

Somali American Boys with Autism: Examining Three Educational Transitions Through Capital Theory

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Abstract

This study examines collaboration between American special educators and Somali American families of boys with autism through the lens of capital theory. Subthemes are organized according to phases in the educational planning process, from ongoing and pre-meeting interactions through finalization of the Individualized Education Program (IEP). Results reveal that within a homogenous group (i.e., families of Somali American boys with autism) differences in, for example, immigration history or parents' educational backgrounds can facilitate or impede access to capital (economic, social, cultural). Across the phases, families who leverage capital effectively participate more actively in educational planning. Additionally, findings suggest that children whose families have more access to social and cultural capital tend to enroll in better-resourced schools even if they themselves live in under-resourced school districts. This fact affects their educational trajectories and their families' experiences of collaboration. Implications for practice are discussed.

Key Words: autism, Somali American, capital theory, culturally and linguistically diverse (CLD) students, IEP process, families, collaboration

Although autism traverses racial and ethnic lines, research suggests discrepancies in terms of diagnosis and access to services (e.g., Baio et al., 2018). The Somali Civil War, which has persisted in various forms since its onset in 1991, has led to a growing Somali diaspora, whose members dwell in refugee camps in the Horn of Africa and elsewhere, including in communities in Europe and the U.S. (Al-Sharmani, 2007). Children born in the Somali diaspora have a disproportionate likelihood of being diagnosed with autism (Barnevik-Olsson, Gillberg, & Fernell, 2010; Kirby, 2008), developing co-occurring intellectual disabilities, and receiving diagnoses later than other groups (Hewitt et al., 2013). Because autism has not historically been diagnosed in Somalia (McNeil, 2013), understanding the disability, navigating the complex array of related services, and engaging actively in the educational decision-making

process constitute particular challenges for Somali American families.

Family and Educator Collaboration in Special Education Decision Making

The influx of Somali American students with autism has resulted in cooperative relationships between American-born special educators and Somali American parents with the goal of making educational decisions. Within the American special education system, the vision of family members as collaborators is not only an ideal but also a “legal fiat” explicitly embedded within the Individuals with Disabilities in Education Act (IDEA) and other special education legislation (Kalyanpur & Harry, 2012, p. 72). Equitable collaboration between family members and educators is grounded in the ideal of “participatory democracy” (Kalyanpur & Harry, 2012, p. 72) and based

on the assumption that “all parents regardless of cultural background perceive disability and education-related issues similarly” (Trainor, 2010a, p. 246). Yet research shows that culturally and linguistically diverse (CLD) families encounter impediments to effective family-educator collaboration (Burke et al., 2018). For example, while most CLD families of students with disabilities *attend* their children’s Individualized Education Program (IEP) meetings, they rarely have “opportunities to contribute” meaningfully to the decision-making process (Rossetti, Story Sauer, Bui, & Ou, 2018, p. 329).

Logistical barriers are a fundamental problem. For example, IEP meetings are filled with technical jargon, which can be indecipherable even for families who speak English proficiently (Lo, 2008). Additionally, although school districts are legally required to provide translation and interpretation services, the process can be undermined by interpreters who are unfamiliar with special education jargon, families who are leery of district-hired interpreters, and conversations that require nuanced interpretation as opposed to straightforward linguistic translation (Harry, 1992; Jung, 2011; Rogers-Adkinson, Ochoa, & Delgado, 2003).

This study is one component of a larger multiple case study project led by the first author. Data were collected during the 2012–2013 school year and analyzed between 2013 and 2017. The initial segment of this project (Baker, 2017) examined the factors that lead multilingual families of children with autism to make decisions regarding language exposure (e.g., English-only vs. home language along with English, simultaneous vs. sequential exposure). The next phase drew on intersectionality theory to uncover the ways in which interactions among social identity categories (e.g., race, [dis]ability, and gender) disenfranchise Somali American mothers of boys with autism (Baker & Kim, 2018). Even in light of the narrow demographic focus of the study (i.e., Somali American boys with autism diagnoses), the collaborative relationships between the three mothers and the special educators working with their sons were found to be decidedly different. Findings exposed that differences in how stakeholders leveraged various types of capital (economic, cultural, and social) throughout the educational planning process influenced decision-making. Therefore, the researchers decided to re-analyze the data this time using Bourdieu’s (1986) capital theory as a lens for looking at the following research question:

- How does capital (economic, cultural, social) influence interactions between Somali American mothers of children with autism and education across phases of the special education planning process (i.e., before, during, and after the IEP meeting)?

Capital Theory and Educational Decision-Making

Bourdieu’s (1986) capital theory can be used to uncover the ways in which families with more capital—*economic* (money and other material assets), *cultural* (tangible and intangible assets such as education, knowledge, skills), and *social* (relationships and networks across which capital is exchanged)—are at an advantage in navigating educational systems (e.g., Rueda, Monzó, & Arzubiaga, 2003; Trainor, 2010a; Trainor, 2010b). Trainor (2010a) contends that parent participation in the special education process “requires a complicated appropriation of both knowledge and dispositions (i.e., cultural capital) and relationships with school personnel” (p. 247). However, capital is not equitably distributed across groups. Specifically, immigrant families, because of their limited familiarity with American educational norms, may be thwarted in attempts to leverage capital and, by extension, garner educational opportunities for their children (e.g., Rueda et al., 2003). The Bourdieuan lens allows us to see instances in which special education practices *reproduce* rather than *interrupt* educational inequity (Bourdieu, 1974).

