

Editorial

Let's Get "AWARE" of Preventing Violence through Good Mental Health Promotion

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In February 2018, the United States experienced yet another devastating mass shooting, this time at a high school in Florida with a total of 17 people left dead. Once again, many politicians who are opposed to stricter gun control shifted the blame to "mental illness" despite themselves having records of seeking cuts to programs that promote good mental health and/or opposing parity between physical and mental health coverage in health insurance.

In fact, people with serious mental health challenges are much more likely to be the victims of violence rather than the perpetrators. There are relatively few with a psychosis or highly distorted thinking that might lead to a deadly shooting. Of course keeping guns out of their hands should be a priority, but real solutions would focus on reducing factors that make some students feel unwanted and alienated, which is true of nearly all students who perpetrate violent acts in their schools.

It is notable that there are evidence-based practices that can be used in schools to promote good mental health and greatly reduce the likelihood of violence. Many of these practices are being promoted through the US government's Advancing Wellness and Resilience in Education (AWARE) grant program for states and school districts. This program was part of the Obama administration's response to the notorious 2012 mass shooting at Sandy Hook Elementary School in Connecticut, which remains the United States' most deadly school shooting with 26 victims. As with the recent Florida shooting, the Sandy Hook perpetrator had a serious emotional disturbance.

The AWARE approach seeks to head off such events through prevention and early identification and treatment. A guiding principle congruent with the disability studies perspective is that students of all abilities need to feel socially valued and accepted if they are to reach their best possible mental and physical health status and gain the most possible benefit from their educations. Social inclusion and mutual respect are therefore strongly promoted.

Key AWARE elements being demonstrated and tested include:

- Raise awareness and conduct program planning through collaboration among families, schools, and communities.
- Establish school teams that collect and use data to identify and address high priority behavioral challenges on campus.
- Increase school and community early intervention capacity.
- Identify and attend to symptoms of trauma.

- Promote social-emotional learning, thereby enhancing overall social skills and mutual acceptance.
- Ensure mental health services are culturally relevant and developmentally appropriate.
- Implement positive behavioral interventions and supports (PBIS), which consist of rules, routines, and physical arrangements that channel students away from negative behaviors without the use of alienating punishments.

When effectively implemented, these practices are known to lead to more welcoming school climates, as reflected in reduced bullying and fighting, fewer students thinking about or attempting suicide, greater mutual respect and acceptance, fewer suspensions and expulsions, and improved academic performance.

Another notable aspect of the AWARE initiative is a focus on increasing interpersonal contacts between students who may be seriously troubled and caring adults. To this end, a required component of all AWARE projects is to train school personnel and community members in Youth Mental Health First Aid (YMHFA), which is modeled on the CPR training approach for cardiopulmonary resuscitation. The eight-hour course enhances the capacity of people to recognize symptoms of distress in youth and to know when and where to make referrals or otherwise provide support.

Mental health first aid courses were developed for the adult population in Australia beginning in 2000, with a youth version added later. Courses are now offered in at least 23 countries. We can all contribute to this movement by completing either or both the youth and adult courses, or even the more intensive train-the-trainer courses. In the United States, you can find courses scheduled near you at www.mentalhealthfirstaid.org/take-a-course/find-a-course/.

Research Article

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

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

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

I¹ had just started to recruit participants for a research study examining educational decision-making for Somali American students with autism. Recruitment efforts had led me to leaders in the Somali community in a large metro area in the Northeastern U.S. When I met Naïm, the head of a local educational nonprofit at his office, he launched into a story about his own daughter, Halima, by then a junior in college.

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

Introduction

A critical mass of Somalis—most of them refugees—began to settle in the U.S. starting in 1991 when military dictator Siad Barre was overthrown in a coup setting alight a civil war that continues today (Pavlish, Noor, & Brandt, 2010; Scuglik, Alarcon, Lapeyre III, William, & Logan 2007). Less than two decades after Barre's overthrow, the population of Somali Americans exceeded 100,000 (Whyte, 2011), constituting the third largest group of

sub-Saharan Africans in the U.S.—after Nigerians and Ethiopians (Campacho, Dirshe, Hiray, & Farah, 2014). The median income for Somali Americans is among the lowest in the country: more than half (51%) live below the federal poverty level (Whyte, 2011) and 90% live in subsidized housing (Campacho, Dirshe, Hiray, & Farah, 2014).

Autism in the Somali Diaspora

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

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

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

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

Autism and the Family System

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

Implications for Family/Educator Collaboration

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

Theoretical Frameworks: Neurodiversity and Intersectionality

Our understanding of autism and of this data have been shaped by the notion of neurodiversity. The Neurodiversity movement emerged in the U.S. in the 1990s—around the same time as the Somali civil war. Neurodiversity proponents, many of them individuals with high-functioning autism, believe that autism "is not a disease to be treated, and if possible cured, but rather a human specificity (like sex or race) that must be equally respected" (Ortega, 2009, p. 426). This framework highlights the fact that autism is not only a static diagnostic category, but a construct that is subject to interpretation and dispute. Because of the various positions and identities of the participants in this research (i.e., individuals with

autism, family members, and educators) and because autism affects the three students in this study in very different ways, the concept of neurodiversity is more relevant in certain parts of our analysis than in others.

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

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

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

Method

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

Setting

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

A Portrait of Cedar Grove.

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

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

Participants

Participant selection was *purposeful or criterion-based* (Creswell, 2006; Maxwell, 2004; Patton, 1990). At the outset, three criteria for inclusion were established: (a) diagnosis (autism spectrum disorder), (b) ethnicity (Somali American), and (c) gender⁴ (male). Participants were recruited through contacts at agencies within the local Somali American community. The first author contacted Somali professionals within these agencies, and they approached families of boys with autism in their networks. Four families were invited and three elected to participate in the study.

Once the three boys had been identified, we set up meetings with their families and asked the families to identify and put us in touch with “the child's primary educator.” We selected mothers (as opposed to fathers) as the family participants in this study for two reasons: (a) two of the families who agreed to participate in the study happened to be headed

by single mothers (one widowed; the other divorced) and (b) because child-rearing is seen as being primarily the mother’s domain in Somali families, mothers were more likely than fathers to be actively engaged in their children’s education on a day-to-day basis.

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

Table 1

Participant Demographics

Child				Mother				Family			Teacher				
Name	G	Age	CB	Name	PF	EL	CB	LH	Religion	Member	Name	G	R/L	EL	YT
Idris	M	17.11	Sweden	Saida	Medical Case Manager	Grad	Somalia	Somali, English, Swedish	Muslim	Mother 1 Brother Cousin	John	M	White /English	M.Ed.	8
Bilal	M	5.6	Canada	Amina	Scientific Writer	Grad	Somalia	English, Somali, Arabic	Muslim	Mother	Katherine	F	White /English	M.Ed.	11
Aadan	M	2.11	USA	Nadifa	Stay-at-home-mother	No formal	Somalia	Somali, English	Muslim	Mother Father 6 Siblings	Kim	F	White /English	BA	6

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

Idris’s⁵ family

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

satisfied with the progress he was making in that placement so he moved to one out-of-district placement and then another. By the time of this study he was a student at the Hope school, a substantially separate school for students with ASDs.

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

Bilal's Family

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

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

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

Aadan's Family

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

Kim, Aadan's EI provider had initially thought that she would like to be a classroom teacher but realized that she was drawn to working one-on-one with children and their families. As an EI therapist, she worked with students with a range of needs and disabilities

but felt particular affection for students with autism. Most of her clients were immigrants and nonnative English speakers because of the geographic area she served. She really liked working this community but as a monolingual White woman she sometimes felt it was hard to communicate openly and she grappled with the expectations of family involvement in the EI model. For a mother like Nadifa, who has seven children, Kim doubted that the ideal of parent participation was “feasible.” She questioned the idea that she should be telling “the mom to sit on the floor and play with her son” in light of so many competing household demands.

Data Collection

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

Interviews

Three interviews were conducted with each mother and educator⁶: one before the annual IEP review; one during the week following the educational meeting (either IEP or EI meeting); and one between the first and second months after the educational meeting. Mothers selected convenient, comfortable locations for their interviews: their homes, workplaces, and area restaurants. Interviews with two of the educators (John and Katherine) were conducted in their school offices. Kim’s busy schedule of providing home-based early intervention made it difficult to identify a time and location for in-person interviews. She requested that we do phone interviews instead so that she could fit them in between home visits and we agreed. Although phone-based interviews are not ideal in the sense that interviewers are not privy to the non-verbal information that can be seen in person, in this case, because the first author had observed Kim doing EI sessions with Aadan, we already had an idea of how Kim interacted professionally. Interviewing each participant at multiple time points allowed the researcher to gauge subtle shifts in participants’ perspectives over time. A bilingual (English-Somali) interpreter attended all interviews and observations with Aadan and his family.

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

Observations

Before the interviews, the first author observed each case student at home and in school. Observations lasted approximately 30 minutes, were informal (i.e., not guided by a formal observation protocol) and took place during a typical academic activity (as identified

by the teacher). Non-educational observations were designed to allow the researcher to observe students interacting with family members as well as general language practices and family dynamics within the households. The first author also observed the decision-making process at educational team meetings for each of the boys. During these meetings, the researcher sat among participants but did not contribute to the conversation and took copious field notes both of verbatim dialogue between parents and educators and of impressions of the meetings and the negotiations. All fieldnotes were transcribed into a computer file immediately following the interaction. This immediate transcription allowed the researcher to remain mindful of initial impressions (Bogdan & Biklen, 2003).

Document Review

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

Data Analysis

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

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

After the initial coding, we used pattern coding and selective coding to articulate themes and implications (Miles & Huberman, 1994; Saldaña, 2013). In addition to compiling the codes in the code list, we also marked other themes and recorded field notes and memos.

Across the entire data collection process, we brought pre-existing categories or “sensitizing concepts” to the sites (Denzin, 1971). The sensitizing concepts guided initial research before definite ideas about the data had been formed and helped shape and modify conceptual frameworks (Denzin, 1971; Patton, 2002).

Trustworthiness and Reflexivity

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

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

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

Results and Discussion

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

Theme One: Parenting Intersections Among Race, Disability, Religion, and Gender

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

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

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

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

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

We argue that several of Saida's own social identity categories intersect with Dris' disability/behavior exacerbating the experience. First, mothers (as opposed to fathers) tend to perform the majority of everyday parenting tasks, which means that they disproportionately

encounter parenting stressors. Also, because mothers from non-dominant backgrounds are more vulnerable to censure than White mothers (Kediye, Valeo, & Berman, 2009), we hypothesize that Saida and the other mothers in this study are disproportionately likely to have experiences like this one.

An Accusation of Child Abuse

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

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

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

However, as with Saida's case, the stress that Nadifa experienced in parenting three boys with disabilities was heightened by other people's judgment of her parenting. When the first author was at Nadifa's house observing an EI session, an official report of “possible child abuse and/or neglect” arrived in the mail. Astur, who was interpreting the EI session translated the letter. In attempting to make sense of this unsettling piece of mail, Nadifa speculated that the receptionist at her pediatrician's office had filed the claim during a routine appointment the previous month. Because Nadifa was not able to access timely and effective

autism services for her three boys with autism, they were still learning how to communicate functionally. In the absence of effective communication skills, the boys engaged in “maladaptive” behaviors to express themselves. Ironically, the very system that prevented Nadifa from accessing the resources that her boys needed is the same system that labeled her boys’ behavior as problematic and accused her of being a “neglectful” mother.

