represent parent concerns in the IEP. In describing her concerns about Bilal’s independence, Amina speaks very casually, “I want him to say can I have the car and 20 bucks? I’ve made plans with my friends.” In the draft IEP that was handed out at Bilal’s meeting, Amina’s previous (Fall 2012) concerns included and there is a blank section labeled “Spring 2013,” so that her new goals can be written in. The fact that she school does not have her current concerns in advance of the meeting contributes to the feeling that the IEP is actually being created during the meeting.

Draft Goals. At both of the IEP meetings observed for this study, the goals in the draft IEP were hardly changed over the course of the meeting. At the Hope meeting, the meeting was fairly brief and the goal of the meeting was really to discuss residential placement: Saida had partially rejected the previous IEP due to placement. Therefore, at the meeting, the goals were reviewed in only a cursory way. At Bilal’s IEP meeting, the draft IEP also remained essentially intact. This happened in spite of lively debate and discussion during the meeting, which I argue was established at the very outset of the meeting.

Open for debate. The IEP meeting is envisioned as a time for substantial educational decisions to be made with input from various team members. In spite of the fact that Bilal’s draft goals were essentially maintained in the final version of his IEP, the nature of the discussion at this meeting implied that changes to the goals could have and would have been made as the Team deemed appropriate.

When Lisa (the preschool director) introduced Bilal’s meeting, she stated that the team’s goal was to “develop” an IEP. This statement set the stage both for the active nature
of the meeting and for the participation from all parties. We can see how this goal unfolds in several ways throughout the meeting. For example, when one of the therapists presented a goal, the director asked why a particular skill was being targeted first, modeling the spirit of active inquiry. Because the preschool director was the meeting facilitator, this questioning early on in the meeting created an environment that promoted discussion and debate. Both Amina and the advocate asked follow-up questions about the plans for teaching Bilal (e.g., what particular social skills curriculum would be used, what instructional techniques would be employed to teach him to attend for longer periods of time).

The IEP document and a school’s own touches in terms of structuring the meeting provide a backdrop for the decision-making process that will take place. However, the individuals at the meeting (each with their own set of lived experiences and beliefs) constitute the most important influences in determining the nature of a particular meeting.

The Players: IEP-Meeting Participants

The institutional culture of a school and the structures in place at an IEP meeting are certainly important in establishing a tone for the ways in which educational decision-making occurs. However, the IEP team ultimately determines the course of the educational decision-making process. Each IEP team constitutes a slightly different set of players: from classroom teachers, to therapists, family members and sometimes the student him/herself. While parents may opt not to participate, they must always be invited to be members of the team, and a special educator and the child’s teachers are among those required to be on the team. At each of the IEP meetings in this study, the central players were: (a) family members, (b) educators, and (c) special educational advocates. Each of these broad
categories of players was represented at each of the three IEP meetings. In the following paragraphs, I will outline each of these categories of players with an examination of their similarities and differences across cases.

**Family Members**

Among the most notable and variable features across meetings in this study was the degree to which family members contributed to the meeting. Theoretically (and legally) parent participation is both invited and expected at IEP meetings. The reality of the matter is more nuanced. For example, although outside of the context of an IEP meeting, Saida is talkative and self-confident, within the IEP meeting she was essentially silent. In my field notes at the midway point of the meeting, for example, I memoed that Saida had not yet spoken. In a subsequent memo, I observed that many participants—including several Higashi staff, but also the BPS social worker and psychologist—were speaking as if on her behalf (e.g., “Mom is concerned about...”; “Mom reports that...”). This observation is important on a couple of levels.

“**Mom:** What’s in a Name. As mentioned earlier, one of the differences I observed across meetings was the use of the mother’s first name versus calling her generically “mom.” The use of the appellation “mom” is important, I argue, in the context of educational decision-making. My first instinct is that this word choice has a certain depersonalizing or distancing effect. Upon reflection, however I contend that several other facets warrant examination. For example, by labeling Saida as “mom” throughout the meeting, the IEP team is consistently reminded of her one-dimensional role at the meeting: she is Dris’s mother, period. This dynamic allows the educators at the meetings and the institutions they represent to maintain their power. During the meeting, Saida is not a professional. Her
Many voices at the table

researcher/physician identity is obscured. Furthermore, the facts that Saida wears a headscarf and speaks in accented English and is a woman are likely incongruent with educator’s notions of a medical research or a doctor.

Beyond this interpretation, I wonder if the traditional American culture IEP participants are less likely to call family members with “non-American” names by their given names. As Katherine articulated not knowing enough about Somali culture to challenge Amina’s ideas, I suspect that educators often feel discomfort about their own lack of knowledge in interacting with families from backgrounds that differ from their own.

Educators may shy away from pronouncing a parent’s name for fear of butchering it. Saida’s name, with a glottal stop between the two vowels might be difficult to pronounce for a monolingual English speaker. It is conceivable that the personnel at the meeting (district and school) had trouble either remembering and/or pronouncing Saida’s name and skirted the issue by referring to her as “mom.” Whatever the reason for referring to Saida as “mom” rather than by her given name, the effect is the same: it disempowers and excludes her from the conversation. How might the dynamic be different if she were called, for example, Dr. Mohammed?

_Parental Interjections._ Amina was a very active participant in Bilal’s meeting. She spoke frequently and at length—both when the school personnel solicited her opinion and by interjecting assertively when they did not. For example, when Bilal’s teacher was talking about his reading scores and the discrepancy between his decoding ability and comprehension, Amina chimed in without an invitation: “It’s fine and dandy that you can read, hon, but can you understand” (field notes)? At another point in the meeting when the
Many voices at the table

A preschool teacher brought up an area that she would like Bilal to work on, Amina concurred “That’s my first bullet, #1 concern.”

In addressing the “parent concerns” portion of the meeting, the Director, Lisa begins: “So the IEP has eight parts and the first part is parent concerns. Talk to me about your concerns, Amina” (field notes). Several things are visible in this short comment. First, Lisa addresses Amina by name (Lisa, the program director, is the member of the IEP team with whom Amina has the least rapport). Next, embedded in Lisa’s invitation is a clear explanation of the process (i.e., “The IEP has eight parts…”). Finally, Lisa’s invitation is casual. She captures the meaning of the IEP language while couching it in colloquial language (i.e., “Talk to me about...”), which I argue allows Amina to respond in her own voice instead of feeling like she has to choose her words carefully and to be sufficiently formal. The degree to which parents participate verbally in an IEP meeting varies considerably and may depend on both institutional factors and the personalities of family members and educators involved.

*The Educator and the IEP Meeting*

The teachers in this study took the IEP meetings very seriously, conceiving of them as among the most fulfilling and important functions in their job description (e.g., “I love the IEP process and I love the meetings. I just really take a lot of pride cause I feel like that’s where I get to document what I do with a child” [Katherine, emphasis hers]). The draft IEP represents the important contributions of a student’s teacher to the IEP meeting. Even if the teacher is not facilitating the meeting (an administrator often takes that role) it is the teacher’s work, in the form of the draft IEP that is showcased.
Katherine articulated well the range of reasons why an IEP meeting is a crucial moment for her as a teacher. For one thing, the meeting is often the most concentrated amount of time that teachers and parents have together over the course of the year. Parent-teacher rapport at an IEP meeting can be envisioned as an outcome of the relationship that the two parties have established over the course of the school year. On the other hand, the meeting can be seen as an opportunity for developing and/or deepening that relationship. Katherine sees her performance at the meeting as an opportunity to win (or maintain) family members’ trust by demonstrating her deep and precise knowledge of the child.

This is how I wanna support you child and the goal for me of every IEP meeting is to make sure that I can communicate that I know the as much as, not as much as the parent, but that I know the child as best as I can. And I know the strategies that are going to work, like I feel so horrible if I go into a meeting and I’m like “I don’t know...I don’t know how I’m going to get them to that point, but I will get them there... I always want to say this is how we’re going to do it. I always want to talk about the child and have the parent say: “yes!” Like she gets my child so that’s how I always want parents to leave.

Along the same lines, Amina expressed the deep frustration that parents feel when a teacher’s goals bespeak his/her lack of knowledge about the student:

When we were doing the preschool IEP just this past year in September, they were like:
“We’re gonna make sure by the end of the year that he can count from 1-10.”
He already counts from 1 – 100.
“We’re gonna make sure that he knows the alphabet, like the small letters”
And I was like “He already reads. That’s not a goal!”

We might wonder what types of assessments they had done to arrive at a goal already mastered by the student. The experiences that family and teachers have at one IEP meeting can determine, to a large extent the mindset with which they enter subsequent IEP meetings. Amina’s frustration at Bilal’s pre-K IEP meeting (recounted previously) likely established within her a certain critical lens as she entered his kindergarten transition
meeting. Among the steps that she took to set herself up for this meeting was to hire a special education advocate to accompany her.