METHODS

Setting

This qualitative multiple case study project (Stake, 2006; Yin, 2009) is set in a large metropolitan area in the Northeastern United States. As of 2014, there were approximately 10,000 Somali Americans living in the state where this study is set (Camacho, Dirshe, Hiray, & Farah, 2014). The three families who participated in this study live in different parts of the same metropolitan area, including an affluent suburb and two different working-class communities comprising primarily Black Americans, immigrants, and refugees (See Table 1 for demographic information about the three communities). Most of the Somali families in this state had arrived after 1991, when the Civil War had begun. By the time this study took place, three community-based organizations (CBOs) had formed to support members of the community. The first author was an adult English teacher at the Center for Somali Advocacy, where she learned that a number of children within the community had been diagnosed with autism and that many community members had concerns and unanswered questions about the condition. In addition to using her expertise to provide her adult students with basic information on developmental disabilities, the first author decided to initiate a research project to uncover the experiences of Somali American families of children with autism. Leaders from the three CBOs connected her with potential participants, and three families elected to participate in the study.

Table 1
Participant Demographic Information

	Aadan	Bilal	Dris
Student			
Age	2.11	5.6	17.11
Age at diagnosis	2.9	3.2	2
Gender	M	M	M
Birth	US	Canada	Sweden
Transition	EI to kindergarten	Preschool to kindergarten	Secondary to residential
Mother			
Name	Nadifa	Amina	Saïda
Birth country	Somalia	Somalia	Somalia
Home language	Somali	Somali, English, Arabic	Somali, English, Swedish
Education level	Primary	Graduate	Graduate
Profession	At home mother	Science writer	OB/GYN case manager
Other family members	Father, 6 siblings	None	Brother, Cousin
Educator			
Name	Kim	Katherine	John
Gender	F	F	M
Edu	BA	M.Ed	M.Ed
Prof	Developmental specialist	Sped lead teacher	Sped Classroom teacher
Years of teaching	6	11	8
Race	White	White	White
Lang.	English	English	English
Community			
ELL	19.90%	4%	31.20%
ED	47.0%	8.4%	49.5%
MHI	\$44,849	\$97,365	\$30,419

Note. EL = percent of students classified as English Language Learners in the participant’s local school district, ES = percent of students classified as “economically disadvantaged” in the participant’s local school district, MHI = median household income in participant’s community.47.0%

Participants

The study includes three case units (See Table 1 for detailed demographic information):

1. Almost three-year-old Aadan, his mother, Nadifa, and his Early Intervention (EI) therapist, Kim
2. Bilal, who was preparing to enter kindergarten, his mother, Amina, and his special educator, Katherine
3. Dris, a high schooler, whose mother Saïda was working with his classroom teacher, John, to secure a district-funded residential placement

Data Collection

In order to develop a textured and multi-perspectival portrait of the educational planning process in each of these three cases, we gathered data from multiples sources (i.e., interviews, observations, educational documents) in

varied contexts (i.e., home, classroom, IEP meeting) and at multiple points in time (i.e., before, immediately following, and approximately a month after the educational planning meeting) (Denzin & Lincoln, 2011; Stake, 2006; Yin, 2009).

Interviews. The first author conducted serial semi-structured interviews with each of the three mothers and with each of the three educators. In Aadan’s case, the family had been working with Nala, a Somali American social worker. When Nala helped the family to enroll Aadan in early intervention (EI), the agency agreed to hire her to interpret all of the home-based EI sessions. Nala also served as an interpreter for this study and translated questions and responses for all three of Nadifa’s interviews.

Interview questions and prompts were developed before the interviews but participants also digressed and steered the conversations to topics that they were inclined

to talk about (Stake, 2006). Questions (e.g., “Can you tell me a little bit about when [child’s name] was diagnosed with autism?”) were followed by a series of prompts to elicit additional information (e.g., “Who made the diagnosis?”; “What information did s/he use to make the diagnosis?”; “Did you agree or disagree with the diagnosis?”).

The first interview with each participant took place before the educational planning meeting, the second interview was directly after the meeting, and the third interview was between two weeks and a month after the meeting. Due to timing of Dris’ annual IEP meeting, his mother, Saida, and teacher John were unable to participate in pre-meeting interviews. Therefore, the first two interview protocols were merged for these two participants. In all of the post-meeting interviews in addition to generic interview prompts, the researchers identified three “important moments” (e.g., “In the discussion about the extended school year program and whether Bilal should be enrolled for a half day or full day . . . 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?”). Mothers and educators were asked to respond to the same moments but the prompts were tailored to their individual perspectives. This gave the researchers detailed and multi-perspectival information about the most complex and important moments in each of the three educational planning meetings, which in turn revealed dynamics related to acquisition and deployment of capital.

Observations and field notes. In addition to interviews, this study included an observation component. The researcher observed Aadan, Dris, and Bilal in both school and non-school settings before the mother and educator interviews, and used field notes to describe the educational sites, which is essential to understanding the nature of family and educator collaboration (Stake, 1995). These informal observations lasted a minimum of thirty minutes and allowed the first author to form initial impressions of the students’ individual learning, communication, and social profiles so that she could make sense of the mothers’ and educators’ comments. During the interview, targeted prompts and follow-up questions were provided as needed.