“He’s a Black Man in America”

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

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

Theme Two: Cultural Assumptions and Family/Educator Communication

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

Discrepancy in Racial Awareness

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

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

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

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

Cultural Assumptions Curb Communication

Implicit biases related to race, ethnicity, religion, language, and other social categories affect how family members and educators engage with one another (Artiles, Sullivan, Waitoller, & Neal, 2010; Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015; Wilkinson, Ortiz, Robertson, & Kushner, 2006). Because these preconceived notions are often subconscious, they can impede communication between the families and educators. For instance, Katherine purports that the fact that her educational priorities for Bilal differ from Amina's is evidence of a cultural difference ("I mean [Amina] works [Bilal] really hard, so that's the piece I think, I think that's a cultural difference from what we would expect.")

We argue, that in fact, Amina's views on Bilal's education are very much grounded in the American middle-class notion that families should be primary advocates for their children, especially during the special education process. Amina clearly viewed advocating for Bilal as being her *own* responsibility ("I always feel inadequate, because I always feel like am [not] I fighting enough for him"). In spite of working full-time and being a single mother, Amina frequently volunteered in Bilal's classroom. As a scientist, she particularly liked to bring her professional knowledge to the school. "I'm going in this Thursday to do three experiments: elephant toothpaste, a volcano, and Coke and Mentos" she mentioned in one interview. Amina's emphasis on parent participation in special education is very much in-keeping with middle-class American values (Harry, 2008; Olivos, Gallagher & Aguilar, 2010; Turnbull & Turnbull, 2001).

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

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

Midway through the study, Aadan became eligible for applied behavior analysis (ABA) services instead of the traditional/eclectic EI services he had been receiving. Nadifa assessed: "[the ABA] was very helpful. More helpful than the [traditional] early intervention ... it's longer, and they were really focusing, how to improve his speech, they were very well

rounded.” Nadifa, who had two older children with autism was particularly aware of the importance of him learning as much as possible at a young age. And based on the gains that she saw Aadan making in his ABA sessions, she felt that this was the best path for her son. Nadifa’s comments reveal a thoughtful understanding of her son’s educational program. Kim’s belief that Nadifa would not want to be involved in the EI sessions coupled with Nadifa’s own reluctance to partake resulted in fractured communication and arguably a less-than-optimal EI experience for Aadan.

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

Theme Three: Diversity and Agency Among Mothers

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

Diverse Trajectories

International migration trajectories can have complex influences on an individual or family and can reveal the way in which SES is, in fact, a fluid and multifaceted rather than static identity marker. Amina, for example, grew up in an aristocratic Mogadishu family: “Like I remember having like nannies and chefs ... and the chef was like ‘What does the princess want today?’” She described the decline in terms of wealth and status that her family experienced when they resettled in Canada. It was hardest on her mother, who “left everything behind.” In spite of having very limited material resources, the family brought with them a strong belief in the importance of education and the prospect that their children and grandchildren would be highly educated and professionally successful: “My mom said that [she would] pay whatever it takes for tutors and things like that.” Amina’s story is helpful in decoupling economic from the social and educational capital. It reminds us that thinking of SES as an indivisible unit is not very useful in understanding people’s lived experiences.

Saida's story shares elements with Amina's. Unlike the other two families in this study, Saida did not come to North America with refugee status. At the time the Civil War started in Somalia, she had already been living in Scandinavia as a student. Her husband (also Somali) was already a U.S. citizen and was able to sponsor Saida and their sons when they decided to come to the U.S. to access autism education and treatment resources for newly diagnosed Dris.

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

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

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

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

Networking and Advocacy

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

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

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

Someone who Speaks "legalese"

Amina and Saida also used their networks to enlist educational advocates. Saida got the idea to hire an educational advocate from other parents at Hope. She was able to hire an advocate used by other families at the school who was already familiar with the nuances of the program. She had been offered a free lawyer from the non-profit organization *Advocates for Children*, but she worried that a free lawyer might not be as good, might not "come on time." And she felt like this meeting was simply too important for her to cut corners: "I don't have to think about money. But I have to think about what's good for him," she reflected. In this case, although Saida was living on a single—fairly modest—income, she had enough discretionary resources that she felt like she was able to decide to spend money on something that was very important to her. Amina's professional network produced a recommendation:

“I was just telling [one of my co-workers] ‘Oh my god, I have a huge IEP meeting coming up and I’m hyperventilating ... and I’m thinking of hiring an advocate. But I don’t even know how to go about it ... I don’t even have the money to pay the hundred and thirty dollars an hour.’ And [my colleague] was like: ‘My friend is an advocate, and she’s very affordable’.”

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

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

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

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

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

The Self-Appointed Advocate

Aadan’s family did not hire an advocate to attend his IEP meeting. However, Kim, the EI provider attended his IEP meeting. She described herself as “someone who’s not directly

involved and can step back and ask the right questions,” implying more neutrality, perhaps, than represented by a paid advocate who inherently has her clients’ (i.e., the parents’) interests in mind.

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

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

Access to Early Treatment and Intervention

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

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

2013), limited access to medical services in areas around refugee shelters and families' lack of English skills often prevent children from receiving timely diagnoses.

Conclusions

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

Implications for Practice

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

In the case of this study, targeted, honest questions would have revealed that Amina's ideas about working tirelessly to teach Bilal were not Somali ideas, but rather grounded in Amina's understanding of what it means to be a Black boy (with autism) in America. And closed ended questions for Nadifa (e.g., “Now that Aadan's been receiving two different types of services do you think one of them is more effective than the other?”; “Do you think that it is helpful when I come at the same time as the OT does, or would it work better for us to come at different times?”) might have signaled to her that it was truly ok to express a preference or share an observation and might have given her the scaffolding to do so as she navigated a foreign educational system.

At the outset of this study, we did not realize the complex ways in which the behaviors associated with autism interact with other identity categories including race, ethnicity, gender, and religion to produce experiences of marginalization. In analyzing interviews with mothers and teachers as well as through observations of educational planning meetings, it became clear that the ideal of truly embracing neurodiversity and de-stigmatizing the behavioral differences associated with autism may not—at least not in this time and place—be equally accessible to all people with autism. As Amina articulated so clearly, being a Black boy in America carries with it a particular burden where any instances of behavior that deviate from the norm become particularly problematic. Interestingly, although all three of the educators in this study had lived their whole lives in the U.S., it was the mothers who quickly figured out—probably out of necessity—what it means to raise a Black boy in America.

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

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

Limitations

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

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Endnotes

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

Research Article

Strengths and Challenges: A Young Adult Pictures FASD Through Photovoice

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Abstract: We initiated an individual case study with one young adult in Canada about everyday life with Fetal Alcohol Spectrum Disorder (FASD). Using Photovoice, we explored his experiences through photography and interviews. Findings highlight his multi-faceted identity based around ability and challenge negative stereotypes. The study supports Photovoice as a strategy to explore FASD experiences.

Keywords: FASD; Photovoice; qualitative research

What is it like to be a young adult living with Fetal Alcohol Spectrum Disorder (FASD)? Despite evidence that exposure to alcohol while in utero can have profound, lasting effects, the life experiences of young adults diagnosed with FASD have largely gone unexplored in research and more broadly. Previously referred to as fetal alcohol syndrome, FASD is the current umbrella term for three alcohol-related neurodevelopmental disorders: FASD with specific facial features, FASD without specific facial features, and Risk for FASD (Cook et al., 2016), each of which manifests as distinct combinations of biological, intellectual, and behavioral outcomes. Research supports that individuals experience diverse fetal alcohol effects, including characteristic facial features, intellectual disabilities, and/or behavioral anomalies (Cook et al., 2016). Therefore, outcomes and severity are variable, and individual experiences and support needs differ. It is thus crucial to recognize the subjective realities of individuals living with FASD, and avoid characterizing this spectrum diagnosis in a universal way.

Through an individual case study, we explored the experiences of a young adult with FASD using in-depth interviews and photography. Our aim was to understand FASD experiences during young adulthood because this life stage is a critical time for many individuals living with FASD, some of whom will age out of care, have fewer supports, and face increasingly negative stereotypes (Chatterley-Gonzalez, 2010; Dej, 2011; Salmon & Buetow, 2012). In addition, this life stage is largely absent from existing research. As such, we investigated the role of FASD in the transition to young adulthood, and self-identity relative to the condition. This specific focus reflects the interests of the research team - an education scholar, a sociologist, and two nurse researchers - that include self-identity, family systems, education, and health care.

The interview and photographic data generated insights into the process of identity

formation and how Nathan¹ negotiated FASD alongside other facets of identity. While the experiences described here are unique to this individual, the findings highlight processes that might be shared by young people living with FASD or similar conditions. In addition to offering valuable information about his lived experiences of FASD, the findings challenge negative characterizations of those affected by fetal alcohol exposure that permeate the socio-cultural landscape. Thus, we seek to stimulate dialogue and confront stigma surrounding this spectrum diagnosis with hopes of expanding how individuals with FASD are understood and supported.

Background

In 2012, over 1.5 million women in Canada participated in heavy drinking (Statistics Canada, 2016), suggesting that risk for fetal alcohol exposure is relatively widespread within the Canadian context. FASD prevalence is reported to be approximately 0.9% of the population in Canada, with indications that the rate is likely higher in reality (FASD Support Network of Saskatchewan, 2015). A recent report from Alberta estimated prevalence to be somewhat higher at 11.7 per 1000 people, with occurrence being consistently higher in males (Thanh et al., 2014). Comparable rates are reported in the United States, with wide variations across regions that might be due to differences in incidence or measurement (Hedwig, 2013). Regardless of variations in prevalence, these statistics emphasize that a significant segment of the Canadian and American populations live with FASD.

However, subjective experiences of FASD have been under-researched, with greater attention given to devising and evaluating prevention programs (Badry & Wight Felske, 2013; Hanson & Jensen, 2015). Studies about individual perspectives largely pertain to caregivers and health care and service providers' views of children with FASD, service delivery, and treatment (Green et al., 2014; Hedwig, 2013; Michaud & Temple, 2013). Meanwhile, research about those with FASD typically employs quantitative surveys or standardized tools (McLachlan, Roesch, Viljoen, & Douglas, 2014; Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004), omitting subjective experiences. The scant research that incorporates the voices of those with FASD focuses primarily on young people in school settings (Duquette & Stodel, 2005; Duquette, Stodel, Fullarton, & Hagglund, 2006; Ryan & Ferguson, 2006), with only a few exploring young adults' experiences (Duquette & Orders, 2013; McGregor, 2011; Rutman & Van Bibber, 2010; Salmon & Buetow, 2012).