*Special Education Advocates and Other Stakeholders*

At the outset of this study I envisioned parents and educators as the primary players in the educational decision-making process. And certainly they are instrumental in making educational decisions. However, all three cases in this study highlighted the importance of other stakeholders in the educational decision-making process. Educational advocates played a very important role in each of the three cases (though in a different way in each case), and because Dris was enrolled in an out-of-district placement, representatives from the sending school district also played an important role in the decisions that were made at his meeting.

Both Amina and Saida hired special education advocates for their IEP meetings included in this study (interestingly, this was the first time either had hired an advocate). In the third case, Kristin the EI developmental specialist, served as an informal (i.e., self-appointed) advocate. The universal presence of advocates in this study may reflect the fact that each of the three cases represents a pivotal educational transition involving a change in educational placement creating a higher stakes environment than non-transitional IEP meetings.

*Alleviating stress and other reasons to enlist an advocate.* Teachers and parents across all three cases described the benefits of having a special education advocate. A recurring theme was the role of the advocate in allaying parental stress. Amina described her initial impetus for hiring an advocate: at Bilal’s previous (advocate-free) meeting, she had spent the pre-meeting-night sick with worry—she actually vomited several times (field
Many voices at the table

notes). Shortly after I arrived at Bilal’s school on the morning of the IEP meeting, I saw Amina and her advocate, Barbara, walking in together chatting comfortably. There was a certain implied solidarity. As I greeted Amina, she introduced me to her advocate, and explained, laughing, that she had brought Barbara (“she speaks IEP”) to decipher the “legalese.” Without a pause, Barbara completed Amina’s thought “it’s alphabet soup.” At the time of the meeting Amina herself was preparing to take the LSAT and was becoming well-versed in legal terminology. The need for someone who “speaks legalese” is presumably even greater for most family members. In these cases, the decision to hire an advocate was clearly intended to allay the stress associated with attending the IEP meetings.

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 assessment, employing an advocate to play the role of “bad cop” would free her up to be sweeter and more likeable and would allow her to let her guard down knowing that someone was scrutinizing what the school was doing in terms of 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 perceived of as being out of place by school personnel. By hiring a lawyer, the parent is potentially able to protect his or her relationship with the school. Having a lawyer serve as the executor of power is more palatable.

Saida articulated an additional reason behind her decision to hire an advocate. She had never hired an advocate for any of Bilal’s previous twelve IEP meetings. For her, it was
the magnitude of the decision being made that she felt warranted formal representation. In fact, she was offered a free lawyer from Advocates for Children to represent her at the meeting. 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.

*The self-appointed advocate.* In Aadan’s case, there was not a parent-appointed advocate. However, Kim, the EI provider attended his IEP meeting. In this role, 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.” For these reasons, Kim tries to attend meetings even if students are no longer on her caseload (i.e., they have already turned three), in spite of the fact that she is an hourly employee not paid to attend meetings. She begins by preparing the parents before the meeting. She starts by asking a few guiding questions: “What exactly are you looking for your child? What would be the best case scenario for them?” From this sort of informal assessment, Kim helps the parents to develop a plan for the meeting: “so this is the ultimate goal and then what of that goal can we get?”

Kim maintains the practice of accompanying parents to IEP meetings, in part, because she feels that she has effected change for previous students. Kim recounted
Many voices at the table

proudly the example of one meeting at which a student’s family was offered a “half day
program.” But, “by the end of the meeting, they...had a full day, where if it was just the
family, I really doubt that would have happened.” Her sense that Aadan’s family might need
help in making sense of the IEP meeting coupled with her experience with previous
families, Kim volunteered to attend Aadan’s IEP meeting. A self-appointed advocate (e.g.,
the EI therapist) can influence the nature of educational decision-making at an IEP meeting
and her role resembles, in some ways, that of a formal advocate.

The advocate during the meeting. Advocates played different, but uniformly
important roles at the IEP meetings. John perceived that Saida’s advocate gave her “a little
more confidence going in.” In my own observations, I noted the subtle ways in which both
official 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).

In Aadan’s case, Kim was not happy with the proposed placement:
“they’re putting him in an integrated class. And I think that he’d do way better in a [self-
contained] ABA classroom.” Kim’s concern about this placement was based largely on her
perception of his ability to function in a structured group setting such as the toddler group
he had attended at the EI agency. In that setting, even with the high staff to student ratio
and thoughtful accommodations, Aadan struggled to participate. Some weeks the teachers
resorted to “swaddling him in a blanket” to calm him. In contrast to the case of a formal
advocate, Kim saw it as her responsibility to advocate on behalf of Aadan himself, and so
Many voices at the table

she pushed for the self-contained classroom even though Aadan’s parents were compelled by the district’s pitch that an integrated environment would be the best fit for him.

Kim did not succeed in opposing the district’s recommendation. Unlike most paid educational advocates (many of whom are trained lawyers), Kim was not familiar with the intricacies of special education law. Her understanding of Aadan’s preschool placement was that “they always have to put children in the least restrictive environment (LRE) and work from there.” She did not understand, it seemed, the nuance of a placement as being the least restrictive, but still effective environment and was thus ill-equipped to argue against the district’s proposal.

The two formal advocates played very different roles in the actual during-meeting discussions. At one extreme, Saida’s advocate was virtually silent the entire meeting. Saida, who expected her advocate to “talk” and “knock the table,” wondered what her “role” was. And when the Higashi staff assured her that the mere “presence” of an advocate can make a big difference in terms of the outcome of an IEP meeting, Saida chuckled “the United States is another world.” In contradiction to this perception, Saida reported a conversation in which the evaluation team facilitator (ETF) from BPS contended that the advocate’s presence had not made any difference. “A lawyer didn’t change me. I decided,” she reportedly insisted to Saida.

At the other end of the spectrum, Amina’s advocate interjected throughout Bilal’s meeting. She asked questions about which social skills curricula would be used in the coming year, how particular skills would be taught, and for details about the extended school year program.
Advocates and the tone of the meeting. Katherine commented about the ways in which having an advocate can change the “tone” of a meeting. “Sometimes,” she explained, the advocate “speaks on behalf of the parents, rather than the parents getting to share concerns.” Notably, in the case of Bilal’s meeting, Amina spoke significantly—asking questions and sharing anecdotes—in spite of the fact that her advocate was talkative. Katherine also reflected that when an advocate is at an IEP meeting, it can be unclear whether teachers should direct comments and responses to questions “towards the advocate or towards the parent.”

Another way in which the presence of an advocate seemed to create a bit of confusion around role was related to who should be clarifying or explaining concepts to the parent. In Bilal’s meeting, the school staff consistently provided clear explanations about special education terminology (e.g., articulating the difference between accommodations and modifications). Working in an early childhood setting, it was obvious that they conceived of parent education as one of the essential goals of an IEP meeting and they were accustomed to providing it. At one point in the meeting, “executive functioning” was raised as an area that is challenging for Bilal and the advocate jumped in to translate “his internal secretary has gone to lunch and she’s not coming back” (field notes). Amina refers to this phraseology in a later interview—clearly it had stuck with her. In this case, the blurring of roles between the advocate and school administrator hardly represents a problem. The outcome is quite simply that Amina receives very thorough explanations about the special education process. (The one potentially negative outcome of this fact is the meetings extended duration: more than three hours).
Many voices at the table

Barbara’s register shifted during the meeting. Early on, she took a collaborative tone. Some of her comments, it appears, are intended to reassure the school staff (e.g., “I promise not to recommend any rejections, just modifications,” “I don’t think that they missed anything. And you know—they know—that I would say something if I thought that they had” [field notes])

Later in the meeting when the discussion turns to services—as opposed to goals and accommodations—the tone became more contentious. Barbara’s comments shifted from reassuring to approaching a confrontational quality. In the discussion of hours of the summer program, the director of the school said, “maybe we’ll just have to agree to disagree” and Barbara responded “and I’ll bet you dollars to donuts what our answer will be when we respond.” This change in register coincides with the shift from discussion of pedagogy to discussion of services that would cost the district money or resources.

*Two Sides? Understanding Alliances Among Participants.*

The richness of the educational decision-making-process at IEP meetings is greater than the sum of the individuals present at the meetings and the ideas, beliefs, and experiences they bring with them. The group of people who attend an IEP meeting is referred to as the “Team” in special education parlance. In many ways the group is a team. But the reality is also more complicated.

The IEP meetings in this study—as most IEP meetings—were held around conference room tables. This physical layout, a group of people sitting around a table gives an impression of collectivity, a group of people united by the task of making decisions on behalf of a child.
Many voices at the table

At IEP meetings, however, a perception can exist that there are “two sides.” This is particularly the case, in my experience, when a weighty decision (e.g., placement) is being made and/or when an educational advocate is present. Both of these conditions existed across all three cases in this study. When there is a sense of having “sides” at an IEP meeting, it is, generally speaking, the case that the parents and their advocate constitute one side and the school personnel represent the other side. There is of course, not always (nor should there be) such a neat division. Several examples from these cases demonstrate that blur of the binary.