Document review. Researchers collected students’ IEPs and other educational documents, such as psychological evaluations. The information from these documents served to corroborate and/or contest data from other sources (i.e., interviews and observations; Yin, 2009). For example, in order to fully understand the IEP meeting dynamics, we collected agendas and other explanatory documents and analyzed these alongside interview transcripts and field notes.

Data analysis. The first author used the web-based

platform, Dedoose, to catalogue data and conduct an initial level of coding. This round of coding organized information about family and educator collaboration according to phase of the educational planning process. Next, the second and third author conducted a second level of analysis focusing on the nature of collaboration and mother and educator interactions. Discussions among the first three authors revealed the importance of capital in determining the nature of collaboration and communication (Miles & Huberman, 1994). The researchers then agreed upon the common themes within the interviews by reviewing all documents multiple times and eliminating underdeveloped themes (LeCompte & Schensul, 1999). Finally, the fourth author, who had been involved in previous phases of this project and had read the complete corpus of data, reviewed conclusions drawn by the first three authors and engaged in conversations about analyses and conclusions. When the researchers had different interpretations, they resolved these discrepancies through dialogue.

Trustworthiness and Reflexivity

The researchers sought to ensure the trustworthiness of the data by limiting the effects of researcher bias, reactivity, and respondent bias (Guba & Lincoln, 1985; Morrow, 2005; Padgett, 1998). Safeguards against reactivity and respondent bias include: prolonged engagement in the field and multiple interactions with research participants (Janesick, 2013). The first author interacted with participants at multiple points in time and in multiple settings over the course of the ten-month data collection process.

Collecting data from multiple sources (observations, interviews, and documents) and including multiple investigators (Denzin, 1989), allowed for the triangulation of various pieces of evidence to explore each phenomenon (Golafshani, 2003). For example, field notes collected during IEP meeting observations in conjunction with interviews with two individuals who had attended that meeting were used to understand nuances of the decision-making process.

In order to ensure trustworthiness of the conclusions drawn, the four authors were explicit about their *positionality* in relation to the educators and family members in this study (e.g., Bogdan & Biklen, 2003). Specifically, as a White former special education teacher and professor in a teacher education program, the first author shared with the educators the experience of teaching students with autism, developing IEPs, and collaborating with families. The second and third authors, both White students studying education, were also naturally aligned with the educators’ perspectives in some respects. However, as a sister of a woman with significant disabilities, the second author also tended to have empathy for the challenges faced by the families in the study. Finally, the fourth author, who holds

a PhD. in special education and is also a non-native English speaker and an immigrant mother to a young boy, had a keen eye for the ways in which language, culture, and race affect people's social and cultural capital across the educational decision-making process.

RESULTS AND DISCUSSION

Findings from this study make visible the ways in which various stakeholders acquire and leverage capital in relation to the special education planning process. At the outset of this section, we describe the three case units and the ways in which capital is relevant in each. Next, we use the phases of the educational planning process as an organizing framework to present the themes that emerged from our data. Finally, we share concluding thoughts as well as practical implications.

Capital Across the Cases

Aadan. Aadan (2.11 years old) lives with his six older siblings, his mother, Nadifa, and his father, Abdi. The family was displaced by the Somali Civil War and spent a stint at a large refugee camp in East Africa before being permanently resettled. At the time of the study, Aadan's nine-person family was living in temporary housing in a post-industrial city in the Northeastern U.S. Four of Aadan's older siblings had been born while the family was still living in the Horn of Africa and all of them are typically developing. The youngest three children in the family, Aadan and two of his brothers, were born in the U.S. and all three have autism.

Research shows that children from CLD families tend to receive autism diagnoses later than the national average (e.g., Tincani, Travers, & Boutot, 2009). Although Aadan and both of his brothers had significant needs in terms of behavior, communication, and social development, none were diagnosed early enough to benefit fully from EI. Aadan received his diagnosis at the age of two years nine months, just in time to receive a couple of months of early intervention before aging out while both of his brothers were diagnosed too late to receive any EI services.

Nadifa recalled having had concerns early on about all three of her sons' developmental trajectories (e.g., "From the beginning he didn't cry and he would not cry for hunger."). Already having had both typically developing children (4) and children with developmental differences (2), by the time Aadan was a toddler, Nadifa was in some senses exceptionally well positioned to assess her son's development. But her attempts to advocate for him based on her motherly instincts were stymied by the medical and educational systems. This is in line with Trainor's (2010a) finding that parents who advocate based on intuitive knowledge are often less effective as compared with advocacy based on more formal or highly specialized types of knowledge.

Nadifa's ability to leverage capital was constrained on several dimensions. First, having neither a car nor private insurance, she could only take her children to see doctors at the public clinic in her neighborhood. Therefore, even if she did not agree with the pediatrician's assessment, she could not get a second opinion. Furthermore, it is easy to imagine that as a newly arrived, non-fluent English-speaking refugee, Nadifa probably did not possess cultural capital (knowledge of medical jargon, etc.) to compel the doctor to refer her to a developmental specialist.