Within this small body of literature, some studies document positive outcomes for those with FASD, despite overwhelming attention to negative issues. For example, Duquette and colleagues' research is quite unique in exploring persistence and success in high school and post-secondary experiences of young people with FASD. Their findings indicate that parental support and advocacy and peer support facilitate young people's success in educational endeavors (Duquette & Orders, 2013; Duquette & Stodel, 2005; Duquette et al., 2006), thus highlighting achievements. Another study examined the accomplishments of parents with FASD, describing successes related to: providing care, developing bonds, and finding strategies to meet their children's care needs (Rutman & Van Bibber, 2010). Evidence

is also given of support needs stemming from primary effects of FASD, such as issues with “memory and organization; perseveration; planning; generalizing from one situation to another... and impulsivity,” and secondary effects associated with substance use, deficiencies in support, problematic relationships, and poverty (p. 356). Accordingly, positive aspects of everyday parenting are somewhat overshadowed by discussion of numerous challenges. Therefore, despite some identification of positive outcomes, the overwhelming tendency in existing research has been to describe negative aspects, such as daily challenges and struggles (McGregor, 2011; Salmon & Buetow, 2012), adverse life outcomes (Streissguth et al., 2004), and unmet support needs (Ryan & Ferguson, 2006).

Beyond outcomes of FASD, some research has investigated intellectual disability experiences relative to self-identity and conceptions of self. Despite providing initial insights into this topic, studies about FASD and those more broadly focused on intellectual disabilities report inconsistent findings. Specifically, some research reveals that young people commonly conceptualize themselves as different. For instance, findings of one study of youth with FASD indicate that “feeling different than other children” was the essence of their experiences (Stade et al., 2011, p. e481). Another study about adolescents with various intellectual and developmental disabilities elicited their understandings of disability labels and self-perceptions (Jones, 2012), revealing that disability was frequently described in terms of social exclusion and limitations reflective of a deficit model (i.e., focus on what is lacking). Accordingly, feelings of difference were framed in negative terms, without much recognition of corresponding strengths.

However, evidence also exists that young people with FASD or other intellectual disabilities identify themselves as comparable to others their age, at least to some extent. A study about friendship experiences of young people aged 16 to 20 years with FASD suggests that both feeling different than and similar to others was common (Copeland, 2001). Another study about young adults’ understandings of prenatal alcohol exposure reports that they felt ‘pretty normal’ at times in their youth, although this perceived normalcy was disrupted by struggles as they grew older (McGregor, 2011). Thus, young people with FASD express perceptions of both difference and similarity.

Additional insight into identity formation emerges from research about youth with learning difficulties or intellectual impairments; participants described seeking to resist labels that emphasize difference, preferring instead to view themselves as ‘ordinary’ (Albjornslett, Helseth, & Engelsrud, 2014). Consequently, they wanted to shed disability labels and adapt to their unique situation. However, the researchers note that participants perceived social-structural and cultural barriers that reinforced their ‘disabling’ condition. Although young people might adopt positive identities, dominant socio-cultural constructions of disability can make this difficult. Individual experiences must therefore be examined within historical, cultural, and social contexts because constructions of FASD shape social interactions and opportunities.

In Canada, FASD has historically been characterized in terms of class- and race-based

stereotypes, often linked with poverty and labelled as an ‘Aboriginal problem’ (Chatterley-Gonzalez, 2010; Dej, 2011; Tait, 2007). Such constructions reflect medicalization of segments of the population who have been deemed problematic (Tait, 2007), and imply that FASD is a concern for only certain social classes and racialized groups. Such constructions influence who is assessed for and diagnosed with FASD, and their social treatment. In contemporary society, adults with FASD are particularly ostracized and receive less sympathy than younger people; children with FASD are framed as victims not responsible for the condition, while adults are labelled as deviants who lack potential and thus end up in the criminal justice system (Dej, 2011). Such stereotypes perpetuate belief that adults with FASD are a burden to society (Tait, 2007), leading to stigmatization and marginalization. While some efforts have been made to promote more accurate depictions of those with FASD, negative constructions remain a powerful influence on how this population is perceived and treated by others (Rutman & Van Bibber, 2010; Salmon & Buetow, 2012), resulting in exclusion and limited opportunities for social participation. These constructions can also shape individuals’ self-identity and outlook on life in a variety of ways; however, research has rarely examined the FASD label relative to self-identity (Rutman, 2013).

In summary, young adults’ experiences of FASD are largely absent from existing research, and there is a particular gap in understanding how these individuals navigate the implications of FASD in everyday life. This research makes an initial contribution by focusing on a young adult’s experiences of FASD and his self-perceptions. Given predominantly negative stereotypes of individuals with FASD and adults particularly, this case study challenges their stigmatization and reveals the multi-faceted nature of self-identity for those living with this spectrum diagnosis.

Theoretical Framework

This research was informed by Symbolic Interactionism, emerging from sociology, and Critical Disabilities Studies (Davis, 2006). Proponents of Symbolic Interactionism propose that meaning is attributed to experiences through interaction and engagement with broader aspects of society (Steckley, 2014), thus being socially generated. Regarding self-identity, Goffman (1963) argues that societies produce categories of normality and abnormality that influence social relations and construction of self-identity. Accordingly, individuals develop a sense of self through social interaction, conceptualizing themselves based on how they think others perceive them (Mead, 1964/1934, as cited in Germov & Hornosty, 2012, p. 192). Individuals who possess attributes deemed abnormal can encounter stigma that discredits them from their own and others’ perspectives (Goffman, 1963).

We therefore explored the subjective experiences and meanings of an individual living with FASD to gain insight into the negotiation of the FASD label relative to self-identity. Existing theorizing and research suggests that a disability label tends to dominate individuals’ self-identity because of powerful social connotations and associated stigma (Zola, 2003).

Such labels are deemed a ‘master status’ that overshadows other facets of identity (Hughes, 1945, as cited in Steckley, 2014). Consequently, a master status can affect everyday life by influencing self-perception and how an individual is perceived and treated by others. However, some individuals might work to conceal or overcome their stigmatized status, projecting a socially acceptable self-identity. As such, identity formation involves negotiation, and possible acceptance or resistance, of labels arising from diagnosis of disability. However, research has not elaborated such negotiation relative to FASD.

Additionally, our research incorporates a social constructionist model of disability according to the Critical Disabilities Studies literature (Davis, 2006). Supporters of this model address the social roots of disability, and connect so-called inabilities to barriers within social and physical environments. Accordingly, we recognize that the ‘disability’ label generates stigma and resultant barriers for individuals to whom it has been applied, rather than true inabilities. Thus, the social constructionist model reveals disabling qualities of social and physical environments, as opposed to individual traits (Davis, 2006). Furthermore, researchers adopting this model critique the concept of ‘normality’ and a normal-abnormal dichotomy, with recognition of ‘disability’ as a social process arriving with institutionalization (Davis, 2006). Therefore, physical and social environments are disabling when they do not accommodate a range of capabilities, despite wide variations in ability regardless of whether labelled as ‘abnormal.’ Accommodations made through physical and social environmental modifications, including shifts in societal characterizations of conditions, can remove barriers to social participation and inclusivity.

Nonetheless, recognition is also important of the embodied nature of disability via the impairments that individuals experience (i.e., cognitive, psychological, mobility, or sensory issues) (Shildrick, 2009; Coleman-Fountain & McLaughlin, 2012). This line of theorizing purports that impairments cannot necessarily be overcome through social-environmental accommodations, regardless of how they are characterized. Accordingly, we adopt a position that acknowledges embodied realities of impairment along with a social constructionist model of disability. Through this lens, we examine the everyday experiences of FASD for one young adult, his negotiation of impairment in daily life, and how social interactions and constructions of FASD shape his self-identity.

Method

Given limited attention to FASD experiences, a qualitative approach is suitable for accessing the unique realities of individuals and their subjective meanings (Merriam, 1998). Qualitative research generates information beyond that already known, thus furthering knowledge (Merriam, 1998). Aiming for rich data emerging from a small number of cases, even a single case can be studied qualitatively using multiple methods to gain holistic understanding of experiences and context (Boblin, Ireland, Kirkpatrick, & Robertson, 2013). Accordingly, we adopted a qualitative Photovoice methodology to explore a young adult’s life with FASD.

Photovoice is a participatory approach that privileges the voices of participants through participant-employed photography and individual or group interviews (Wang, 1999). Participants are engaged as experts on their lives and, through photography and verbal explanations, share what they believe is important, thus generating new understandings. Developed as a health promotion approach, Photovoice is flexible and adaptable to diverse populations (Wang, 1999), including youth (Vaughn, Rojas-Guylar, & Howell, 2008), and has been modified to study experiences of illness and embodiment due to its participatory, empowering nature and capacity for generating in-depth data (Burles & Thomas, 2014). For this study, the modified Photovoice approach involved completion of interviews and the photography project on an individual basis, rather than on a group basis.

An outcome of the photographic component is increased participant involvement in data generation and analysis. Participants determine the focus of their photographs and assign meanings during interviews, rather than being “passive subjects of other people’s intentions and images” (Wang & Burris, 1997, p. 371). Furthermore, participants capture photographs when they wish, outside the confines of research meetings, thus generating more authentic understandings of everyday life (Jurkowski, 2008). Additionally, participant-employed photography prompts heightened reflection because individuals must think about what to convey via their images (Burles & Thomas, 2014). Therefore, this approach can generate rich insights into subjective experiences and engage participants on an equitable level, producing participant-driven data reflective of lived realities rather than dominant constructions (Wang, 1999).

A Photovoice approach also promotes multiple forms of expression, which is beneficial because words cannot necessarily capture all aspects of experience (Guillemin & Drew, 2010). Visual expression can have advantages when completing research with populations who face communication challenges, such as individuals with language difficulties or intellectual or developmental disabilities (Jurkowski, 2008; O’Brien et al., 2009). Accordingly, participant-employed photography was deemed to have potential for capturing aspects of FASD that might elude verbal description. Additionally, Photovoice is reportedly effective in research involving individuals with intellectual disabilities because of the possibility of increasing involvement, pride, confidence, and empowerment, producing a sense of ownership over data, and generating valuable insights (Jurkowski, 2008; Ottomann & Crosbie, 2013; Povee, Bishops, & Roberts, 2013). Foremost, Photovoice offers participants with intellectual disabilities a voice and the opportunity to challenge stereotypes of disability, thus yielding transformative outcomes (Fudge Schormans, 2013). We therefore incorporated Photovoice to enhance the richness of data and meaningfulness of the research.

Recruitment & Data Collection

Upon ethical approval from a university research ethics board, we sought participants through advertisements at a local support organization and word-of-mouth. The target population was young adults, aged 18 years and older, with an FASD diagnosis who were willing to share personal experiences in interviews and Photovoice project. We also wanted to

include family members or support persons of young adults, if possible. We aimed to recruit a few individuals with whom we could pilot test our modified Photovoice approach to determine suitability for a larger study. One young man and his parents expressed interest and were enrolled in the study. This article focuses on findings emerging from the data generated with the young man, while other aspects are discussed elsewhere (Brenna, Burles, Holtslander, & Bocking, 2017).