Dris’s placement at the Hope School (unlike Bilal and Aadan’s placements) was out of his home district (the Boston Public Schools) and so his IEP meeting was attended by three distinct groups: (a) the family (i.e., mother and advocate), (b) the Hope School (e.g., administrators, teachers, therapists), (c) the Boston Public Schools (e.g., administrators, social worker, psychologist). Generally speaking, meeting participants sat in groups based on these affiliations. There were a couple of exceptions, based, apparently, on the availability of seating (field notes).

In this case, where the child’s school and sending district are represented, thinking about the meeting in dichotomous terms is not helpful: it would be inaccurate to conceive of the meeting as being organized into two sides of family and school. These cases are defined by a complex three-way dynamic. In my experience teaching in out-of-district schools much like the Higashi, the IEP meetings were almost always attended by family members as well as school and district personnel. I found that families generally had a closer relationship with one party than the other.
In some cases, a family had been working with the same out-of-district liaison for many years (and sometimes through several school placements) and had developed a close and trusting relationship with that person. If the family also had complaints or concerns about the current school placement, the district representative served almost as an educational advocate championing the interests of the family. On the flipside (and I found this to be the case more often) a family had a close working relationship with their child’s school, particularly the classroom teacher with whom they might have daily contact. In these cases, the school and family often held a shared vision of the child’s educational goals and functioned as a unit.

This scenario was very much the case with respect to Dris’ IEP meeting. It was quite obvious to me, as an observer, that the Hope personnel supported Saida’s bid for residential placement. In fact, one of the Hope administrators at the meeting was admonished by the Boston Public Schools representative who was facilitating the meeting for speaking out of turn and for stating his support for the residential placement too strongly. “I really wish you hadn’t said that,” she reprimanded, explaining that the decision should be made by the team and that it was out of order for an individual to state his opinion. This administrator and the others at the table were clearly taken aback by this brusque comment. The original opinion-stater countered tentatively “It’s true.” Saida, however, appeared to be the most shaken by the interaction. She explained to me later that the meeting was already very stressful for her and this tension-inducing comment had made her feel even less at ease.

At moments, it appeared that the adversarial relationship between the school and the district existed outside of this particular student or family. Toward the end of Dris’
meeting, after the residential placement had been agreed upon by all parties, the BPS administrator who had been facilitating the meeting said “I've been upset with Higashi in the past throwing things at us that we aren’t expecting.” And when, as a follow-up question, she asked: “Is there anything that isn’t included in the bill?” One of the Hope administrators replied evenly “it's all push-in.”

This example illustrates well the complex nature of IEP meeting dynamics. Intuitively, we know that every player at the table is motivated by his or her own lived experiences. None of the negotiations that happen are pure in the sense of being related only to what is happening at a given moment. This exchange is important in that it lays bare the degree to which each IEP meeting participants attend is colored at least to an extent by the IEP meetings they have attended previously.

*Blurring boundaries.* Apart from this example of the three-sidedness of a case involving both a school and an unaffiliated district, observations of IEP meetings revealed that there are certain factors that can dampen the sense of there being “sides” altogether. One player who often blurs this line is the student’s primary teacher. As mentioned previously, for example, Saida and John and Amina and Katherine both had appreciably close relationships. In her reflection on Bilal’s IEP meeting, Amina commented that she felt that Katherine understood her concerns and goals for Bilal much better than the preschool director, Lisa, who was officiating the IEP meeting:

> Katherine, I mean, Katherine and I talk every month. Multiple times a month, a lot of times a month, so where Lisa and I rarely talk... (Amina).

In the case of Bilal’s IEP meeting, Katherine, therefore, functioned as a sort of intermediary between the other school personnel and the family. In this IEP meeting, the most contentious aspect was whether Bilal would qualify for a full-day or half-day summer
Many voices at the table

program. In the end, Katherine supported the director’s assertion that a half day program would be sufficient in terms of meeting Bilal’s needs. Her explanation, however, included specific anecdotes about Bilal’s ability to return to school after breaks without having regressed in terms of academics and social skills. Amina was more receptive to Katherine’s personal explanation than she was to Lisa’s more generic assertions. But even so, the meeting ended without agreement on this issue. In this case, part of the reason that the meeting ended without consensus was that it had already lasted over three hours. It is not uncommon for the discussion of educational decisions to continue after the meeting.

Money and Other Resources

Of course the interactions between family members and educators in making educational decisions for children on the autism spectrum are mediated by myriad factors. One of the recurrent themes, both in my observations and as reported by family members and teachers in the interviews, was money. In terms of time, the IEP meetings focused disproportionately on decisions related to the provision of services that would require schools or districts to pay extra money (e.g., special education transportation v. regular school bus [Bilal], school vacation programming [Dris], placement in inclusion v. substantially separate classroom [Aadan]) as opposed to true curriculum and instruction decisions (e.g., what types of prompts should be used when teaching a child to attend for longer periods of time). In the context of finite resources, individual parents and school personnel are driven by different priorities and meetings can become “contentious” [John].

A parent is first and foremost an advocate for her own child. At a very baseline level, it her job to ensure that the school district will “do no harm” when it comes to her own child. In contrast, the school district—and by extension the school personnel—are charged
Many voices at the table

with serving all of the students within a given district. They are thus operating based on the principal of *the greatest good for the greatest number*.

When I asked Saida why the discussion of Dris’s vacation programming had been central to the IEP-meeting discussion, she replied succinctly “it’s money.” John’s perception of the discussion at Dris’s meeting was similar: “with money issues being so tight these days” districts are more likely to push back against costly decisions.

The conversations about Bilal’s extended school programming had a similar tenor, and Amina’s assessment of the disagreement was simply put: “I think they don’t have the money.” In this case, though, Katherine’s explanation of why she supported the more limited summer programming had to do with her perceptions of Bilal’s educational needs—not money. The reality is not black and white. There is probably truth in both Amina and Katherine’s interpretations. Parents of children with disabilities are often in the position of advocating for resources and services for their children. Savvy parents like Amina learn quickly to consider the scarcity of resources and are often reinforced by systems that intentionally or not respond to the requests of assertive parents, the “squeaky wheels.” In this particular case, though, it is possible that Amina’s assumption that the school district did not want to pay for a full day summer program caused her (and her advocate) to advocate for something that was not actually in Bilal’s best interest. If she had not been primed to think that she needed to champion her son’s needs at every turn (Amina described having fought for Bilal’s educational rights since he began school), she might have been able to listen more openly at the IEP meeting to Katherine’s description of what type of summer program would benefit Bilal most.
Many voices at the table

Amina, in spite of her very personal investment in Bilal’s educational planning, was able to see the negotiations at her own son’s IEP meeting in light of these complicated, almost political dynamics.

You want *everything* for your child...[and the district has] a dueling interest. They wanna do what’s right for the child, but they’re also limited by their funds...and there’s a lot of kids and he’s not the only one.

Acutely aware of this inherent tension, Amina explained that, as a single mother, she has fewer options for engaging strategically in this dynamic. She cannot play “good cop, bad cop,” as she might if she had a partner. But rather she has to deal with them all the time:

And you don’t want them to be like ‘oh my god, here comes the bitch on heels’ kind of thing. So you hire advocates who can be the dog and be like all aggressive.

*Resources in the out-of-district context*

The distribution of resources was clearly an underlying theme in all three cases. But whereas financial discussions are often implicit in the context of an in-district IEP meeting, the conversation can be more explicit in the context of an out-of-district placement, where the entity paying for the services (i.e., the school district) is not providing the services. Just before the end of Dris’s meeting, the out-of-district liaison from Boston said that she has been “upset” in the past when the school has unexpectedly “thrown things at them” and she asks the financial representative from the Hope School point blank, “Is there anything that isn't included in the bill?”

Phase III: Post-Meeting Decisions and the Outcome of the IEP

Once an IEP meeting ends, the next step in the process is for the school to compile a complete version of the IEP to send to the parents for approval. This version of the IEP is based on the draft that was brought to the meeting and includes any changes raised during the meeting. Some of these changes are quite minor (e.g., correction of a typo). But other
times there are substantive changes as well (e.g., changing the delivery of speech therapy from two half hour sessions per week to two forty-five minute sessions per week.) The new version of the IEP is then sent to a student’s family to sign off on, or not.