At the time of the study, Aadan was receiving home-based EI sessions with Kim, a developmental specialist, along with occupational therapy (OT) and speech therapy. As mentioned previously, Nala, a bilingual (Somali/English) social worker, was officially hired to interpret the EI sessions. Theoretically, this should have promoted communication between the mother and EI provider, and it did but only to an extent. Nadifa's household of nine, including three energetic young boys with autism, hummed with activity and, as indicated by the first author's field notes, Nadifa seldom participated in the EI sessions (e.g., learning to model the sign "more" along with the corresponding English word). More often, she used Aadan's sessions as an opportunity to tend to her other children as well as to household tasks such as cooking.

Bilal. Bilal (5.6 years old) was diagnosed with autism at 3.2 years of age when his mother, Amina, noticed that his development was different than his peers. Amina was born in Mogadishu, but the Civil War began when she was in elementary school and her well-to-do family was resettled in Toronto. Amina's family's resettlement experience illustrates the ways in which possession of and ability to leverage capital is complex and dynamic. To begin with, one of the reasons that her family was able to leave Somalia immediately after the Civil War started was because they were wealthy. As Amina put it, "the people who had money got out first." However, the family lost virtually all of their money and material possessions in the resettlement process. In terms of cultural capital, the family also experienced a dramatic shift: "[we went] from being at one place in society to being the new person ... like the bottom." But they also retained knowledge and values that helped them to succeed in North America. For example, Amina remembers her mother saying that she would pay for tutors and do whatever she could to help her children succeed in school, a view which bespeaks her familiarity with how formal educational systems operate.

As a young adult, Amina married Bilal's father and enrolled in a doctoral program in chemistry. But both of these endeavors were short lived and by the time of the study she had separated from Bilal's father, left the doctoral program, and was working as a scientific writer. She and Bilal live in an apartment in an upper-middle class suburb

of a major city in the Northeastern U.S. A self-proclaimed urbanite, she had reluctantly chosen this exurban town based on the reputation of its schools.

Bilal attends a public preschool program for students with and without identified disabilities. He receives special education services to allow him to access the general education curriculum. His special education teacher, Katherine, provides small group and 1:1 pullout support, provides consultation to his classroom teacher, and also oversees Marsha, the 1:1 paraprofessional who supports Bilal in the classroom setting. Katherine's role had become especially important as she worked with Amina to facilitate a successful transition to kindergarten. Teachers at the preschool offered monthly face-to-face meetings for family members to discuss their children's progress.

Dris. Dris (17.11 years old) was born in Sweden, where his mother Saïda had moved, before the onset of the Somali Civil War, to attend medical school. When Dris was diagnosed with autism at the age of 2.9 Saïda and her husband, Ahmad, both highly educated and professionally connected, leveraged their resources to identify the best constellation of autism services for their young son. The couple already had familial networks in the U.S., which allowed them to relocate transnationally and begin the process of seeking high quality educational opportunities for Dris. Saïda recalls that within 24 hours of arriving in the U.S. she had already scheduled a developmental assessment at a prominent clinic.

Trained as a doctor and working in the field of medicine, Saïda continued to leverage her knowledge and connections to ensure that Dris' educational services were tailored to meet his individual learning needs. When she noticed that the local public schools were not serving Dris adequately, she advocated for an out-of-district placement. After several years when she realized that Dris was no longer thriving in that school, she requested that he be transferred to Hope Academy whose philosophy she thought would best suit his learning style. By the time of the study, Dris' father had passed away and he was living with his mother, brother, and a cousin in a working class urban neighborhood. The family had been selected to buy a brand new single-family house through the Habitat for Humanity program.

Now, with a single income and three dependents, Saïda's financial resources were constrained. However, through connections with other families at Dris' school (Saïda was active in the Parent Teacher Association) she had learned about the potential benefits but also scarcity of high quality residential placements. Saïda decided to hire an educational advocate to help her persuade the school district to pay for a residential placement in addition to the out-of-district tuition they were already paying. In this act, Saïda is leveraging all three types of capital to gain access to more capital (i.e., a fully funded residential placement).

Specifically, she deploys *economic capital* (in paying for a highly qualified advocate rather than a free advocate who she perceives as being less effective) along with *cultural* and *social capital* in the sense of understanding and engaging in the discourse of the residential appeal and tapping into a family network to get a recommendation for an advocate who has a track record of success.

Phase I: Before the Meeting

Research regarding educational decision-making for students with disabilities typically focuses on IEP meetings and the legally binding decisions that follow (e.g., entitlement to particular direct and consultative services, partial rejection of goals or services) (Lo, 2012, Mueller, 2009). Results from this study are unique in demonstrating the importance of family-educator interactions outside of that formal process.

Prom, drop off, and "elephant toothpaste": Family involvement three ways. The three cases in this study illustrate the extent to which opportunities for family-educator interaction vary from one case to the next. John (teacher) explained that Hope Academy (Dris' school) emphasizes family participation in school events, from athletic events to formal dances and stage performances, and has an active parent teacher organization. In this way, the school offers students with autism and their families the opportunity to do all of the things that they would do at a "typical school."

As an out-of-district placement, the school draws from a broad geographic catchment area and so the level of family participation is particularly impressive: Saïda joked that she had probably used "like two hundred dollars in gas" in just a couple of weeks going back and forth to events at the school. We speculate here that, because Saïda had limited economic capital (single household income and 3 dependents), the cost of driving back and forth to Hope was a significant expense for her. But because of her understanding of the extent to which the school values family participation and because of her desire to strengthen her social capital by making connections with Dris' educators and the families of his classmates, she prioritized these frequent visits to the school.