Two members of the research team, a sociologist and nurse researcher, met with the family, first explaining the study aims, exploratory nature, and what participation involved. Next, we discussed ethical considerations, including the voluntary nature of participation and possibility of withdrawal, confidentiality, and knowledge dissemination. Once written consent was obtained from all participants, two separate audio-recorded interviews were performed; the first author interviewed the young adult in one room, and the second author talked with his parents in another room. Interviews involved open-ended questioning to elicit descriptions of FASD experiences from diagnosis to the present, which prompted participants to discuss life with this spectrum disorder in the past and at the present.

Following the interviews, the Photovoice project was explained, along with how to use the digital camera provided for taking photographs. We asked the young man to create images related to his experiences of FASD without specifying a focus, and suggested that any number of photographs could be generated but that he might aim for 4 to 12. We only requested that he refrain from including photographs of himself or others to ensure confidentiality, which might have influenced their content; specifically, the participant might have focused more on his relationships if this request had not been made.

The first author arranged a second meeting with the participant approximately two weeks later. This meeting involved an in-depth interview revolving around his photographs and follow-up questions. The digital images were uploaded onto a computer for viewing, and the participant was encouraged to select a photograph to begin with and control when to move on to a subsequent image. The researcher used an unstructured approach to interviewing the participant about the photographs, as the young adult took the lead by explaining each image and its relation to life with FASD. The participant generated six images and offered substantial commentary on the aspects of experience that they conveyed. When necessary, elaboration or clarification was requested. Once photographs had been viewed and discussed, the researcher asked follow-up questions about topics broached previously, which helped to confirm the researcher's understanding and interpretations. The participant was also asked whether there were any photographs not taken or topics not discussed. Once complete, interview recordings were transcribed verbatim, producing 34 pages of transcripts between the two interviews with many lengthy descriptions of the participant's life.

Data Analysis

Interview transcripts were analyzed using an inductive, thematic approach that included categorical and holistic analysis (Mason, 2003). First, preliminary readings of the data were performed to generate a holistic understanding of the participant's experiences.

Additional readings were then conducted regarding the literal and interpretive meanings of the data (Mason, 2003), attending to the concrete ideas expressed and interpreting what these revealed about life with FASD. To promote rigorous and unbiased findings, the first and third authors, a social scientist and a nurse researcher, performed separate analyses to identify emerging themes. We then met to discuss our impressions, debate differences in interpretation, and return to transcripts for context to ensure accuracy. These discussions generated a coding structure grounded in the data (Mason, 2003) that guided additional coding by the third author, resulting in a refined set of themes.

While analysis of visual data can be performed in various ways, we focused on the descriptions given by the participant. We reflected on what his explanation of each image revealed about his lived reality (e.g., specific strengths and challenges) and characterization of FASD. This analytic process prompted thematic categorization of images based on verbal descriptions, along with interpretation of how the meanings related to his holistic experiences. Although themes emerging from qualitative data are not generalizable, the rich data offer insight into this individual's experiences. Therefore, the findings foster holistic understanding of the participant's navigation of everyday life with FASD within his social context. We recognize that other individuals living with FASD might face unique impairments and variations in context, support, and resources; however, insights gained from this case study can increase awareness of experiences that might be shared by others and inform supportive practices (Boblin et al., 2013).

Results

The emerging themes revealed aspects of the participant's transition to young adulthood and formation of self-identity. These processes involved: recognizing strengths and challenges, seeking independence while maintaining support, reconciling FASD with a desire to fit in, and developing resilience and putting challenges in perspective. Nathan was negotiating FASD relative to self-identity, and his words and images emphasize that this diagnosis was one dimension rather than entirely defining him. Recognizing benefits and detriments, the FASD label existed alongside other facets of who he was and aspired to be. His self-awareness and adaptability highlight Nathan's resilience and efforts to move beyond negative characterizations of FASD to see his capabilities and future possibilities.

Recognizing Strengths and Challenges

Nathan demonstrated profound awareness of areas in which he thrived, and those that were challenging. He recalled subjects and activities with which he struggled during secondary school: "I'm not good at numbers or writing things down or anything like that." He elaborated on these perceived deficits when explaining an image of a pen and paper (Figure 1), noting that, along with mathematics, neat printing and productive typing took significant

effort. He also described reading difficulties relative to an image of an open book (Figure 2), indicating that he typically read slowly and was unfamiliar with certain words.

Figure 1. Pen and Paper

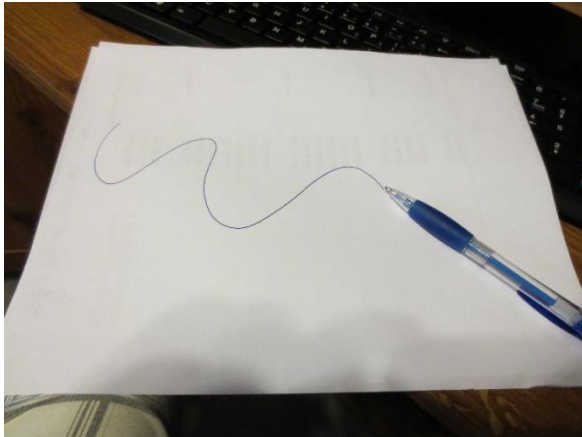


Image Description: This photograph is of a pen with a single wavy line drawn horizontally across a piece of paper, which Nathan described relative to difficulties with writing and similar tasks.

Figure 2. A Book

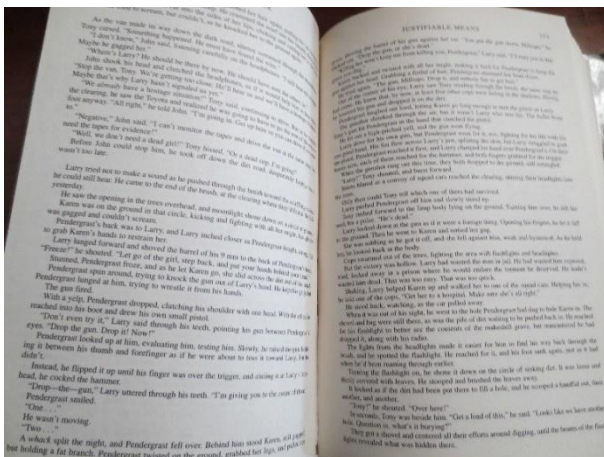


Image Description: This photograph shows an open book with pages filled with text, which Nathan used to represent challenges with reading.

Although he connected these deficits to FASD, Nathan believed that he could improve in these areas with greater effort. Furthermore, he framed some weaknesses in terms of disinterest, linking challenges to dislike of certain activities:

“Because I don’t want to be some accountant or anything like that, that’s not what I want to do, so it’s really good that I don’t have, I’m not strong in these subjects where I don’t want to be strong, I really don’t care, it doesn’t matter.”

Thus, Nathan viewed deficits as resulting from lack of effort, rather than in terms of disability. Consequently, perceived weaknesses were reconciled with his conceptualization of self and aspirations.

Alongside challenges, Nathan highlighted areas in which he excelled: “Those are my strengths that I do believe that FAS gave to me. Being able to observe and adapt quickly to things, and being able to work with my hands.” To illustrate strengths, Nathan shared two photographs. One depicted a screwdriver (Figure 3), conveying his ability to perform activities related to construction work. The second portrayed a theatre program in which he was featured (not shown), reflecting his acting prowess. Nathan explained how his adaptability was beneficial to acting, and that passion for it prompted him to find strategies to overcome challenging aspects, such as learning the script. For instance, he found singing lines assisted with memory, as did physical movement during rehearsal. Nathan also noted strength in visual learning and communication: “I always get pictures in my head and stuff like that... and I can really visualize what the character might look like.” Accordingly, Nathan’s words and images demonstrate recognition of strengths alongside challenges, and a self-identity founded on abilities rather than deficits.

Figure 3. Screwdriver



Image Description: This photograph is of a screwdriver with a yellow handle, which Nathan discussed relative to his ability to work with his hands and preference for active pursuits.

a Desire to Fit In

Throughout the interviews, Nathan described negotiating the FASD label in interactions with peers. Foremost, he emphasized not viewing himself as different or wanting others to see him as such. Calling himself a “normal kid,” he believed his challenges were comparable to those of others. Regarding his secondary school years, Nathan recalled that his diagnosis was not widely known: “Cause it’s not like any of the students or anyone knew, and [the teachers] didn’t make it clear. It was just me and the teachers and they wanted to help.” He reflected on disclosure to others, stating that he told only close friends who reportedly perceived him as normal and did not discuss it further.

Despite not feeling different or that others perceived him as dissimilar, Nathan recalled actively seeking acceptance by trying to fit in with peers. He described observing the behavior of those around him to use as a model, drawing upon his acting skills to present himself as similar. However, while in secondary school, he explained that he “started trying to do

Reconciling the FASD Label with

whatever to fit in,” referring to times when he acted out to gain peer acceptance. Thus, his desire to fit in sometimes led to behavior that he knew was inappropriate. Nathan also suggested that he gravitated toward ‘bad kids’ because of shared experiences of challenges. This example highlights Nathan’s awareness of friendship choices and the influence of his desire for acceptance from peers. While this might signal unconscious feelings of difference, it also suggests self-awareness related to acceptance and belonging.

Balancing Independence and Support

Another aspect of the transition to young adulthood and formation of self-identity involved negotiating independence alongside support from family and others. Nathan described challenges experienced during secondary school arising from wishes for autonomy: “From grade 8 to grade 11, that was like a really bad time for me and my family... ‘cause I acted out but, like I said, I just wanted to be independent.” Thus, he became resistant to his parents’ efforts to interject themselves into his daily activities. However, he has since realized that their assistance was crucial to navigating this difficult period: “My mom and dad, they never gave up. They always wanted to find help and everything like that, but I didn’t appreciate that.” Accordingly, he currently recognizes the significance of parental support to learning to cope with FASD-related challenges while pursuing education and extracurricular interests. Nathan further emphasized: “Support is something that definitely is positive and essential to FAS.”

Nathan also discussed wanting to strike a balance between independence and support as a young adult. He acknowledged difficulties with certain tasks, such as some forms of reading, writing and math, and continued to live with his family. He expressed appreciation of parental support with managing financial responsibilities and tasks like filing taxes, despite an immense wish for more independence. Nathan worked part time while pursuing acting in hopes of becoming financially independent. Reflecting on the transition to young adulthood and increasing independence, he expressed: “At the same time, doing stuff on my own excites me and scares me.” This statement highlights his feelings of anticipation and trepidation regarding the prospect of relying less on family. Thus, Nathan was amidst a process of striking balance between accepting assistance and managing independently.