_On Signing the IEP_

In some ways, the signing of the IEP—by both parents and educators is the culmination of the IEP process. And like all aspects of the IEP process, IDEA has set out guidelines for how the signature process should take place. At the same time, there is leeway for schools to develop a unique set of norms. Although the document brought to an IEP meeting is technically a “draft,” it is common, at many schools for parents to sign the document on the spot. This is explained by school personnel as a logistical move; it expedites the process allowing service delivery to begin without delay. At Leapfrog Preschool, families are strongly discouraged (almost prohibited from) signing in the moment. Katherine explained:

I don’t want to ever sign off on a plan right then. I want them to go home, look at it, check out my typos, like check out, I mean, not just mine, I know the whole team works on it, but when they’re my students, I definitely take more ownership over the document, um, and I want them to ask questions to say like, well, how are you going to get them to do this and I want them to come back with questions before they sign it.

By requiring time to elapse before signing, Leapfrog Preschool is institutionalizing another layer of parent participation. It sets the expectation that family members will review the document and contribute to it. And the school has implemented a step in the process, to allow services to begin immediately without having parents officially sign off. Katherine explains:

We have something called ‘summary notes’...it’s just a documentation of what has been talked about at the meeting, and what’s happened and it does allow services to get started without signing the IEP. So you’re not agreeing to the IEP, but you’re
Many voices at the table

saying ‘these are the services that we’ve agreed upon today. Please get started on them.’”

In the case of Bilal’s IEP, the decision not to sign on the spot was more than just the school’s standard practice. As mentioned in the previous section, the IEP meeting ended with the school and family “agreeing to disagree” on two aspects: (a) the length of the extended school year program, and (b) transportation to Bilal’s kindergarten placement (at the end of the meeting Amina had requested “door-to-door transportation;” the school had not yet agreed that this service was needed).

After the IEP meeting and once she had received the “official” draft IEP sent by the school (this took longer than the legally sanctioned ten business days), Amina’s immediate response was that she would file a partial rejection: “Definitely we’re going to reject the half day summer school thing.” Amina planned to meet with her advocate, though to prepare her official response to the school: “And my advocate is out of the country. She’ll be back on the 15th so we’ll put together a response then.” The degree to which the advocate is involved after the IEP meeting depends in large part on how the meeting itself ends. Because Amina was not fully satisfied at the end of Bilal’s meeting, her advocate becomes instrumental in navigating the written exchanges of the post-IEP-meeting process. Because the communication during this phase is almost exclusively written, it can be even more daunting for a non-native-English speaking parent to tackle alone. In contrast to Bilal’s meeting at which many decisions were made/addressed, Dris’s meeting focused almost exclusively on the residential placement decision. At the conclusion of the meeting all parties were in agreement on this topic. Therefore, Saida’s advocate had essentially no role in the post-IEP-meeting process.
The school’s response to Amina’s partial rejection was to send a “stay put” letter meaning that Bilal would be entitled to the same level of ESY programming that he had been the previous year (i.e., full day program). On the surface, this decision was a victory for Amina and for Bilal. In talking to Katherine, though, I realized that the situation was a bit more nuanced.

During the school year, Bilal had been included in a general education preschool program for the majority of his day. During the summer, however, public preschool classrooms were available only to students with disabilities. Therefore, the only summer option for Bilal was in a self-contained special education class. This would represent a significant departure from his school year environment. Katherine worried that Bilal would be “bored” in this type of environment, that he would “really miss his friends.” Katherine believed that Bilal would fare better in a summer program – outside of the public schools—where he had the opportunity to interact with peers without disabilities. In thinking about his summer programming and curriculum, which Katherine was responsible for designing, she explained, with resignation: “we’ll definitely be as creative as possible with the students we have.” This perspective serves as a reminder of the importance of an IEP in terms of establishing both certain foundational goals and services for a given student. Once the IEP is signed it functions as a contract between the family and the school, and although most of the important decisions related to an IEP meeting are agreed upon by the end of the actual meeting certain decisions are made in the process of ratifying the document after the meeting has ended. For that reason, policies that prevent parents from signing an IEP on the spot have important implications in terms of this final phase of educational decision-making.
Many voices at the table

Summary

Taken together, the findings from these three cases indicate that the educational decision-making process in the context of Somali-American students with autism is complex with many variables affecting its trajectory. Although I anticipated that the dynamics between each educator/family pair would be idiosyncratic, I was struck by the scale of the differences. To begin, I expected to find more similarities among the three Somali-American families and was consistently reminded of how very different they were from one another. This, I believe has important practical implications for educators and their ability to assess the needs of individual families (just as special educators are trained to do for individual students with disabilities) rather than learning techniques for working with "culturally and linguistically diverse" or even Somali-American families as a monolithic group.

The findings from this study emphasize also the importance of both institutional factors (e.g., school culture, policies guiding parent-educator communication) and individual attributes of family members and educators (e.g., language, beliefs about autism, class and education) in determining the how educational decision-making occurs across all three phases of the educational decision-making process (i.e., from on-going interactions to the IEP meeting and post-IEP meeting negotiations). The following paragraphs highlight some of the most salient findings from this study organized into institutional factors and attributes of individual team members.

Institutional Factors

In the context of on-going family member-educator communication, for example, school policies requiring a minimum frequency and nature (e.g., written, oral, face-to-face)
Many voices at the table

of communication had important implications in terms of how parent/educator communication happened (or did not happen). While the culture of school, less concrete than explicit policies, was also profoundly important in establishing how frequently and under what circumstances family members and educators came into contact with one another (e.g., at pick-up and drop-off, school events or while volunteering).

In the context of educational decision-making at the IEP meeting and that the negotiations that happen in the wake of a meeting institutional factors (e.g., time allotted for a meeting, presence an composition of a meeting agenda, rules about when and how IEPs are to be signed) are similarly important in inviting or discouraging family members into the IEP process. These institutional factors interact in important and complicated ways with the attributes of individual members of the IEP team.

Attributes of Various IEP Team Members

In designing this study, I selected Somali-American families of boys with autism for two reasons. First, research indicates that autism affects that population disproportionately. However, I also anticipated that Somali families and American-born educators, having had very different lived experiences, would hold decidedly different beliefs about educational collaboration and educational goals for students with autism. I expected that these stark differences would translate to important implications that would be applicable to a range of populations.

In two of the three cases in this study, however, the differences between the beliefs of family members and educators were more minimal than I was prepared for. These cases, however, highlighted the importance of teachers’ perceptions of cultural differences and their uncertainty in terms of how to negotiate the educational decision-making process
when they are unsure about how (or if) family’s cultural beliefs are at play (e.g., Katherine’s reluctance to challenge Amina’s belief about practicing skills with Dris as opposed to giving him free time.) Importantly, this suggests that even perceived cultural differences can influence the trajectory of educational decision-making.

A substantial body of literature addresses the challenges of establishing family educator collaboration in the context of special education services for students with disabilities from culturally and linguistically diverse families. This literature emphasizes language and other logistical factors (e.g., transportation, scheduling). Because these factors are well-covered in the literature and only relevant in one of the three cases in the present study, I devote less time to discussing the implications for practice.

One phenomenon that was surprisingly prominent in this study was the role of the special education advocate (both family-hired and self-appointed), which was relevant across all three cases. Like family members and educators the three advocates engaged in the educational decision-making process to different extents and in different ways. However, the consensus of teachers and family members across cases was that the mere presence of an advocate changed the nature of the educational decision-making process. Effects included: allaying parental stress, changing the services written into an IEP, and creating confusion about who educators should address during the meeting.

These findings, and others, are important in understanding not only how educational decision-making occurred in these three specific cases but also in thinking about practical implications more broadly. Observations of both institution- and individual-level factors guide recommendations for practice, which will be discussed in the next chapter.
CHAPTER VI: DISCUSSION, IMPLICATIONS, AND LIMITATIONS

We have never seen snow, I mean coming from the sky. And we never had kids with autism. They said she has autism and I said “What is that?” and they explained to me and it was so hard for me to take it. I didn’t tell anyone. I didn’t tell my parents, my siblings, his father—no one. I didn’t tell anyone for a good six months.

In our community and our culture, there is a huge stigma with the unknown. And autism is the unknown. So I didn’t want my son to be labeled that.

Not Americans, but within our community, people judge each other. You must have done something wrong for your kid to be autistic. It’s hard to explain. So we hide instead of explaining.

(Autism—A Somali-American Story)

Family member-educator collaboration is envisioned as an important component of the educational decision-making process for students with disabilities (e.g., Lo, 2012). Friend and Cook (2007), define such collaboration as “a direct interaction between at least two coequal parties [educators on the one hand and parents/guardians on the other] voluntarily engaged in shared decision-making as they work toward a common goal” (p. 5). In the case of immigrant families, this ideal of coequal collaboration is often elusive for a variety of reasons (e.g., language barrier, disparate ideas about what familial involvement should be in educational decisions) (e.g., Lo, 2012).