Bilal's school, a public preschool program in an affluent suburban district, is an interesting counterpoint. Unlike Hope, where some students are residential and most others travel to the school by bus, many families of children at the Leapfrog Preschool drive their children to school. This provides daily opportunities to check in with the teachers and chat with other parents, allowing them to consolidate social capital in the form of relationships with educators and other parents, but also requires possession of a private vehicle. Although Bilal generally took the bus to school, his mother spent a considerable amount of time in the classroom. Specifically, Amina volunteered in Bilal's

classroom each week sharing science experiments such as “elephant toothpaste, a volcano, Coke, and Mentos.” Like Saïda, Amina was highly educated and professionally connected, and she clearly prioritized participating in her son’s education. In addition, her native-like English fluency and scientific knowledge had currency in the school setting and allowed her to contribute in a way that was valued by the preschool teacher and other parents.

Observations revealed that Amina and Bilal’s teacher had a close relationship and shared information freely with one another. For example, during one observation, Bilal’s teacher asked Amina about a family wedding she had attended recently and the two casually swapped iPhone photos and stories. We argue that Amina leverages cultural capital to develop relationships with her son’s educators that become a particularly salient form of social capital during the formal IEP process (to be discussed later). Amina articulated that she was intentionally interacting with Bilal’s educators in a positive way so that she could advocate for him effectively when the need arose (I don’t want to them to think, “here comes the bitch on heels,” she explained in one interview).

In contrast to the other two mothers, Nadifa had cursory or infrequent contact with Aadan’s educators. For example, because she did not have a car, two-year-old Aadan rode the bus to and from his EI toddler group precluding opportunities for interaction with the toddler group teachers. In addition, as mentioned previously, even though most of Aadan’s EI services took place in her home, Nadifa had only limited interactions with Kim because of the language barrier (lack of cultural capital). But as evidenced by the fact that Nala’s (social worker) presence did not significantly increase collaboration, we contend that other factors were at play. For instance, Nadifa had observations about and knowledge of what was working best for Aadan’s learning (e.g., she thought the applied behavior analysis methodology was working better for him than other formats, she found it more effective for therapists to come separately rather than together). But she did not leverage this capital in order to influence her son’s education; she kept quiet. We hypothesize that both her own ideas about family-teacher collaboration and the EI therapist’s assumption that she would not want to contribute (Kim imagined Nadifa thinking “Oh, the teacher’s here. The teacher’s gonna’ teach him”) conspire to create an environment in which Nadifa does not participate.

Whereas Saïda and Amina had cars, flexible professional jobs, proficient English skills, and knowledge of the American special education system, Nadifa had none of these. Findings reveal that when families possess and are able to leverage capital they, in general, have more frequent opportunities to interact with educators. In turn, frequent (and especially in-person) family-educator interactions

support the development of social capital, creating strong networks across which other types of capital flows. This conclusion is aligned with Bourdieu’s (1974) notion of *social reproduction*. In essence, capital begets more capital.

Phase II: During the Meeting

Name tents and agendas: Organizing educational meetings. Research suggests that certain practices (e.g., providing an agenda, offering participants water) promote collaboration and reduce familial stress in relation to IEP meetings (e.g., Mueller, 2009) particularly in the context of immigrant and refugee families (e.g., Lo, 2012), who, in order to participate, are required to “establish new social networks, acquire new forms of cultural capital (e.g., learning English) and learn new ways to access medical and educational services for their children” (Carreón, Drake, & Barton, 2005, p. 469). In addition, schools themselves have differential access to and ability to leverage capital (e.g., personnel, training, resources). Notably, families with less capital often attend schools in districts with less capital. This is another way in which access to capital is compounded in the context of schooling in the U.S. See Table 2 for a comparison of the characteristics of Bilal’s and Dris’ IEP meetings. Aadan is not included in this comparison because he was not school-aged at the time of the study.

Bilal’s IEP meeting included several best practices for promoting parent-teacher collaboration. First, the team chairperson provided all of the participants with a written agenda at the outset of the meeting so that it was easy for everyone to follow along and to know when they would be asked to participate. In addition, the table was set with name tents so that participants could address one another by name rather than role (e.g., Amina was introduced by her first name rather than as “mom.”). IEP meetings, in general, tend to be hierarchical with educators possessing more cultural capital in the form of knowledge of the process, jargon (e.g., “PLEP-A,” “service-delivery grid”) and discourse surrounding the IEP development process. The fact that the name tents labeled all of the participants with their first names serves, at least to an extent, to democratize the process. In addition, during the “introductions” section of the meeting, the director, Lisa (who served as the meeting chairperson), shared several personal and specific anecdotes about Bilal, which sent the message that personal, in addition to technical, input were welcome during the meeting. We argue that these practices served to create an atmosphere in which Amina was able to leverage her capital (e.g., her knowledge of her son, her educational priorities for him) and to effectively influence the decisions made during the IEP meeting and even to contest proposals put forth by the educators.