Resilience and Putting Challenges in Perspective

Nathan conveyed understanding of how fetal alcohol exposure has affected him, contributing to deficits and unique abilities. He explained his attitude to life relative to one photograph (Figure 4): “This is of a *Life* cereal box, ‘cause when you have FAS, life is the hardest thing because you’re living it, and my life had its ups and downs.” Here, Nathan reveals the variable nature of FASD, noting both good and bad aspects that arise in day-to-day life. He expanded further when asked about advice for others: “Never think, ‘Oh, the FAS is 110% evil’ or something. It’s like, no, there’s bit of good [too].” This comment conveys Nathan’s understanding of FASD as having positive and negative outcomes. Consequently, despite facing FASD-related challenges, he demonstrated resilience by putting them in

perspective. When he encounters difficulties related to FASD (and Attention Deficit Disorder), he revealed: “If it comes up, I deal with it, then I go on living life because that’s, you never just give up or anything like that.” These words highlight Nathan’s coping ability and desire to avoid letting challenges defeat him.

Figure 4. “Life”



Image Description: This photograph is of a box of “Life” cereal, which Nathan used to highlight his approach to living with FASD.

He also discussed coping strategies relative to a photograph of running shoes (Figure 5):

“Every time I’m feeling stressed or overwhelmed, going outside and going for walks and doing anything active really helps a lot. It calms me down and everything, if I get frustrated, it’s a great stress reliever... the outdoors and everything like that [are] a good escape for me.”

Here, he expresses optimism and an interest in identifying ways to persevere through struggles. This resilience was evident at other times, but was especially notable in his management of reading difficulties when learning new lines for a theatre production; his passion for acting motivated his efforts and adaptation to deficits. Nathan summarized his outlook: “It’s always a good thing to find the motivation behind what you’re doing.”

Figure 5. Running Shoes



Image Description: This photograph is of Nathan's white running shoes, which have faint stains from being worn outside. Nathan explained that these shoes represent how he copes with emotions.

Discussion

The findings provide insight into the experiences of this young adult with FASD. The rich data obtained via Photovoice enable understanding of Nathan's life and his formation of self-identity that includes the FASD diagnosis alongside other facets. His experiences offer evidence of the ongoing negotiation of fetal alcohol effects and FASD label whilst encountering life events typical of young adulthood, such as establishing independence, making decisions about education and work, and establishing meaningful relationships. Recognition of strengths and challenges enabled Nathan to develop coping strategies and accept support with some tasks. While independence and acceptance were desired, Nathan forged a self-identity encompassing diverse abilities that allowed him to put challenges in perspective and resist the FASD label becoming his 'master status.' The themes, as depicted in Figure 6, reflect interconnected psychosocial processes that are related to the development of resilience.

Figure 6. Overview of Themes

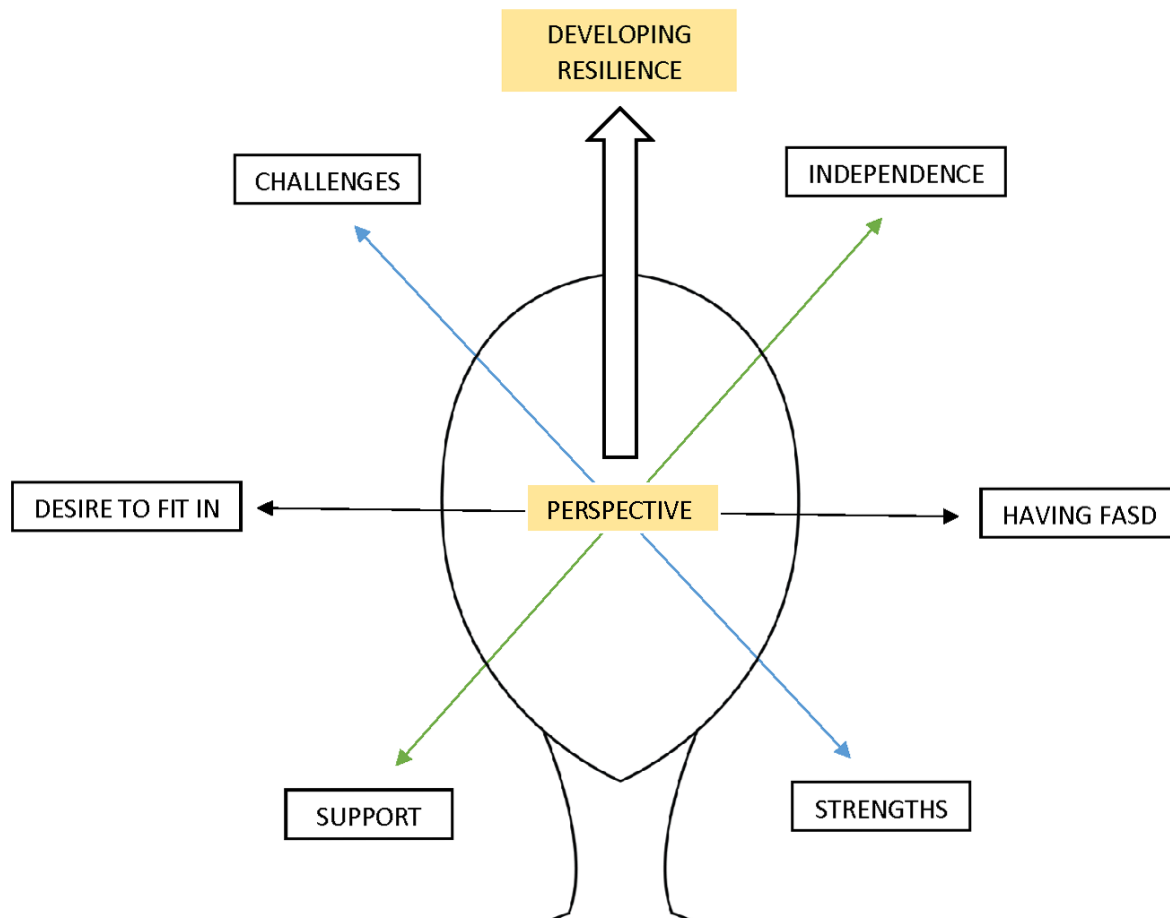


Image Description: This figure depicts the first three themes organized on axes around an outline of a face, which intersect at the word “perspective.” An arrow points upward from “perspective” to the words “developing resilience,” highlighting how putting difficulties in perspective contributed to resilience. Other arrows pointing out from “perspective” are challenges, desire to fit it, support, strengths, having FASD, and independence.

Within existing literature, the overwhelming focus is on negative outcomes associated with FASD (Salmon & Buetow, 2012; Streissguth et al., 2004). Such studies neglect recognition of positive aspects, reinforcing stigmatization of individuals with FASD and their characterization as burdens to society (Dej, 2011; Tait, 2007). In juxtaposition, the photographic and interview data generated in this study reveal another side of FASD, and emphasize the importance of identifying social-environmental barriers that hinder those with diverse abilities. Although the participant faced challenges through his education and transition to young adulthood, he also encountered supports that helped foster resilience, self-awareness of strengths, coping strategies, and recognition of how much he could accomplish on his own and with support. This young adult thus identified many positive aspects of life and placed emphasis on abilities rather than difficulties.

FASD includes spectrum disorders with varying implications across individuals. There remains stigma surrounding FASD, and individuals with this label tend to be negatively characterized regardless of abilities. However, the findings illuminate that individuals living with FASD possess positive attributes and strengths, alongside deficits and support needs in some areas. Therefore, we critique negative conceptions of individuals with FASD, and emphasize the imperative to re-frame FASD in terms of both strengths and challenges. Attention to positive attributes can help individuals with FASD and others to recognize their unique abilities, alongside areas in which they struggle, and facilitate development of a self-identity that transcends stigmatizing stereotypes. For Nathan, support from family, educators, and theatre production members was pivotal to recognition of his abilities and perceived 'normality.' Accordingly, he conveyed hope for happiness and success despite certain fetal alcohol-related difficulties.

Nonetheless, we acknowledge that some impairments associated with FASD cannot be easily overcome, such as cognitive and memory issues due to fetal alcohol exposure. Although Nathan was optimistic, he acknowledged weaknesses stemming from FASD, which prompted him to develop resiliencies and put challenges into perspective. He related that coping strategies and support were crucial for success, as emphasized elsewhere (McGregor, 2009). Exercise and being outdoors were especially beneficial to coping with overwhelming feelings. Although this strategy might not be effective for everyone with FASD, it is an example of how solutions can be developed to manage challenges. Thus, rather than suggesting that individuals learn to overcome impairments, which might be unlikely, efforts should be focused on fostering self-awareness and providing appropriate supports and accommodations.

Our findings also offer insight into Nathan's negotiation of identity formation during his transition from teenager to young adult. Prior research largely focuses on youth and adolescents with FASD, and those studies that include young adults pay insufficient attention to successes and accomplishments. Therefore, our pilot study helps to narrow the gap in knowledge of young adults' experiences of FASD and navigation of this life stage. Similar to many young adults, Nathan faces changes in everyday life and decisions about the future. Much discussion revolved around efforts toward independence, such as seeking financial independence through work, considering career options, and establishing important relationships outside his family. Furthermore, Nathan was concerned with acceptance and not appearing different than peers. Accordingly, the transition to young adulthood involved reconciling FASD and associated challenges with other aspects of self-identity, arriving at a multi-faceted sense of self: weaknesses were put in perspective by recognizing that he was not alone in having diverse abilities. Therefore, this study offers understanding of processes related to identity formation for this young adult.

Conclusions

This case study is an initial step to addressing the paucity of research on young adults' experiences of FASD. While many studies adopt quantitative methods or report on negative outcomes more so than positive ones, our research adds a strengths-based approach to the literature. This research reveals the multi-faceted nature of individuals with FASD who possess various abilities and deficits like everyone. Consequently, this study challenges negative stereotypes and stigma surrounding FASD, seeking to shift public discourse away from a focus on disability toward one of possibility.

The research provides evidence of the optimism and hope that exist for individuals with FASD; specifically, Nathan was negotiating the transition to young adulthood and finding his path in life, a common experience at this age. His experiences reveal his navigation of interests, difficulties, and abilities, and incorporation of the FASD label into a multi-dimensional identity. Central to this process of self-discovery was striking a balance between independence with support. Further exploration of this transition could yield additional insights into best practices for supporting individuals with FASD through this process, and identify possibilities for flexible support interventions, given that individuals have unique abilities and support needs. We have begun to outline such implications for curriculum in educational contexts (Brenna et al., 2017), but further work is needed, particularly related to work contexts.

Support for populations with FASD is emphasized as critical in the literature (Duquette & Orders, 2013; Duquette et al., 2006; Rutman & Van Bibber, 2010; Ryan & Ferguson, 2006), and Nathan's words resonate clearly about how support has benefitted him. Specifically, support is crucial so that young people who bring their best abilities to school or work settings are not disadvantaged by negative perceptions of disability or social-structural factors. However, the tension that Nathan experienced between independence and support also highlights the importance of developing of coping strategies for managing challenges and enhancing relaxation in people with FASD. Thus, we advocate for the creation of a 'toolkit' of ideas that could assist young people like Nathan in selecting techniques to try when faced with particular challenges. Also, access to the life stories of individuals with FASD has potential to assist with motivation to seek personal solutions. Participatory action research is recommended for developing and evaluating such a toolkit, and for further generation of life stories that illustrate authentic situations reflective of individual and universal challenges and possibilities. Because of the evocative nature of the photographs in Nathan's communication with our research team, photographs or images connected to these stories might operate as classroom or workplace cues. For example, a photograph of a running shoe could be used to communicate the need for a 'body break' when words are complicated.