This qualitative multiple case study into family-educator collaboration, seen through the theoretical lenses of (a) intersectionality, (b) phenomenology, (c) explanatory models, and (d) institutional ethnography, examined the educational decision-making process in the context of Somali-American families of boys with autism. The study examined the following research questions:
1. What is the nature of the collaboration between Somali-American parents and educators in devising educational and treatment goals for children on the autism spectrum?

2. In what ways do Somali-American parents’ explanatory models about autism resemble or differ from those of educators?
   
   - To what extent do parents’ and educators’ explanatory models influence their own notions of appropriate education for students on the autism spectrum?
   - How do families’ and educators’ multiple identities and lived experiences interact and influence ideas about educational goals for students with ASDs?

3. How are parents’ and educators’ notions about what constitutes appropriate education for students on the autism spectrum reflected in the outcome of the IEP process (e.g., signed IEP, refusal of special education services, mediation)?

In examining the educational decision-making process in the context of Somali-American families and American-born educators, I anticipated that the two groups (i.e., educators and family members) would hold divergent explanatory models regarding autism and educational collaboration and that those divergences would influence the decision-making process. In fact, as was discussed in greater depth in Chapter 4, my cases were defined by significant intra-group variability. Specifically, two of the mothers in this study were highly educated and influenced by ongoing interactions with Western notions of autism and disabilities. These two mothers were perceived as “other” by many American-born individuals even as they understood the essence of American norms with regard to special education and disability. Their beliefs regarding autism, autism education, and collaboration resembled the educators’ beliefs in many regards. In contrast, the third
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case in the study revealed many of the expected communication barriers that arise when parents and educators bring very different lived experiences and expectations to the special education process. That Somali-American mother, for example, had distinct but unvoiced opinions about her son’s education. Her son’s educator did not solicit her opinions and the result was diminished communication between the pair. The diversity among families and educators resulted in very different decision-making processes and led to a set of richly nuanced results. In particular, the intersection between (Somali) ethnicity and class became much more salient in my analyses than ethnicity alone.

Findings from the present study echo many conclusions of previous research in the realm of family-educator collaboration in special education decision-making, while also challenging other aspects of existing literature. First, much has been written in regard to best practices for structuring IEP meetings to elicit parent participation—from well-structured agendas to name tags and clear, jargon-free explanations of special education concepts (e.g., Lo, 2012; Mueller, 2009). The present study, likewise, highlighted the importance of practices such as these. Many studies have also identified divergent beliefs (e.g., Lui, 2005; Ryan & Smith, 1989) and language and logistical barriers (e.g., Jung, 2011; Lo, 2012) as important impediments to truly collaborative educational planning. These phenomena were also observed in the present study, but were differentially important across cases.

This study, meanwhile, revealed the importance of certain factors that have been discussed little, if at all, in existing educational literature. For example, institutional ethnography (IE) (e.g., Smith, 2006; Tummons, 2010), one of the conceptual frameworks
Many voices at the table

guiding this research, allowed me to analyze findings related to the cultures of different schools.

Analysis revealed that influences on the trajectory of collaboration include not only by official school policies (e.g., requirement of minimum type and frequency of educator–family member communication)—which have been analyzed considerably—but also by less concrete phenomena (e.g., norms of parent participation in school activities, from dances and races to PTA meetings and in-class volunteering)—which have been examined very rarely in special education research. My observations indicated that school/institutional culture was highly variable and had important implications in terms of how educators and family members entered relationships with one another and engaged in educational collaboration. Specifically, observations and interviews suggested that increased incidental interaction between educators and family members engendered an intimacy that carried over to the IEP meeting and other formal settings.

According to much special education research, cultural sensitivity is an important factor in promoting educational collaboration (e.g., Harry, 1992). By examining the educational decision-making process in the context of a newer (the vast majority of Somali immigration began in the 1990s after the outbreak of civil war) and less familiar (to American educators) immigrant/refugee group, I was able to reveal a twist on the preeminence of cultural sensitivity. Specifically, I found that oversensitivity to a family’s culture can impede educational collaboration. In several instances, the educators in this study were either deferential to or reluctant to challenge the viewpoint of a family member. This deference, or reluctance, was based on little knowledge of Somali culture coupled with an abiding desire to be culturally sensitive (e.g., Kim not wanting to “step on” Nadifa’s
“toes”). As depicted in Chapter 5, I argue that in these cases, heightened cultural sensitivity coupled with “colorblindness” and/or white hesitation (e.g., Crenshaw, 1991) led to diminished communication between educators and families.

The findings from this study—both those that echo and those that challenge previous research—suggest important implications for practice (see Table 6.1), which extend beyond the population included in this study (Somali-American families; students with autism). And yet, because of the nature of the present study, limitations exist in terms of how broadly relevant the findings might be. In the following sections I discuss practical implications followed by limitations of this research.

Implications for Practice

Table 6.1
*Translating Results of This Study into Broader Implications for Practice*

<table>
<thead>
<tr>
<th>Implications for practice</th>
<th>Support from the present study</th>
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<tr>
<td>1. Flexible guidelines for family-educator communication</td>
<td>• Teachers reported that certain forms of communication (e.g., home logs, clinic meetings) were differentially useful to individual families.</td>
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<tr>
<td></td>
<td>• Written forms of communication (e.g., session notes, home logs) were not accessible to family members who are not literate.</td>
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<tr>
<td>2. IEP meetings structured to promote collaborative decision making</td>
<td>• Certain features (e.g., agenda, information and definitions presented in multiple modalities) were observed to be positively correlated with family participation.</td>
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<th>3. Nuanced understanding of culturally responsive decision making</th>
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<tr>
<td>• Longer IEP meetings were associated with less jargon, more detailed and personalized discussions.</td>
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<tr>
<td>• Educators’ stated assumptions about families’ cultural backgrounds appeared to influence educational decision making.</td>
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<tr>
<td>• Educators reported (sometimes inaccurate) beliefs about the influence of culture on family members’ roles in children’s education.</td>
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<tr>
<td>• In one case, family members did not volunteer opinions regarding educational decisions and educators did not solicit opinions. The result: incomplete communication hindered service delivery.</td>
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<th>4. School cultures that foster family-educator collaboration</th>
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<td>• Certain practices (e.g., pickup and drop-off at classroom, parent participation at school performances and events) were observed to be associated with increased parent-educator intimacy at formal meetings.</td>
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<td>• Mothers and educators expressed appreciation for opportunities to interact.</td>
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<th>5. Educators’ understanding of the American middle/upper-class orientation of the special education system</th>
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<tr>
<td>• Educators discussed educational goals (e.g., independent feeding) that are influenced by American values (e.g., independence) and</td>
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<th>not always shared with families.</th>
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<tr>
<td>• Parents discussed shifts in thinking resulting from the American system (e.g., benefits of residential placement for an adolescent)</td>
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Five specific implications for practice derived from this research:

1. **Flexible Guidelines for Family-Educator Communication**

   Frequent contact—both formal and informal—is instrumental in developing family member-educator relationships (e.g., Conroy, 2012). The most effective type of contact, however, is context specific. For example, Grassi and Barker (2010) found that in the case of immigrant families, home visits can be a particularly effective way for educators to get to know families. Home visits allow educators to understand family dynamics and home life in much richer ways than school-based contact alone. However, the guidelines at many schools encourage a one-size-fits-all communication policy regardless of family or educator preferences and circumstances.

   In each of the three institutions in this study, standardized expectations for minimum type and frequency of communication established regular communication between family members and educators. Analyzed more closely, however, results indicate that rigid adherence to school/institutional policies resulted in rote and inauthentic communication in certain cases. Across all three cases, educators mentioned that the particular mode of communication they used worked with differential success across families.
Many voices at the table

The clearest illustration of this is the example of the early intervention (EI) session notes that Kim gave to Nadifa each week. As described in Chapter 5, Kim used a template to write a note each week with a summary of the EI session, suggestions for carrying over the work, and so on. Nadifa, however, could not read the notes and did not feel that going over her son’s sessions “step by step” was a good use of her time-limited access to a Somali-English interpreter. During the course of this study, she did not request to have a single session note translated.

A more useful tactic, perhaps, would be for schools and agencies to provide educators with a range of options for communicating with families (e.g., weekly or daily written notes, translated phone calls, in-person meetings). In addition to the options for appropriate forms and frequencies of communication, educators should be provided with guidance in terms of thinking about the goal of family-educator communication more holistically and in assessing the best techniques for meeting families’ individual needs.

2. IEP Meetings Structured to Promote Collaborative Decision Making

The Individuals with Disabilities Education Improvement Act (IDEA, 2004; 2006) and other legal underpinnings of the American special education system emphasize the importance of family member participation in the educational decision-making process for students with disabilities. This emphasis is predicated on the notion that increased familial involvement will lead to improved outcomes for students with disabilities (e.g., Lo, 2012). The belief, however, is imbued with middle/upper-class American values such as individualism and self-determination. As Kalyanpur and Harry (1999) assert, these values are not necessarily shared by all families. The goal of universal family participation is therefore inherently limited. Assuming that families do believe it is their role to serve as
active participants in their children’s education, the complex and jargon-filled IEP process can be difficult to penetrate (e.g., Lo, 2012; Mueller, 2009).