Furthermore, Amina, who was preparing to go to law school, also had command of legal special education discourse. She mobilized, for example, the discourse

Table 2
IEP Meetings: Similarities and Differences

	Dris	Bilal
Type of placement	District-funded private	Public
Physical space	Conference room with a rectangular table.	Conference room with a rectangular table.
Length	1 hour	3 hours
Parent name used	No (Saïda is referred to as “mom” throughout the meeting.)	Yes (name tents provided)
Agenda provided	No	Yes
Number of participants	16	8
Advocate present	Yes	Yes
Student attended meeting	No	No
IEP signed during meeting	No	No

Note. Aadan’s (2.11 years) meeting characteristics were not provided because his services were at the EI level and his meeting was not comparable to the other two.

surrounding inclusivity and “the least restrictive environment” to argue that the district should pay for an aide to support Bilal in a town-run summer camp rather than for him to attend the special education summer school program in which all of his peers also have disabilities (field notes). The outcome of this decision was not known at the completion of the study.

Time allotted. The amount of time that a school sets aside for the meeting can have important implications in terms of the extent to which family members leverage capital and participate in the meeting. Bilal’s meeting, according to the agenda, 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. We contend, however, that scheduling a longer meeting signals that a school views the IEP meeting as a valuable structure with enough time to hash out important decisions. Moreover, 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 just one hour, in spite of the fact that a high stakes educational decision—district funding for a residential placement—was on the table. The result was a quick-paced meeting with few opportunities for pleasantries or digressions (field notes). Decisions and negotiations were rapid, and Saïda was essentially excluded from the jargon filled conversations. At several points during the meeting, school personnel turned to her (researcher’s field notes suggest that these were at points in the meeting when Saïda’s facial expressions suggested confusion) and explained that these were just “business” discussions, seemingly implying that her participation was neither required nor invited. The first

author’s interactions with Saïda show her to be outgoing and self-confident (field notes). In keeping with other research, this suggests that in spite of being a highly educated professional, in the educational planning process, many families “lose some of the authority [they had] in [their] home country because [they] lack knowledge of the nuances of language called for in particular situations” (Carreón, Drake, & Barton, 2005, p. 470).

Is a draft only a draft? The IEP meeting is envisioned as a time for substantial educational decisions to be made democratically with input from various team members, including families (Cheatham, Hart, Malian, & McDonald, 2012). Unlike Dris’ meeting, which essentially consisted of a series of professional reports with little room for comment or discussion, the tone at Bilal’s meeting invited conversation, debate, and revision of IEP goals. 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, Lisa gently challenged the therapist’s decision to target a particular skill first. Because Lisa was the meeting facilitator, establishing a tone of inquiry early on in the meeting created a forum for discussion and debate. Both Amina and her advocate subsequently asked 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). Their gentle challenges represent an effective mobilization of power in the sense that it pushed the educators to re-think some of their initial assumptions

and perhaps to modify their approaches to working with Bilal.

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. Although IDEA has specific guidelines for how the signature process should take place, schools have some leeway to establish their own practices. 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 decision; it expedites the process allowing service delivery to begin without delay. Data from this study suggest that access to capital affects family members' participation in the post-meeting phase in a couple of ways.

At the end of Dris' IEP meeting, Saïda was encouraged to sign the IEP on the spot. In contrast, at Leapfrog Preschool families are strongly discouraged (almost prohibited from) signing the IEP during the meeting. 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 . . . 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. 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' . . . and it does allow services to get started without signing the IEP. So you're not agreeing to the IEP, but you're saying 'these are the services that we've agreed upon today. Please get started on them.'

After the IEP meeting and once she had received the "official" draft IEP sent by the school, Amina's initial inclination was to file a partial rejection: "Definitely we're going to reject the half-day summer school thing." Amina planned to meet with her advocate to craft the partial-rejection statement. Because the communication during

this phase is almost exclusively written, it can be even more daunting for non-native English speaking and especially not-fully-literate parents to tackle.

We posit that differences in the IEP finalization process across districts are based on the advocacy efforts of previous families who have passed through the district. Thus, in an affluent district like Bilal's, most families are highly educated and well versed in the legal aspects of the IEP process (cultural capital). They also have the resources (economic capital) and access to networks (social capital) that allow them to locate and hire highly competent educational advocates. It therefore comes as little surprise that Bilal's district had enacted a family-friendly IEP process. In effect, families with more capital are likely to live in towns and school districts where other families also have more capital. This increased capital within the school benefits all families within the district while, on the flipside, families who do not possess high levels of capital are likely to live in towns and communities where most other families also do not have access to capital.

CONCLUSIONS, LIMITATIONS, AND IMPLICATIONS FOR PRACTICE

This study was designed to provide a fine-grained analysis of the ways in which subtle sociodemographic differences in CLD families of children with disabilities in combination with school policies and practices can result in profound differences in the way that the educational planning process unfolds.

Interactions Among Language Ability and Other Forms of Capital

Amina and Saïda are useful foils for each other in the sense that their social identities overlap considerably. They are both highly educated, professional, Somali American mothers of boys with autism. Each of them was strategic in advocating for the complex educational needs of their sons with autism.

Amina articulated that, in spite of being a city person, she chose to rent an apartment in an affluent suburb so that Bilal could get the best education possible, while Saïda and her family leveraged social capital allowing them to relocate transnationally (from Scandinavia to the U.S.) when Dris was diagnosed with autism to secure the most effective autism services for him. Once in the U.S., Saïda effectively navigated the special education system, expertly requesting that Dris be transferred from a public school placement to one district-funded private placement and then another and finally to a residential secondary school program to find just the right combination of services to meet his needs.