Finally, this case study highlights the potential of Photovoice for research with this population. Visual methods have been incorporated into previous studies with people with

intellectual disabilities, but none are about everyday experiences of FASD. Given the range of impairments resulting from fetal alcohol exposure, we cannot conclude that a visual approach is universally suitable; however, the successful use of participant-employed photography with this participant suggests Photovoice as a possibility for effective and inclusive data generation, offering insight into everyday life with FASD. Additionally, Photovoice has potential to inform creative, adaptable support interventions. Future research should continue exploration of the suitability of visual methods with a larger sample of individuals with diverse FASD experiences. Therefore, our research raises the immense possibilities that exist for visual research to promote greater understanding and acceptance of those living with FASD.

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Endnotes

1. The participant was assigned a pseudonym to protect his identity from public recognition.

Research Article

“Every Vote Matters:” Experiences of People with Intellectual and Developmental Disabilities in the 2016 United States General Election

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Abstract: This study explores the experiences of people with intellectual and developmental disabilities voting in the 2016 United States general election. Although the majority of participants voted, they still faced a number of barriers that point to larger problems with the United States’ election process and discrimination against people with disabilities.

Keywords: 2016 general election; people with intellectual and developmental disabilities; civic engagement

The United Nations General Assembly (2011) asserts “the right to vote is arguably the most important political right” (p. 4). Voting allows citizens to shape decisions that can indirectly and directly effect their quality of life (Agran, MacLean, & Andren, 2015). For this reason, Agran et al. (2015) call voting “the ultimate act of American citizenship” (p. 388).

Although election results can have many direct consequences for people with disabilities, historically they have been disenfranchised (Beckman, 2007). In the past, many people with disabilities in the United States were denied the right to vote because of a requirement of independence, a concept intertwined with ideas of competence and guardianship (Beckman, 2007). Even today, people with intellectual and developmental disabilities (IDD) and/or psychiatric disabilities are often denied voting rights based on restrictions at the state level (Beckman, 2014). As a result, the application of voting rights for people with IDD is inconsistent across the United States (Bell, McKay, & Phillips, 2001).

States can bar people with disabilities from voting based on ‘competence’ standards. This disenfranchisement occurs through four main methods: (1) the use of general guardianship status or a determination of general incapacity conferred by the court; (2) the court’s restriction of voting eligibility for specific individuals; (3) the application of outdated descriptors like “idiots” or “insane persons” to justify voting restrictions; or (4) the attribution of the status *non compos mentis* (i.e. not sane or in one’s right mind) as defined by individual states (Bazelon Center for, 2008, p. 6). As of 2016, 10 states barred voting by individuals under guardianship, 25 by a voting specific court determination, and four by *non compos mentis*. Eleven states had no disability-related restrictions (Bazelon Center for et al., 2016). People who lost the right to vote based on a state voter competence requirement may be able to challenge the requirement on the ground that it violates federal law. Laws that bar people who are ‘mentally incompetent’ or under guardianship from voting generally violate the Constitution and the Americans with Disabilities Act if they are used to take away a person’s

right to vote based on disability even if the person has the capacity to vote. These laws, however, typically require certain people—usually those who are the subject of guardianship proceedings—to meet standards that are not imposed on other voters. Probate courts in these states sometimes ask individuals who are the subject of guardianship proceedings to demonstrate an understanding of elections and politics that goes far beyond what is expected of the general public before they are permitted to vote (Bazon Center for, 2008, p. 12-13).

Recently, however, there has been state-by-state momentum to ensure people with IDD have voting rights (Bazon Center, 2008; 2012; Beckman, 2014; Bell, McKay, & Phillips, 2001). The voting rights of people with disabilities have changed over time through legislation and court decisions. For example, successful litigation against voting restrictions often uses arguments that competence ineligibility violates the Equal Protection and Due Process Clauses of the Fourteenth Amendment (Bazon Center for et al., 2016). The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act also bar discrimination against people with disabilities, including the denial of a citizen's right to vote. However, both the ADA and Section 504 "require an individualized assessment to determine if a person with a disability is qualified" (Bazon Center for et al., 2016, p. 8). Self-advocates have also been pushing to increase people with IDD's access to voting. Self Advocates Becoming Empowered (SABE), the largest self-advocacy group for and by people with IDD, spearheaded the Go Voter movement, providing training about voting for people with IDD and technical assistance to make voting accessible for everyone (Go Voter, n.d.). Further, the United Nations Convention of the Rights on Persons with Disabilities (CRPD) recently reaffirmed the right to vote for people with disabilities, including those with IDD (Beckman, 2014; Kjellberg & Hemmingsson, 2013). Unfortunately, even when people with IDD possess or secure the right to vote, doing so can still be difficult because of barriers. Large disparities exist between disabled and nondisabled people, with people with IDD having one of the largest voting gaps (Schur, Adya, & Kruse, 2013). According to the United States Election Assistance Commission, these disparities largely derive from barriers to access (Government Accountability Office, 2009; Schur, Adya, & Kruse, 2013). Of voters with IDD in the 2012 general election, approximately half reported polling place difficulties (Schur, Adya, & Kruse, 2013).

Various barriers may make voting difficult for people with IDD, or prevent them from voting altogether. With regards to physical barriers, people with IDD may have trouble getting to a polling place as transportation is a large need for people with disabilities (Agran et al., 2015; Bell et al., 2001; Belt, 2016; Schur et al., 2013). Not all polling places are physically accessible for people with IDD who use wheelchairs or mobility devices either (Schur et al., 2013). Moreover, without accessible materials people with IDD may have difficulties understanding ballots or voting machines because of their cognitive impairments (Agran et al., 2015; Bell et al., 2001; Keeley et al., 2008; Schur et al., 2013; Weiss, 1988). Attitudinal barriers may also negatively affect people with IDD's ability to vote. Service providers may not see voting as a priority for people with IDD because of low expectations about their abilities. However, research has found people of IDD are capable of making

informed decisions regarding voting (Agran & Hughes, 2013; Agran et al., 2015; Schriener et al., 2000).

Millions of people in the United States have intellectual and developmental disabilities (Boyle et al., 2011). They have the ability to be a powerful voting block that can direct attention to disability issues that affect millions of United States residents. Yet, people with IDD remain largely an untapped resource. For these reasons, this study aims to explore the experiences of people with IDD in the 2016 United States (U.S.) general election. The 2016 U.S. general election, noted for its heated presidential contest between Donald J. Trump (Republican) and Hillary R. Clinton (Democratic), was one of the most polarized U.S. elections to date (Huang et al., 2016). To reinforce that people with IDD are important constituents who are interested in and capable of engaging in the election system, our central intent was to explore people with IDD's engagement – both as citizens in anticipation of the voting process, and their ideology about the voting process in general – and to determine the barriers and facilitators to voting participation for people with IDD as they are key to expanding access and engagement of people with IDD. Rather than engaging in a discussion of which political ideology of people with IDD in the 2016 election, the subject of another study (see Friedman (2017), this manuscript focuses on the broader analytical points of this process, linking them to systems and attitudes.

Methods

Participants

This study took place in Chicago, Illinois. The location was beneficial for such an exploration of voting experiences because Chicago is complex and multifaceted, both in terms of the general climate and disability community. The study took place in urban environment in a left-leaning city but one that is located in a generally conservative state. Chicago is portrayed as a mix of liberal politics and 'midwestern sensibilities'; it is also very diverse yet very segregated. According to the 2000 census, approximately 23% of Chicagoans had a disability (Facts and Figures, n.d.). However, despite a longstanding and persistent disability rights and advocacy movement in Chicago, Illinois consistently ranks as one of the worst states for institutionalization of people with IDD (Braddock et al., 2015).

Participants were recruited via flyers, distributed through self-advocacy organizations, organizations that serve people with IDD, and the state protection and advocacy agency. Study information was also distributed through word of mouth. To participate, people needed to self-identify as having an intellectual and/or developmental disability, be 18 years old or older, and speak English. Participants received \$30 compensation to help pay for transportation and time.

Thirty-four people with IDD participated in this study; demographics are presented in Table 1. About three-quarters of participants ($n = 26$, 76.5%) voted in the 2016 general election. Most participants ($n = 24$, 70.6%) had voted in a government election prior to 2016.

Although participants were not asked about the severity of their impairments, as a proxy measure they were asked about some of the skills that can make civic engagement more challenging. The majority of participants (61.8%, $n = 21$) reported having trouble understanding complicated information; about half of the participants (47.1%, $n = 16$) also had trouble reading.

Table 1

Demographics ($n = 34$)		
	%	N
Age		
18 to 24	17.6	6
25 to 34	55.9	19
35 to 44	5.9	2
45 to 54	5.9	2
55 to 64	8.8	3
Gender Identity		
Man	64.7	22
Woman	32.4	11
Race		
Asian or Pacific Islander	5.9	2
Black or African American	26.5	9
Hispanic or Latinx	44.1	15
Middle Eastern	5.9	2
Native American or Indigenous	2.9	1
White	17.6	6
Other	5.9	2
Where do you live?		
Own home or apartment	8.8	3
With parents or family	61.8	21
With a foster family	2.9	1
In a group home	23.5	8
Guardianship		
Own guardian	44.1	15
Has legal guardian	52.9	18

Process

Focus groups were held three days after the 2016 general election, November 11, 2016. Participants first completed informed consent forms and surveys about demographics. While the majority did so independently, a portion of participants were supported by the research team or their support person, most often by having the items read aloud. They were then divided into four focus groups held simultaneously in separate rooms. A researcher with a doctorate in disability studies, Carli Friedman and three advanced doctoral students in disability studies facilitated the focus groups, which lasted approximately one to one and a

half hours. All facilitators had experience doing research with and/or working with people with IDD. The focus group questions especially focused on participants' experiences with voting the 2016 general election, including any barriers they may have faced trying to vote. Examples of topics and prompts included:

- For those of you that voted in the general election what did you like about voting?
- Were there any difficulties while trying to vote? If so, what were they?
- Based on what we just talked about and some of the things that were hard to do, what changes should be made to make it easier for people with disabilities to vote?
- How do you think we can get more people with disabilities to vote?

The facilitators did permit participants to bring support people (e.g., personal attendants, family, etc.) if they wanted (only a handful did so), but reminded support people of their role to only support the participants and not participate in the research.

Analysis

I analyzed demographic data using descriptive statistics. Focus group data were analyzed using thematic analysis (Braun & Clarke, 2006). First, the researcher listened to the audio recordings of the focus groups and read the verbatim transcripts becoming immersed in the data. The transcripts were then examined again for patterns; initial codes were generated based on these patterns. Codes were grouped into major and minor themes (described below) and revised when necessary.

Findings

Findings fell into three major themes: 1) Leading up to the election: decision making; 2) Participating in the election: barriers and supports; and 3) Future elections: the importance of voting.