It is notable that all three of the IEP meetings associated with the present study were attended by educational advocates (two paid, family-appointed; one unpaid, self-appointed) and that across cases educators and parents articulated the importance of these advocates in allaying parents’ anxiety and navigating the byzantine special education system (e.g., deciphering the “legalese”). Note that this perception exists even from the perspective of the mothers in this study, of whom two are highly educated professionals. In this context, it is important to acknowledge that the use of technical jargon serves as a boundary maintenance strategy, including professionals in the discourse while excluding family members from meaningful participation and accentuating the power differential already at play in many cases.

IEP meetings, however, do not need to be so formal and jargon-filled as to impede the family member participation they are ostensibly intended to invite. Research shows that schools can take certain concrete steps to create a family-friendly atmosphere (e.g., Mueller, 2009). Results of this study support existing literature and research findings suggesting that significant variability exists in the structure of IEP meetings across schools. Certain practices observed in the present study appeared to promote family member understanding of the IEP meeting proceedings and to facilitate active parental involvement. Observed best practices included: (a) providing name tags/tents to encourage team members to call one another by given names (as opposed, e.g., to calling parents “Mom” and “Dad”), (b) supplying clear and detailed agendas of the meeting, (c) offering clear and multimodal explanations of key special education concepts (e.g., accommodations vs.
Many voices at the table modifications, executive functioning), and (d) scheduling longer meetings (e.g., two hours instead of one) to allow time for thorough explanations and anecdotes about the student.

Guidelines (e.g., *Massachusetts IEP Process Guide*) exist to support schools in establishing effective and supportive IEP meeting structures. Also important to note, however, is that each school and family context is unique and that no one set of structures will be universally effective. Schools must, therefore, be flexible enough to adapt practices over time and even to adjust during the course of a given meeting if it becomes clear that certain practices are not working well (e.g., some parents may wait for school personnel to solicit their opinions while other parents may feel uncomfortable being put on the spot). As articulated in Chapter 5, ongoing family member–educator communication is instrumental to collaboration at actual IEP meetings.

3. *Nuanced Understanding of Culturally Responsive Decision Making*

The concept of culturally responsive special education practices has gained traction in recent years (e.g., Griner, Stewart, & Lue, 2013; Utley et al., 2011). Results of the present study correspondingly suggest that educators are aware of the importance of culture in the educational decision-making process. Educators reported awareness, for example, that family members might hold different beliefs about (a) the nature of family member participation in educational planning, (b) educational priorities for students with disabilities, and (c) the cause and course of autism. Findings from this study suggest, in fact, that educators may be oversensitive to the importance of culture in family members’ ideas in the context of educational decision making. As reported in Chapter 5, Katherine interpreted Amina’s tireless work with Bilal on skills development as a manifestation of Somali culture. However, interviews with Amina suggest that her work ethic and
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perspective on her son’s education are the result of temperament and individual-/family-level rather than cultural variation. Katherine’s perspective represents an overgeneralization of the importance of culture as well as a misguided belief in culture as monolithic (i.e., “Somali culture”) rather than an acknowledgment of the intersectionality (e.g., Bowley, 2012; Collins, 2000) of an individual’s multiple experiences. The result of Katherine’s perception was that she was reluctant to challenge Amina’s perspective, fearing that her actions would be culturally insensitive. This, in turn, stilted communication between the mother and educator.

In another example, Kim’s belief that Nadifa did not want to be involved in Aadan’s educational decision making (e.g., “She’s like, ‘Oh, the teacher’s here, the teacher’s gonna teach him.’”) resulted in her adopting a hands-off approach (e.g., “not wanting to step on her [Nadifa’s] toes”). My observations indicated that this approach led to diminished communication. Namely, Nadifa had fairly developed opinions about Aadan’s educational services (e.g., wanting the developmental specialist and occupational therapist to provide services at separate times, preferring ABA over traditional service delivery) to which Kim was completely oblivious. In this case, Kim’s assumption that a Somali mother would not want to share opinions regarding her son’s education, paired with Nadifa’s hesitance to volunteer unsolicited opinions resulted in a communication breakdown and service delivery that was less than satisfactory to the child’s family.

In light of this finding, I suggest that educators need more support in developing effective assessment skills. I contend that teachers do not need more information about particular cultural differences, but rather that they would benefit from learning to sensitively solicit family members’ perspectives and explanatory models. For example, an
informal tool with sample questions to guide this process would be helpful. If educators understand better what family members believe and why, they will be more successful in bridging differences of opinion and negotiating the educational decision-making process.

4. School Cultures That Foster Family-Educator Collaboration

As mentioned previously, significant literature exists to guide educators in establishing culturally competent and family-friendly IEP meetings (e.g., Lo, 2012; Mueller, 2009). Little attention has been paid, in contrast, to the relationship between school culture and the dynamics between family members and educators at IEP meetings. Findings from this study suggest that school culture can be important in determining the amount and type of incidental contact that family members and educators have throughout the school year and that such family member–educator contact lays the groundwork for collaboration at IEP meetings.

In this study, certain practices were observed to promote intimacy and comfort between educators and family members. These include: (a) parents being invited to volunteer in classrooms, (b) schools encouraging drop-off and pickup at the classroom so incidental conversations could occur, and (c) parents being invited to various school events such as proms, performances, and races. Teachers and mothers alike commented on the importance of these types of opportunities for getting to know one another.

Based on these findings, I propose that schools should be intentional about creating opportunities for parents and teachers to interact in and outside of the classroom. Because individual teachers and family members will feel more or less comfortable in different environments, providing a range of opportunities is critical. Creating opportunities for family-educator interaction requires resources on the part of schools. I contend that if
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schools view these activities as instrumental in establishing positive relationships in the educational decision-making process—and possibly in helping avert contentious situations (e.g., rejected IEPs, mediation)—the investment will be viewed as worthwhile.

5. Educators’ understanding of the American middle/upper-class orientation of the special education system

The American special education system is imbued with a set of values, including independence and self-determination (e.g., Kalyanpur & Harry, 1999). In fact, these values are embedded in the laws and paperwork that guide the IEP development process. For example, the IEP Process Guide (2001) developed by the Massachusetts Department of Elementary and Secondary Education includes the following statement: “The Team is required to write IEPs that prepare students with disabilities for independence and employment and other post-school activities” (p. 5). I do not suggest that this orientation be modified in the context of immigrant and refugee families, but rather that educators acknowledge the cultural underpinnings of the process and develop language to help families understand why certain goals exist for families of students with disabilities and to facilitate an open conversation that allows family members and educators to negotiate mutually agreeable goals.

In the present study, for example, Katherine described working with an Indian family that was surprised when the school proposed a self-feeding goal for a preschooler with autism, the family was still spoon feeding a typically developing older child. In this case Katherine was caught off guard, because she had not previously recognized the cultural values undergirding the self-feeding goal. Understanding that educational priorities are grounded in cultural beliefs could help educators like Katherine lead families in nonjudgmental conversations about the school’s rationale to teach students with
Many voices at the table

disabilities particular skills. Through this conversation, family members and educators would be able to decide whether or not the initially proposed goal was in fact appropriate for a particular student.

In another example from the present study, Saida articulated well the ways in which her beliefs about Dris’s education were the product of both the Somali values with which she was raised and the American values she had encountered while living in the United States. For example, Saida had historically believed (based on the Somali emphasis on family and collectivity) that a child with disabilities should be cared for by his family indefinitely. As she became acquainted with American families of children with disabilities, she was persuaded of the benefits of residential placement in terms of fostering independence and social development in adolescents with disabilities. In her perception, she was able to choose between and benefit from diverse elements of two very different systems of thought. This notion echoes Roscigno and Swansen’s (2011) finding that parents’ beliefs about disabilities are not preordained but ever evolving and shaped by the perspectives of the many individuals they come into contact with. I argue that awareness and acknowledgment of different ways of thinking can foster authentic dialogue between family members and educators. This open communication will ultimately allow individuals and groups (both families and school personnel) to shift their perspectives and to arrive at decisions that benefit individuals with disabilities. The ability to shift one’s perspective rests on the awareness that one’s own beliefs are culturally relative. I propose that pre- and in-service teacher preparation programs should explicitly discuss the cultural assumptions embedded in the American special education system.
Many voices at the table

Limitations

Any study is inherently limited in terms of types of conclusions researchers can draw and the extent to which specific findings are generalizable to larger populations. This qualitative multiple case study (Yin, 2009) has limited generalizability both because of the small number of cases and due to the particular attributes of the individual cases (Lincoln & Guba, 1985). As described in Chapter 4, participant recruitment was among the greatest challenges of conducting this particular study. Autism, like other disabilities, is highly stigmatized and rarely discussed among Somali families (Boynton et al., 2010; Ellis et al., 2010). The first several families who I invited (via trusted leaders in the local Somali community) to participate in this study declined. My contacts in the Somali community inferred that stigmatization of disability was the primary reason families were reluctant to participate.