Although both Amina and Saïda had historically attended their sons' IEP meetings alone, because of the important educational transitions underway at the time of

this study, each of them hired educational advocates to make sure that the outcomes of the IEP meetings were favorable to their sons. Although Saïda's finances were tight at the time, she turned down a free advocate in favor of finding the most skilled advocate possible. In this context, the fact that Amina participated frequently and at length during Bilal's meeting while Saïda was marginalized and silenced during Dris' meeting point to the fact that subtle differences in school policy and family status can make a tremendous difference in terms of how family and educator collaboration plays out. To begin with, the difference between Amina and Saïda's experiences reaffirm the idea that English language facility plays a significant role in family participation. Although Saïda's English language was highly competent and allowed her to hold professional jobs, it did not allow her to comfortably navigate Dris' rapid-fire and jargon-filled IEP meeting.

Oftentimes, school systems focus on provision of interpretation and translation services at the expense of investigating other policies that might facilitate participation among non-native English-speaking family members. However, the differences between Dris and Bilal's meetings demonstrate the many things that schools and IEP teams can do to facilitate participation aside from (or in addition to) providing interpreters and translators. These practices include: providing a written agenda, scheduling longer meetings, setting a tone that invites rather than excludes participation, institutionalizing that IEPs are to be signed *after* rather than *during* the IEP meeting.

Families with Capital End Up in Well-Resourced Schools

This study also highlights the relationship between a family's possession of the various forms of capital, their effective use of this capital, and the type of school their child is likely to attend. For example, although in theory publicly funded out-of-district placements are available to all students, regardless of their family's access to economic, social, and cultural capital, in practice families with more capital have an easier time securing such placements for their children. In Aadan's family, he and both of his brothers with autism diagnoses were all enrolled in the local public school system. And although, on some level, Kim saw herself as an educational advocate for the family (albeit self-appointed and unpaid), our observations reveal that she simply did not have the legal expertise or understanding of the special education system to advocate for the most effective placement for Aadan. This observation supports the wisdom of Saïda's decision to hire a highly recommended paid advocate rather than using the free advocate she had been offered. (After all, the cost of hiring an advocate for a couple of hours pales in comparison to the value of years of residential placement).

Taken together, these cases illustrate not only the profound effect that family capital has on determining a child's educational placement but also the ways in which the level of resources that a school has determines the extent to which they supported family participation. Differences in the school's educator and family communication policy, for example, or the length of scheduled IEP meetings can shape the experiences of families as they participate in the educational decision-making process.

Implications for Practice

Although this study was not designed with the intention of offering practical suggestions to families and educators, several implications for practice emerged from our findings. Here are some steps that schools and institutions can take to facilitate collaboration between family members and educators:

- Allow family members and educators to communicate using the modalities they prefer (e.g., face-to-face, written home logs, phone, text or e-mail)
- Ensure that interpreters are well versed in special education terminology and concepts and provide true interpretation rather than simply linguistic translation before, during, and after IEP meetings.
- Evaluate families' aspirations and students' needs through comprehensive assessments and structured conversations before preparing the draft IEP.
- Encourage low-stakes meetings between families and educators outside the formal IEP development process.
- Provide accessible information at IEP meetings (e.g., name tents identifying the members and roles represented on the IEP team, agenda of events).
- Institute a policy wherein families sign IEPs *after* as opposed to *at the end of* or *during* IEP meetings to add an opportunity for family involvement when families cannot participate or are uncomfortable participating during the meeting.

Limitations

Because none of the researchers shared a language with Nadifa (Aadan's mother), the interviews were conducted through an interpreter. Nadifa's interviews were notably shorter and less detailed than Amina and Saïda's, which may have had to do with the language and/or other barriers between her and the researcher. Having had a Somali American member of the research team would likely have yielded richer data, especially in Aadan's case.

REFERENCES

- Al-Sharmani, M. (2007). Contemporary migration and transnational families: The case of Somali diaspora(s). *Rep. Cairo: American University in Cairo: Forced Migration and Refugee Studies Program.*

- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., ... & Durkin, M. S. (2018). Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveillance Summaries*, 67(6), 1. DOI: 10.15585/mmwr.ss6706a1
- Baker, D. (2017). The Language Question: Considering three Somali American students with autism. *Multiple Voices for Ethnically Diverse Exceptional Learners*, 17, 20-38.
- Baker, D. & Kim, H. (2018). Unsettling the resettled: An intersectional analysis of autism in the Somali diaspora. *Review of Disability Studies: An International Journal*, 14, 1-28.
- Barnevik-Olsson, M., Gillberg, C., & Fernell, E. (2010). Prevalence of autism in Somali children living in Stockholm: Brief report of an at-risk population. *Developmental Medicine and Child Neurology*, 52, 1167-1168. DOI: 10.1111/j.1469-8749.2010.03812.x
- Bogdan, R. C., & Biklen, S. K. (2003). *Qualitative research for education: An introduction to theories and methods* (4th ed.). New York, NY: Pearson Education Group.
- Bourdieu, P. (1986). The forms of capital. In J. G. Richardson (Ed.), *Handbook of theory and research for the sociology of education* (pp. 241-258). New York, NY: Greenwood.
- Bourdieu, P. (1974). Cultural reproduction and social reproduction. In R. Brown (Ed.), *Knowledge, education, and cultural change*. London: Tavistock.
- Burke, M. M., Rios, K., Garcia, M., Sandman, L., Lopez, B., & Magaña, S. (2018). Examining the perspectives of Latino families of children with autism spectrum disorder towards advocacy. *Exceptionality*, 1-14. DOI: 10.1080/09362835.2018.1433041
- Camacho, P. R., Dirshe, A., Hiray, M., & Farah, M. J. (2014). The Somali Diaspora in Greater Boston. *Trotter Review*, 22, 6.
- Carreón, G. P., Drake, C., & Barton, A. C. (2005). The importance of presence: Immigrant parents' school engagement experiences. *American Educational Research Journal*, 42, 465-498. DOI: 10.3102/00028312042003465
- Cheatham, G. A., Hart, J. E., Malian, I., & McDonald, J. (2012). Six things to never say or hear during an IEP meeting: Educators as advocates for families. *Teaching Exceptional Children*, 44, 50-57. DOI: 10.1177/004005991204400306
- Denzin, N. K., & Lincoln, Y. S. (2011). *The SAGE handbook of qualitative research*. London: SAGE.
- Denzin, N. K. (1989). *The research act: A theoretical introduction to sociological methods*. Englewood Cliffs, NJ: Prentice Hall.
- Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8, 597-606.
- Guba, E. G., & Lincoln, Y. S. (1985). *Naturalistic inquiry*. Newbury Park, CA: SAGE.
- Harry, B. (1992). *Cultural diversity, families, and the special education system: Communication and empowerment*. New York, NY: Teachers College Press.
- Hewitt, A., Gulaid, A., Hamre, K., Esler, A., Punyko, J., Reichle, J., & Reiff, M. (2013). *Minneapolis Somali autism spectrum disorder prevalence project: Community report 2013*. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.
- Janesick, V.J. (2013) Oral history, life history, and biography. In A. A. Trainor & E. Graue (Eds.), *Reviewing Qualitative research in the social sciences*. New York, NY: Routledge.
- Jung, A. W. (2011). Individualized education programs (IEPs) and barriers for parents from culturally and linguistically diverse backgrounds. *Multicultural Education* 19(3), 1-25.
- Kalyanpur, M., & Harry, B. (2012). *Cultural reciprocity in special education*. Baltimore, MD: Brookes.
- Kirby, D. (2008). Minneapolis and the Somali autism riddle. *Huffington Post*. Retrieved April 3, 2012.
- LeCompte, M.D., & Schensul, J.J. (1999). *Analyzing and interpreting ethnographic data*. Walnut Creek, CA: SAGE.
- Lo, L. (2008). Chinese families' level of participation and experiences in IEP meetings. *Preventing School Failure: Alternative Education for Children and Youth*, 53, 21-27.
- Lo, L. (2012). Demystifying the IEP process for diverse parents of children with disabilities. *Teaching Exceptional Children*, 44, 14-20. DOI: 10.3200/PSFL.53.1.21-27
- McNeil, D.G. (2013, December 17). Study links autism and Somalis in Minneapolis. *New York Times*, p. D2.
- Miles, M.B., & Huberman, A.M. (1994). *Qualitative Data Analysis*. Thousand Oaks, CA: SAGE.
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, 52, 250-260.
- Mueller, T. G. (2009). IEP facilitation: A promising approach to resolving conflicts between families and schools. *Teaching Exceptional Children*, 41, 60-67. DOI: 10.1177/004005990904100307

- Padgett, D. K. (1998). *Qualitative methods in social work research: Challenges and rewards*. Thousand Oaks, CA: SAGE.
- Rogers-Adkinson, D. L., Ochoa, T. A., & Delgado, B. (2003). Developing cross-cultural competence: Serving families of children with significant developmental needs. *Focus on Autism and Other Developmental Disabilities*, 18, 4-8.
- Rossetti, Z., Story Sauer, J., Bui, O., & Ou, S. (2018). Developing collaborative partnerships with culturally and linguistically diverse families during the IEP process. *TEACHING Exceptional Children*, 50(4), 172-182. DOI: 10.1177/0040059918758163
- Rueda, R., Monzó, L. D., & Arzubiaga, A. (2003). Academic instrumental knowledge: Deconstructing cultural capital theory for strategic intervention approaches. *Current Issues in Education*, 6, 1-13.
- Stake, R. E. (2006). *Multiple case study analysis*. New York, NY: The Guilford Press.
- Stake, R. E. (1995). *The art of case study research*. Thousand Oaks, CA: SAGE.
- Tincani, M., Travers, J., & Boutot, A. (2009). Race, culture, and autism spectrum disorder: Understanding the role of diversity in successful educational interventions. *Research and Practice for Persons with Severe Disabilities*, 34, 81-90.
- Trainor, A. A. (2010a) Reexamining the promise of parent participation in special education: An analysis of cultural and social capital. *Anthropology & Education Quarterly*, 41, 245-263. DOI: 10.1111/j.1548-1492.2010.01086.x
- Trainor, A. A. (2010b). Diverse approaches to parent advocacy during special education home—school interactions: Identification and use of cultural and social capital. *Remedial and Special education*, 31, 34-47. DOI: 10.1177/0741932508324401
- Yin, R. K. (2009). *Case study research: design and methods*. Thousand Oaks, CA: SAGE.

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