Leading Up to the Election: Decision Making

Leading up to the 2016 general election, participants used a variety of different methods to gather information to make informed decisions when they voted. An overwhelming majority of participants watched the presidential debates for the general election. One participant acknowledged, "That's how I knew what to vote for, and then I saw the debates I was like 'okay, now I know who to vote for'. They really helped me to figure out who I want to vote for." In addition to watching the debates, other participants spoke with family and friends. Others used other media, such as newspapers, local news, and the radio. Social media also affected the decision making processes of participants. For example, a number of participants read the articles they found on their Facebook newsfeeds. Another participant explained YouTube helped him make a decision in the 2016 presidential election. He added, "YouTube...I was just scrolling down to see...There are some good videos about what...judging about Trump or Hillary and all that. I wasn't sure which one should I pick so that helped me a lot."

Participating in the Election: Barriers and Supports

Participants faced a number of barriers when trying to participate in the election process, though some were not necessarily disability specific. For example, a handful of participants experienced long lines when trying to vote. One participant noted their were “long lines, like unemployment.” Another general problem was the lack of information in languages other than English. Staff had to help a handful of participants translate some of the text into Spanish because although they spoke both English and Spanish, reading in English was difficult. However, the majority of the barriers faced by the participants with IDD were more specific to people with disabilities. A number of participants were unable to register to vote because they did not have state identification. In many states voters can register with other forms of identification, such as a birth certificate or a utility bill that includes name and address. People with IDD, however, are less likely to have access to these types of items, particularly if they live in a provider-managed group home.

Although the majority of participants found voting in the 2016 general election to be easy overall, they did note a number of basic accessibility barriers. One participant recommended, “Maybe if they had more places with wheelchair ramps that would make it easier for people with disabilities.” A group of participants who went to the polls together also mentioned a lack of signs, which made it difficult for them to locate their polling place. In addition to being more physically accessible, the participants also believed that a greater number of more conveniently located polling places with longer hours would facilitate voting for people with disabilities.

Despite a number of physical barriers, the majority of participants who used voting machines found them very easy to operate (e.g., “It was easy for me. It was the machine;” “I think it was pretty straightforward”). One participant even noted the machine made things more accessible for her. She explained the machine “was better” because “my hands shake. I have endpoint trembles [that make writing difficult].” Another complained that in comparison to the voting machines the paper versions of ballots can be difficult; the participant explained, paper ballots “sometimes can be a little confusing or hard. If I mess up I have to cross it out and get a new one.” Only two participants had trouble with the voting machines. One participant’s machine kept getting “stuck” and “breaking down,” while another had trouble because there was a lot of typing required.

Attitudinal barriers also played a role in the voting process of the participants in the 2016 general election. One participant had a negative interaction with the poll workers that were supposed to help him. He said, the poll workers “were giving us attitude. They were giving me and my stepmom attitude... I wanted to ask a question and they were giving me attitude. I was like, ‘I just wanted to ask a question.’” Ultimately, he decided not to ask his question because of the experience. Meanwhile, other participants described barriers that were both institutional and attitudinal. For example, one participant was unable to vote because his agency support staff did not bring him on Election Day or during early voting. Although he told his staff ahead of time that he wanted to vote and the organization was aware of his plans

to do so and agreed to facilitate, on the day of the election his group home staff did not drive him to his polling place. He explains, “They actually didn’t think it was important to me.” Although he believed voting was important “to make a change” when asked if this experience frustrated him he explained, “I didn’t think it would be nothing to be frustrated about” as if the problem was out of his hands. It is not uncommon for people with IDD to not be seen as experts about their own lives; for example, proxy research with family or staff instead of people with IDD themselves is still prominent in the IDD field. Undervaluing the knowledge and expertise of people with IDD, whether in research or in their personal decision making, is common, particularly when it comes to dignity of risk (Perske, 1972). However, people with IDD have unique experiences and understandings to which others many not have access; it is critical that staff and other support people recognize this moving forward.

Other participant comments also nodded to the idea that the reason many people with IDD do not vote is because of low expectations, that is they are not encouraged to vote because of the attitudes of the abilities of people with IDD. One participant noted, “They’re probably scared. Not scared but ‘look I don’t know if I can do it or not...It’s like ‘no try it, you know.’ That’s all that matters. You need to try and vote, that’s all that matters.”

In fact, with the right support, barriers were not a problem for participants and they voted successfully in the 2016 general election. Staff supported many of the participants in the study by helping them complete paperwork, finding the polling places, and getting to their polling places. For example, one participant said, “It was my first time voting and I wasn’t really registered. So I registered and voted. It was pretty cool. They [staff] were really good at explaining it. It was really cool.” Another participant noted, “If you can’t use your hands to vote, you can tell your staff to help you. Do you see what I mean? Making it for people to make it more easier for them to vote.” A number of other participants also went voting with their family members such as one participant who recounted, “When I went to the library [to vote] I had to put a card in [the voting machine]. I didn’t have no problem with mine, no problem whatsoever. She [my sister] helped me, and I thanked her for helping me”

Future Elections: The Importance of Voting

Participants agreed it is important to continue to vote in future elections. One participant instructed, “You have the right to vote, and you’re supposed to vote. If you don’t vote, your vote won’t count.” Another participant proclaimed, “Spread the word so lots of people with disabilities can be like your vote matters. It will matter. Or it does matter.” In addition to announcing the importance of voting, participants also went on to discuss why this is the case. Participants recognized voting as a mechanism to voice their opinions, captured in statements such as: “We have the right to speak!”; “You can get your voice”; and “You ain’t voting for who somebody else told you to vote. You vote because you want to vote.” They also recognized the role voting plays in shaping the government. As one participant explained, “[People] just need to get out there and vote for who they believe in. Who they feel would make the country stronger.” Another conceded, “We don’t want the president to suck...I didn’t want to vote at first but I said ‘You know what? I’m going to vote because every vote

matters. You don't be missing the vote.'" Participants also recognized that the election's victor would impact the issues they care about as well as them directly. Many discussed key issues such as services and supports, domestic violence, and international relations as factors that determined who they voted for in the 2016 presidential election (see Friedman (2017)).

Discussion

With the proper supports, people with IDD are willing and able to participate in the voting process. Participants with IDD in our study actively engaged with the 2016 U.S. general election. They watched the debates, they spoke with their families and friends, and they researched candidates via new and old media. In other words, they participated in very similar ways as the general population. The participants also understood the impact the election could have on both their lives personally and the larger direction of the country.

The majority of participants had few problems when voting in the 2016 general election. However, parallel with previous research (e.g., Agran et al., 2015; Bell et al., 2001; Keeley et al., 2008; Schur et al., 2013; Weiss, 1988), people with IDD faced accessibility barriers in the 2016 general election. Some of these barriers point to larger problems with the U.S. election process, such as long wait times or a lack of non-English language information, while others specifically relate to inaccessibility and discrimination against people with disabilities. Although the majority of participants did not have trouble with the voting machines or the voting itself, attitudes, both individual and institutional, served as barriers for some participants. Support professionals and organizations that serve people with disabilities either have the ability to facilitate election participation of people with IDD or serve as gatekeepers that make voting more difficult. In fact, research has found that organizations can play a key role in increasing people with disabilities' ability to exercise voting rights (Friedman & Rizzolo, 2017). As shown in this study, for many people with IDD, the ability to vote may hinge on the organization's commitment to bringing them to the polls. Unfortunately, because of societal attitudes about people with IDD, organizations and direct support professionals may not recognize that people with IDD are not only capable of voting but also are interested in doing so. Historically, the voting rights of people with disabilities were denied because of competence. Prior to suffrage women were denied the right to vote under similar pretenses (Baynton, 2001). However, suffragettes reinforced people with disabilities' exclusion in order to win the right to vote, arguing, "They [women] were not disabled...and therefore were not proper subjects for discrimination" (Baynton, 2001, p. 34).

IDD's etiology is and always has been intertwined with ideas of competence. Early constructions of IDD in the United States were tied to "a failure of the will" (Trent, 1994, p. 16). As a result, IDD was not only pathologized but also people with IDD were institutionalized and later sterilized (Trent, 1994). While today there are more complex understandings of people with IDD, the devaluation of people with IDD is still explicitly and implicitly evident in the ways that persons with IDD are characterized and discussed (Carlson, 2010). Such constructions and their overwhelming emphasis on impairment "give rise to

further discourses of *personal pathology*, of *individual difficulties* and of *dependency* in the face of *care* (Goodley, 1997, p. 369).

These stereotypes regarding the presumed competence of people with disabilities carry forward even today as many states deny voting rights based on ‘competence’ standards (Bell et al, 2001). One self-advocate explains, people:

“Quickly assume that people [with IDD] don’t have the capacity to understand or know what’s happening in their lives, or somebody has to help them, or somebody has to explain it. And that’s not the case. Sometimes that kind of thinking gets you riled up. We are always needing to explain to people that people are capable. You know, most other disabilities, people look at people as, ‘Oh, look what they can do, that’s wonderful. Oh.’ They sort of get amazed. You say a [intellectual or] developmental disability and, ‘Oh! There’s something wrong, or that’s dangerous’” (Caldwell, 2011, p. 319).

Thus, it is not enough for organizational structures to be changed or physical barriers to be addressed. Stereotypes about the abilities and interests of people with IDD need also to be dismantled in order for more people with IDD to have the ability to exercise their voting rights. As their effects can trickle down to smaller acts such as voting participation, more attention to systemic barriers is also needed, not only regarding competence (and by extension guardianship) but also community integration. Although deinstitutionalization of people with IDD has reached an all-time high, for many people with IDD community integration is still rare (Braddock et al., 2015; Friedman & Spassiani, 2017). However, changes to these systems are necessary, especially as with community integration comes choice making opportunities. For example, when people with IDD have choices about their support staff, they are twice as likely to vote (Friedman & Rizzolo, 2017).

Our study has a number of limitations which should be noted, particularly regarding our sample. Although I paid subjects for participating in focus groups, they volunteered to participate based on flyers distributed mainly by word of mouth. As a result, there is a chance of self-selection bias. Moreover, because of the design of my study participants were required to communicate verbally. Thus, the experiences and views of people who use nonverbal communication, or have more severe impairments were not necessarily captured. This study was limited by a lack of member checking or data review by additional researchers. It should also be noted that participants were from a large urban area and its suburbs. Although diverse, the city is solidly Democratic. Moreover, there are contextual factors, such as the state’s bias towards institutionalization (Braddock et al., 2015), that may have impacted participant’s ability to and interest in voting. The 2016 U.S. general election in particular was noted for its heated presidential contest; as such, participants’ enthusiasm may have been unique to the 2016 general election. It remains to be seen if the participants’ enthusiasm for future elections will continue. This passion, however, is certainly reflected in large segments of the American populace at the very outset of the Trump Administration. Within the first 100 days of Trump taking office, the nation has already seen its largest collective protest in U.S. history, The

Women's March, as well as a surge of people, particularly women, registering to run for office (Cauterucci, 2017; Gajanan, 2016).