The first two families who agreed to participate were highly educated and professionally involved in research themselves. These two families are not demographically representative (e.g., income level, educational attainment, multilinguality) of the Boston area Somali community more broadly. I believe that the demographics of these families influenced the nature of their participation in the educational decision-making process.

The third family was very different, demographically, from the first two and more similar to most newly arrived Somali-Americans (e.g., monolingual Somali speakers, little formal education). The observations and interviews for this case revealed many important challenges in the context of educational decision making (e.g., language barrier, widely divergent views on collaboration, autism, and autism education) which were not relevant
to the same extent in the first two cases. I was not able to collect as much data for this case as compared with the first two. To begin with, I could not gain access to the IEP meeting in this third case. Whereas approval to attend the first two IEP meetings—at highly resourced schools—was easy to attain, the third (less well-resourced) school did not seem to have a system in place for granting approval. Missing this IEP meeting compromised my ability to comment on the educational decision-making process. In addition, while it was easy for me to establish a rapport with the mothers in the first two cases, the third was much more difficult: the mother and I did not share a common language and our life experiences were decidedly different. While the interpreter who attended all interviews and observations allowed us to communicate proficiently, the presence of an interpreter resulted in a stilted or more distanced quality to the interviews. In addition, the interviews with mothers constituted a primary source of data within this study. This fact inherently privileges the mothers’ perspectives over the vantage points of other members of the family and community (e.g., fathers, extended family members, siblings).

Just as the families in this study brought with them unique sets of lived experiences, so too did the teachers (as does any participant in any study, for that matter). When I initially approached John to participate in the study, he expressed concerns that his point of view would not typify the perspective of autism educators. In particular, he felt that his experience as the brother of an individual with autism had colored his beliefs about autism education. And it is true that the perspectives of the three educators in this study do not represent the views of all autism educators. But each of the participants’ unique experiences only made the overall portrait more intricate and interesting. The richness of
Many voices at the table

the findings of this study is based in part in the analysis of participants’ experiences and the nature of their participation in the educational decision-making process.

Similarly, my own beliefs and life experiences certainly influenced the types of questions I asked in this study and how I observed as well as the ways in which I interpreted the data. As the sole researcher, I collected and analyzed data independently. I acknowledged my own positionality at the outset (see Chapter 1), and although it would be unrealistic to believe that I could eliminate my own biases, I contend that my own experiences (e.g., as an autism educator, as the mother of a child receiving early intervention) added nuance and richness to the study and served, in places, as a foil for my participants’ perspectives.
References


Many voices at the table


Title I--Improving the Academic Achievement of the Disadvantaged; Individuals With Disabilities Education Act (IDEA); Final Rule (2007 April 9).


Appendices

Appendix A: Initial Interview Protocol, Family Members

In the following interview protocols, I outline the broad domains that I hope to address with each interviewee during each interview. Within each domain I have listed examples of questions and prompts that I might or might not need to use depending on how much information a particular individual provides. As much as possible, I will allow participants to tell their own stories.

INTRODUCTION

I’m a doctoral student at Boston College. I used to teach children with autism spectrum disorders in schools. Teachers and parents who grow up in different countries and cultures may have different ideas about autism, school, and raising children. I want to understand better how parents and teachers work together to set important goals for children with autism spectrum disorders

BACKGROUND

- Describe your own school experiences.
  - Prompts: In what countries did you attend school? Until what age? What was good about your time in school? What do you wish had been different? Tell me about your favorite teacher/least favorite teacher. Tell me about the principal or headmaster. How did your parents or elders relate to the school? How were they expected to be involved?
- When did you move to the US?
- What is different about raising children in the US than where you grew up?
Many voices at the table

- Tell me about the schooling of your other children. Prompts: Do you have children who went to school in Africa? In the US?

- How did you feel the first time you entered a US school with your child? What were you most concerned about? Happy about? What did the teacher or principal do to help you understand your child’s schoolwork? How did others in your community/family help you to understand the school?

- Did you communicate with your children’s teacher? How? How often? How well do you think your children’s teachers understand their needs and challenges/gifts and talents? How well do you think your children’s teachers understand your concerns as a parent? From your perspective, what has been good about their school experience so far? What could have been better? Are there people who have helped you to make their school experience better? How?

- Do you have other children in your family have Individualized Educational Plans (IEPs)? Could you please describe for me the process of getting an IEP for this child? What did you like about this process? What could have been better? How well do you think the IEP is working for that child?

BACKGROUND ON CASE STUDENT

- Tell me a little bit about [son’s name].

- What is he like?
  - What does he like/dislike?

- When did you first notice that he was growing (or acting) differently than other children? Tell me a little bit about when and where you first noticed. What did he do that was different than other children? What did you and your family do when...
Many voices at the table

you noticed this? How did you feel about it at first? How have your feelings changed over time? What has been the most difficult/easiest part of raising [child’s name]?

Had you ever encountered children who acted this way or were “different” kind of like he is?

• How do the things your son does compare to the way other children in the Somali community act/behave?

• Has your child’s behavior ever changed the way you participated in work, family or community events (e.g. mosque prayer, Islamic school, Eid festivities, Somali national day, weddings, funerals...)? How?

• How do people in your family and community talk about children who act like he does? Prompt: What Somali words do they use to describe these behaviors? What do these different words mean? How do people in your family talk about [son’s name]? Do people tell you directly, or do other people tell you about how other people are talking?

• Do people talk about/act toward children like your son differently in the US than they did in Somalia or in Kenya? What kinds of things did people say/do in Somalia? What have you heard people say in the US? What did parents do for their children who were different?

AUTISM

Can you take me through the experience of when ________ was diagnosed with autism.

  o Where were you when you first heard the word “autism” used to describe your child? What was the experience like for you?
Many voices at the table

- Who was the person who first used the word “autism” to talk about him? Had you heard about autism before? What did they tell you about what autism means? Did they tell you why they thought your son had autism? How did they know?

- What is your understanding about why children develop autism? What causes it? Why do some children have autism and others do not. Is there anything that people can do to stop a child from having autism? Do other people in your family or community have different explanations? If so, tell me more about them. How do you respond to these ideas?

CHILD’S EDUCATION

- What parts of school is your son best at?
- What do you hope that your son will learn this year in school?
- What do you think that your son’s teacher will like most about teaching him?
- What do you think that teachers will find the hardest about working with your child?
- What do you think that [son’s name]’s teacher thinks about what autism is like?

What causes autism? How children with autism learn/

EDUCATIONAL COLLABORATION

- How’s it going working with [son’s name]’s teachers? What’s surprising? Frustrating?
- How much are you in touch with [son’s name]’s teacher(s)? Do you talk on the phone? Write notes in a home log (in English, Somali)? Talk to him/her at school?
Many voices at the table

• Tell me how parents and teachers work together in American schools? Is this the same as or different than from how parents and teachers worked together in Somalia/Kenya?

• Is the amount of time that you’re spending with the teacher enough? Too much?

THE IEP MEETING

• Why do students have IEPs? What do they do for students?

• Did you go to [son’s name]’s IEP meeting last year? What was it like for you? Take me through how it went. (What was good? What was not so good? Who was there? Who do you feel did the best job trying to help your son get what he needs? What did they do? Did you feel anyone was working against you or not understanding you or your son? Why?)

• Tell me about what [son’s name] has learned over the last year. What parts of this learning do you think are related to his IEP? Did you notice that anything at school changed after the IEP meeting last year?

• You have been invited to take part in [son’s name]’s IEP meeting this year. What is your understanding of what this IEP meeting is for? What is the goal? What do you think it will be like? What are you excited about? Anxious about? Are you planning to have someone go with you? If so, why do you need them there?
Appendix B: Initial Interview, Teachers

BACKGROUND

- Tell me a little bit about your professional trajectory? How many years have you been teaching? How many with students with autism? What was your path to teaching children with autism? Do you have a teaching credential? If so, what area is it in? What kind of teacher education program did you attend? What aspects were most helpful for you in teaching children with autism?

- Can you tell me a little bit about your own schooling? What are your most vivid memories of school? What did you like? Not like? What were you like as a student? Did you know people who had disabilities? What was school like for them? What were your parents’ goals for your education? Did they choose to send you to that particular school? If so, why?

- What was your neighborhoods like? How did the school fit into the neighborhood?

- In what ways, if at all, did your family, other people in your community shape your beliefs about people with disabilities? Can you describe the first time you met someone with a disability? With autism?

- Who or what in your teacher education program shape your beliefs about people with disabilities?

- What did you learn in your teacher education program about working with students and families from different cultural/ethnic/racial backgrounds? What was most helpful to your learning in this area?
Many voices at the table

- Before working with [student’s name], had you taught other Somali students? What was your impression of the Somali student’s family? Did the students do well in your classes? Did they need any special assistance or accommodation?
- What do you know about Somali culture? History? Refugees? Immigrants?
  Where/how have you learned about it?

AUTISM

- What is autism? What are the symptoms of autism? How can you tell if someone has autism?
- What is your understanding about why children develop autism? (additional prompt, if needed: What are the causes of the autistic condition?) Is there anything that people can do to prevent a child from developing autism? If so, what?
- Have you encountered people who have different beliefs about the causes of autism? If so, how do you respond to these people?
- What do you know about how Somali families understand autism?

AUTISM EDUCATION

- What are the primary goals of education for children with autism? Why do you believe these goals are important?)
- What makes an educational plan for a child with autism effective? What gets in the way of an effective plan?
- If you were giving advice to a novice teacher of children with autism what advice would you give him/her? Why?
- Thinking about [student’s name] in particular, what are the most important things for him to learn this year? Why?
Many voices at the table

• How will you know you have succeeded this year with (child’s name)?

EDUCATIONAL COLLABORATION

• Do you think that parents and educators should collaborate in determining educational goals for children with autism? Why? How? What are the most valuable things that parents bring to the table?

• What are some things that you do to facilitate collaboration with the families of students in your class? Can you give a specific example?

• In your experience, what is the hardest thing about working with families?

• Thinking about [student’s name]’s family in particular, how has the collaboration been so far? What has been the hardest part? Why? Can you describe a decision that you’ve made with this family? An issue that you’ve worked on with this family? An interaction that you’ve had with them?

• How much are you in touch with [student’s name]’s parents(s)? Do you talk on the phone? Write notes in a home log? Talk to them at school?

THE IEP MEETING

• What is the goal of an IEP? How does an IEP meeting go? Can you tell me about the process? Tell me a bit about your experiences at IEP meetings in general. What makes IEP meetings go more/less smoothly?

• What is the IEP process like in BPS? When are IEPs drafted, developed? Who drafts IEPs, who provides input? Who makes changes to a draft IEP following the IEP meeting? Who leads IEPs meetings? How do teachers participate in IEP meetings?
• If you have worked in school districts outside of BPS
• Have you been to an IEP meeting with [student’s name]’s family before? If so, how did it go? In thinking about [student’s name]’s upcoming IEP meeting, how are you feeling about it? What do you hope will come out of it? What are you most nervous or excited about? How will you prepare for it?
Appendix C Post-Meeting Interviews, Parents

This interview protocol contains some general open-ended prompts. However, the primary focus of this set of interviews is to allow the researcher to probe interactions and comments that were made during the IEP meeting.

- How did [student’s name] IEP meeting go?
- What was it like for you? Was it what you were expecting? How did this meeting compare with previous meetings that you have attended? Can you give me an example of something that happened during the meeting that caused positive or negative feelings for you?
- Was there anything at the meeting that you didn’t understand?
- Do you think everyone in the meeting wanted the same thing for __________? Why or why not?
- Whose comments were the most/least helpful?
- Was there something at the meeting that you wanted to say but that you did not say?
- I remember when you told me that you were most concerned about X and Y. How well do you think the meeting addressed these things?
- How well was your perspective understood?
- How do you think the other people in the room understood what you were trying to say?
  - Are there some who seem to understand you better than others?
  - How can you tell?
  - What would make it easier for you to express your opinions in the meeting?
Many voices at the table

• If you had another meeting like this, who else do you think should be there? What would they add?
• Are there people you wish were not there? Why?
• Can you think of a decision that everyone made together at the meeting? Tell me about it?
• What do you think the IEP will do for your child?
• Are you optimistic about the future of his education (or even this year)?
• And what is an example of something that was decided by one party alone (school, teacher, parent, etc.)?
• How well do the outcomes of this IEP meeting represent a positive outcome for ________ and his educational needs?
Many voices at the table

Appendix D: Important Moments

Case #1

1.) In the BPS social worker’s report of the home visit at Dris’ house, he says that you/Saida describes Dris as “not being a student.” What do you think that she means/you meant by this?

2.) In the meeting, after the BPS administrators announced that they believed that a residential placement is warranted for Dris and they started to talk about the two options—304 day versus 365, one of the Higashi administrators jumped in and said that he thought the 365 program was more appropriate for Dris. But the BPS administrator retorted “I really wish you hadn’t said that.” What did she object to his comment? Was her reaction justified? Do you think that him offering his opinion changed the way in which decisions were made at the meeting?

3.) Do you think that the fact that you/Saida brought an advocate to the meeting changed the way the meeting went, the outcome? What was her role?

Case #2

1. When Barb was asking you/Katherine about what curriculum she would use to teach attention, what do you think that she was trying to get at? Did you feel like Barb was satisfied with your/Katherine’s response? What do you think about having a particular curriculum vs. embedding scaffolds for attending throughout the day?

2. During the discussion of continuing to work on Bilal’s imaginative play skills in the kindergarten environment, why do you think the director proposed moving this to the modifications category instead of including it as an accommodation? Do you think that having in one place over the other would affect his instruction?

3. In the discussion about the ESY program and whether Bilal should be enrolled for a half day or full day, and whether or not (how?) he would be supported in the enrichment program, what do you think was going on? Do you think all of the school personnel were in agreement? Had you and your advocate discussed this before the meeting?

Case #3

Because this interview was a bit different than the previous two, I have included the entire interview protocol with the important moments embedded.

• How did Aadan’s session today go?
Many voices at the table

- How did it happen that you and Amy (occupational therapist) see Aadan together?
  - How would it be different if you each came at a separate time?
  - Do you and Amy have pretty similar ideas in terms of how to work with Abdir? Any differences?

- To what extent did you feel like Nadifa understood what you were working with Aadan and why?
  - What do you think is most important to Aadan's family?
    - What do they most want him to work on?
  - Have you ever given her direct feedback about something like how to respond to Aadan’s behaviors?
    - Do you feel like she understands when you explain things to her?
    - Like she is able to implement your suggestions?
    - What's the one thing that you would like to communicate to his family?

- Thinking about the services that were supposed to be provided by NAC, did your agency initiate the request for more intensive services or did Aadan’s family?
  - How do you think his family felt when the services fell through?

- When did you start working with Aadan?
  - What are the biggest changes that you’ve seen in him since you started working with him?
Many voices at the table

- Has his progress been slower or faster than you anticipated?
- What factors do you think have affected his learning?

- In terms Aadan’s placement in an integrated classroom for preschool next year, do you think that his parents have ideas about the pros and cons of one type of placement or another?
  - Do you have a sense of which they prefer?
  - Do you see your role more advocating for what you think is best for the child?
    - Or representing the parents wishes (assuming you know what those are) What if the two are in conflict with one another?

- If such a thing existed, do you think that it would be helpful for the Yusuf’s to have a Somali service provider?
  - How do you think that this would change their experience—or not?
  - What is Halima’s role in terms of the sessions?
    - Are there times that you ask her to translate things for you?
Appendix D

Post-Meeting Interview, Educators

- How did [student’s name] IEP meeting go?
- What was it like for you? Was it what you were expecting? How did this meeting compare with previous meetings that you have attended?
- Do you think everyone in the meeting had the same goals? Why or why not? Whose comments were the most/least helpful?
- Was there something at the meeting that you wanted to say but that you did not say?
- How well do you think [student’s name]’s parents understood the meeting? How could you tell? Do you think that there were parts of the meeting that they understood more or less?
- If you had another meeting like this, who else do you think should be there? What would they add?
- Are there people you wish were not there? Why?
- Can you think of a decision that everyone made together at the meeting?
- What do you think the IEP will do for [student’s name]?
- Are you optimistic about the future of his education (or even this year)?
- And what is an example of something that was decided by one party alone (school, teacher, parent, etc.)?
- How well do the outcomes of this IEP meeting represent a positive outcome for _______ and his educational needs?
Many voices at the table

*In addition to these general questions, specific prompts will be generated based on each of the specific meetings.
Appendix G
A Priori Codes

- Family member previous educational experiences
- Family member notions about autism (includes, words used to describe the autism, ideas about causes of autism)
- Family member ideas about autism education (includes parent concerns, suggested goals)
- Understanding of autism/disability in the context of religion
- Family member ideas about education collaboration/decision-making
- Education educational experiences
- Educator training (teacher prep etc.)
- Educator ideas about educational collaboration/decision-making
- Educator experiences working with families from different cultural backgrounds