Despite enjoying participating in the 2016 general election and having an interest in voting in the 2018 general election, participants had mixed responses when asked if they would vote in the next local election. While some participants said they would, others did not think they would. When asked why, one participant said: "I don't know [why]. It's because... I mean not concern me, but it doesn't really. I don't know how you say it, [it isn't as] interesting to me." This finding suggests more education is needed so that people with IDD, like the general public, understand the important role of non-presidential elections. Perhaps if the election process is more accessible and relatable for people with IDD, it will help more people with IDD become engaged. As one participant admitted, "I wasn't relating to politics until this election, [then] I was like 'okay, pretty interesting!'"

Voting is a critical form of civic engagement because it allows people with IDD to contribute to decisions that will both directly and indirectly impact their lives. As one of the largest social minority groups in the United States, if actively engaged, people with disabilities have enough collective power to draw attention to issues that could directly facilitate their empowerment and equity of opportunity. Yet, even among the disability community, people with IDD's opinions and participation are often devalued (Charlton, 1998). This study was influenced by the understanding that people with IDD are legitimate producers of knowledge, especially about their own experiences and perceptions, they are important constituents in the election system. Yet, because of power imbalances people with IDD often need to advocate for their rights, especially rights many nondisabled people take for granted. Facilitating equity of access to voting and other forms of civic engagement requires attention to barriers including structural power inequalities and entrenched ideas about competence "because every vote matters."

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Multimedia

Review of *To Siri with Love*

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In a market crowded with autism memoirs, Judith Newman's *To Siri with Love* (2017) stands out. For one thing, Newman, a professional writer whose work has appeared in publications ranging from *YM*, the now-defunct teen magazine, to the *New York Times*, is a conversational and utterly relatable narrator of her family's experience with autism: her twin boys—Gus, who has autism, and Nate, who does not—are now teenagers.

Newman succeeds in avoiding certain tendencies that make autism memoirs feel predictable. For example, while most narratives of autism hew toward the extremes, describing perhaps a boy “smashing his head against the wall and finger painting with the blood” or, even more likely, “the eccentric genius who will one day be running NASA” (p. xvi), Gus's strengths and challenges, as depicted by Newman, are like those of many people on the autism spectrum: more mundane.

As an educator of future teachers at a liberal arts college, I find that many of my students assume *most* people with autism have savant-like attributes. Which makes sense. Because unless they have friends or family members on the spectrum, their points of reference are probably people like Temple Grandin, whose gift for “thinking in pictures” allowed her to revolutionize the modern field of animal husbandry, or Shaun Murphy, the protagonist in the ABC drama *The Good Doctor* (which aired in 2017 and is based on a 2013 South Korean series), a pediatric surgeon who has autism and savant syndrome. Indeed, an inadequate understanding of the full range of the autism spectrum can have consequences beyond mere misperception. For educators, the cost can be ill-preparedness to meet the needs of students in their classrooms.

In Newman's memoir, Gus is portrayed as a gifted pianist with a (mostly) easygoing temperament. While serving as his apartment building's doorman, a paid gig that he nabbed long before his brother or peers were gainfully employed, Gus got into the habit of “escorting” his neighbor Becky, a recent divorcée, and her pit bull, Francesca, to their door after their last walk of the evening. Becky said that on the rare nights she didn't see Gus, her “day felt incomplete” (153-4). But in spite of tender interactions like these, Gus, like many people on the autism spectrum, requires support in many domains—social interactions among them.

The hook for Newman's narrative is Gus's humorously fulfilling relationship with Apple's personal assistant, Siri. Indeed, the memoir is an elaboration of Newman's 2014 *NYT* essay of the same title. Newman includes several snippets of Gus-Siri dialogue and these—more, perhaps, than her own observations and recollections—help readers understand autism as a phenomenon, at least in a day-to-day sense.

GUS: OK! Well goodnight!

SIRI: Ah ... it's 5:06 pm.

Gus: Oh sorry, I mean good-bye (131)

With this exchange, readers can easily imagine how Gus and his peers with autism might be soothed by Siri's precise language and gentle frankness. Wryly, the author notes that the bot "doesn't let my communications-impaired son get away with anything."

If precision is one hallmark of autistic conversation, perseveration is the other. The fact that Siri indulges Gus in "semidiscuss[ing]" his favorite topics "tirelessly" (133) quickly endears her to him:

GUS: Siri, will you marry me?

SIRI: I'm not the marrying kind.

GUS: I mean not now. I'm a kid. I mean when I'm grown up.

SIRI: My end-user agreement does not include marriage

GUS: Oh, OK. (142)

Newman's humorous style and asides to the reader makes the memoir engaging but at times can strip situations of the more complex emotional resonance they likely deserve. In ruminating on why Gus developed autism, for example, Newman jokes: "older father + reproductive technology + twins = trifecta of bad juju" (24). Yet another shortcoming involves the placement of the Siri material, most of which was pulled from the *Times* article. For some unknown reason, the author withholds almost all of it until two-thirds the way into the narrative. Readers will wonder why.

And yet, in moments, the memoir does delve into the thornier questions related to raising a child with autism. For example, realizing that Gus's obliviousness protects him from certain discomforts of a neurotypical childhood, Newman muses that "through pain there is growth. I think about this all the time" (88). And she concludes ultimately that she *does* want Gus to feel more self-conscious and embarrassed—that such steps are part of becoming a more fully realized person. She also grapples with whether or not Gus will one day want to have children. Her current stance is: "A vasectomy is so easy. A couple of snips, a couple of days of ice in your pants, and voila. A life free of worry. Or one less worry for me" (116). And while readers can undoubtedly see the compassion (and anxiety) underlying Newman's perspective, as the author herself admits, you can't say something like that without sounding a little bit like a "eugenicist."

Reflecting on the broader theme of the text, Newman observes the ways in which technology can promote independence and even *interaction* for Gus and others with disabilities. Such a perspective, she contends, is an important counter to the "current notion

that technology dumbs us down and is as bad for us as Cheetos” (p. xvi). Technology, as this book shows, often soothes Gus while also drawing out a certain relaxed social self. Readers may wonder if, with time, his easy interactions with Siri will eventually help him develop more comfort in the more complex arena of human-human interactions.

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Multimedia

Diffability Hollywood Review

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What does disability mean in film? What is life like for a working actor with a visible disability? What are the contradictory ways in which those who self-identify as disabled respond to cinematic portrayals of disability? These are some of the questions explored in filmmaker Adrian Esposito's remarkable documentary *Diffability Hollywood*. The film explores representations of disability in film as well as the lives of young performers with disabilities, tracking their careers in film and television. It is a unique work, hosted within the film by Esposito, who himself identifies as autistic.

Diffability Hollywood provides a well-rounded historical overview of representations of disability in film. Drawing on the voices of film scholars, the film leads us through some of the most compelling and recurring stereotypes of disability, including hyper-sexualized or infantilized characters. It also explores the ways in which these make believe characters may at times have a real impact on real life perceptions of disability, and in turn, actual policy.

While not comprehensive (its historical overview is organized by theme rather than strictly chronologically), its survey offers what will be fascinating new territory for many viewers. Particularly interesting is the film's coverage of 'crip-sploitation' films like *The Amazing Mr. No Legs* (1978).

The film not only offers a bird's eye view of the ways in which those with disability had been portrayed on the screen, it also offers unprecedented, intimate glimpses into the lives of contemporary actors with disabilities and their experiences in the industry. It also is enriched by insights from non-disabled actors (e.g., Johnny Knoxville) about their experiences working with actors with disabilities in film. The stories of their professional lives also benefit from the voices of the parents and mentors who have facilitated their training and careers. The film's insights into the lives of actors with disabilities, largely in their own words, is without peer in any documentary of which this writer is aware.

The film's unique structure, moving between historical overview and portrait of artists, allows it to offer some unusual and very compelling content. This includes an informal reception study conducted by the director. In this portion of the film, a group of people with disabilities are gathered together for a screening of Tod Browning's 1932 film *Freaks*. Watching their real-time reactions to the film and hearing their responses offers a rare and valuable glimpse into the varied ways in which real audiences respond to film and talk back to the screen. This is particularly valuable as very little research has been done on spectators with disabilities.

The film is recommended for the casual viewer but suitable also as a supplemental text

in an extended seminar on disability in film and media. Overall this unique and compelling film fills a major gap. It is essential viewing for those interested in representations of disability and helps contribute to our understanding of the contradictory and often surprising ways in which film and disability may intersect.

Diffability Hollywood is available for educational licensing. Information available at: <https://espocinema.wordpress.com/diffability-hollywood/>

Diffability Hollywood. Dir. Esposito, Adrian. Espocinema, 2016.

Notes

Disability Studies 2018 Summer Online Courses

Genesis Leong
University of Hawaii at Manoa
Center on Disability Studies

University of Hawaii at Manoa, Disability Studies Summer Online Courses are now available. Register for both undergraduate and graduate courses through UH Outreach College www.outreach.hawaii.edu. Classes start on 5/21/2018, reserve your seat today for the following 2018 Summer courses:

Undergraduate Courses

DIS 380 Foundations Disability & Diversity

Focuses on disability as a category of diversity and identity, as well as diversity within disability. Different strategies used to increase the freedom or liberty of people with disabilities are critically examined. This is an excellent foundational course with content applicable and relevant to all fields of study. Instructor Lauren Ho, lauren.ho@hawaii.edu. Online, 3 Credits, CRN: 97230, Summer Session I, 5/21/2018 - 6/29/2018

Graduate Courses

DIS 675C Supporting Multilingual Learners: Tech

Using technology is an effective way to connect with students of all learning styles and provide alternative ways to teaching. This course is designed as a guide for teachers who are interested in using simple computer and internet applications to supplement their classroom lessons and increase student engagement and achievement. Instructor Mautumua Porotesano, mautumua@hawaii.edu. Online, 3 Credits, CRN: 96974, Summer I & II, 5/21/2018 - 8/10/2018

DIS 682 Special Topics in Disability “Telling Our Stories”: Auto/biographical Portraits of Disability

This course invites participants to explore what happens when personal histories are told across different platforms. Tapping insights from Disability Studies and the emerging field of Transmedia (storytelling across different platforms), this interactive course examines examples of personal histories told in different forms, and invites participants, using simple digital authoring tools, to draw upon personal histories, primary documents, and personal accounts to create auto/biographical portraits. The course will interrogate assumptions about disability and deepen our understanding of the ways in which storytelling format may shape auto/biographical portraits. Instructor, Raphael Raphael raphael@hawaii.edu. Online, 3 Credits, CRN: 96973, Summer I, 5/21/2018 - 6/29/2018

Graduate Certificate in Disability and Diversity Studies

We offer both undergraduate and graduate coursework in Disability and Diversity Studies (DIS), including a 15-credit, interdisciplinary Graduate Certificate in Disability and Diversity Studies. For more information contact Megan Conway, mconway@hawaii.edu or visit www.cds.hawaii.edu/certificates.

Dissertation Abstracts

Compiled by Jonathon Erlen, University of Pittsburgh

Edited by Megan Conway

Able-bodied womanhood: Disability and corporeally exclusionary narratives in black and white women's rights discourses, 1832-1932. Temple, H. A. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: Maryland: University of Maryland, College Park, 2016. Publication Number: 10159138.

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