Parents’ Experiences as Educational Advocates for Children with Autism in Public Schools: Parent-Educator Relationships

By
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Jennifer A. Dueñas
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__________________________
Chair: Tracey LaPierre

__________________________
Shirley Hill

__________________________
Emily Rauscher

Date Defended: 5 May 2017
The thesis committee for Jennifer A. Dueñas certifies that this is the approved version of the following thesis:

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Chair: Tracey LaPierre

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Abstract

While global, interdisciplinary debates continue regarding increased prevalence in autism spectrum disorders, there is no doubt that the visibility of individuals with autism have increased in public schools. Families of children with autism are placed in an unprecedented position as they become educational advocates by default when their children become students in public schools in an age of austerity (Caruso 2010, Itkonen and Ream 2013, Kalaei 2008, Ong-Dean 2009, Tincani 2007). Using Bourdieu’s Cultural Capital theory as a guide, the purpose of this research is to gain a deeper understanding of how parents of children with autism negotiate their child’s education within the constraints of public schools through the interpersonal interactions with IEP teams. What types of parent-professional relationships exist between parents of children with autism and IEP teams? What factors influence parents’ advocacy styles?
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INTRODUCTION

Autism is defined as a neurological disability that is heterogeneous nature, meaning there are multiple areas of one’s body that will experience developmental deficits. Autism will manifest as early-onset deficits in social skills, communication and behavioral challenges that may include repetitive behaviors and limited interests (Lai, Lombardo and Baron-Cohen 2014). While global, interdisciplinary debates continue regarding increased prevalence in autism spectrum disorders, there is no doubt that the visibility of individuals with autism has increased in public schools. Families of children with autism are placed in an unprecedented position as they become educational advocates by default when their children become students in public schools (Caruso 2010, Itkonen and Ream 2013, Kalaei 2008, Ong-Dean 2009, Tincani 2007).

LITERATURE REVIEW

Prevalence and distribution of ASD

As the prevalence of autism spectrum disorders is on a dramatic rise and breaches the sociological barriers of race and class. Baio (2014) notes that there had been a significant rise in the prevalence of autism between the years 2002 and 2006. The current prevalence rate is 1 in every 68 children. Male children seem to have a higher likelihood with an occurrence of 1 in every 42 and an occurrence of 1 in every 189 females. Baio does acknowledge that the increase in prevalence could partially be due to increased awareness and shifts in assessing and diagnosing this disorder. However, after controlling for changes in assessments, the current prevalence rate is still far beyond what would have been anticipated in the 1990s.
Policy Considerations

With the rise of Education for all Handicapped Children Act (EAHCA 1975) came the rise of inequality in special education advocacy (Caruso 2010, Itkonen and Ream 2013, Kalaei 2008, Ong-Dean 2009, Tincani 2007). This implies a certain amount of irony since advocacy is almost always about equity. The Act, did indeed, provide educational rights to children with disabilities and their families, including due process and the right to advocate. However, the policy was structured so that it was not just the parent/caretakers right to advocate but it was their responsibility to do so. This placement of responsibility assumes that all parents/caretakers will have the literacy skills and other abilities necessary to navigate and interpret special education law successfully. In other words, the policy fragments advocacy into different ability levels illuminating the variability in advocacy skills and access to resources that is rooted in race and class inequalities (Ong-Dean 2009).

Since 1975, social policy significantly changed how schools and parents would address the increasing inclusion of students with a spectrum disorder. In 1990, EAHCA evolved into IDEA (Individuals with Disabilities Education Act) when it grew to include children with an autism diagnosis. Students with autism and their families were now provided a platform to legally defend their children’s right to a free appropriate education with access to a general education curriculum and to be mainstreamed with neurotypically developing children as much as possible via due process. Students covered under IDEA were also provided the Individualized Education Plan (IEP), since a primary focus was to create a student-centered education model with the parent/caretaker having equal input as to diagnoses, placements and accommodations. However, there are existing policy constraints that require public schools to engage in negotiation and balance interests which do not always place the education of each individual student with special
needs as a primary concern for educators and creates a necessity for advocates to have a thorough understanding of these constraints.

While IDEA was primarily concerned with providing access to education for students with disabilities, No Child Left Behind (2001) was concerned with the quality of education these students receive rather than just access to education. Prior to this policy, Federal control over public education was limited to funding only. The development of No Child Left Behind led to the expansion of Federal control to include the development of educational policy. State school districts are held to certain standards and have to prove AYP of students meeting those standards. If States fail to meet adequate yearly progress for two consecutive years they are sanctioned with loss of funding. In the early stages of No Child Left Behind, annual yearly progress was being measured through State assessments, which all students, with or without disabilities, were required to take. This requirement was in direct conflict with IDEA, which mandated the individualization of education for students with disabilities.

In an effort to reconcile this conflict between the two policies, a well-intentioned alternative academic achievement standard was developed which assesses students with disabilities on limited grade level curriculum and oversimplifies the content of the material, dumbing things down. Another option, for the higher functioning students is modified academic achievement standards which provide more grade level curriculum but still over simplifies the content (Kalaei 2008). Rather than focusing on improving special needs students’ access to grade level curriculum, the expectations are merely lowered. The consequences result in students with disabilities falling further and further behind. These alternative achievement standards provide a false profile of these students making academic progress through a quality education in order to meet adequate yearly progress when really lack of progress is being hidden behind the alternative
achievement standards. Further, in the classroom educators are now concerned with preparing students with disabilities to pass oversimplified state assessments rather than focusing on providing access to a grade level curriculum. While No Child Left Behind had well intentioned goals to reconcile the conflicts with IDEA, the results actually cultivated a climate of inequality for students with disabilities. In addition to the use of alternative achievement standards, the policy also gave the green light to lower goals on an IEP. For example, there are time limits imposed on IEPs so that a school has a certain amount of time to prove the student has been making sufficient progress towards all of his/her IEP goals. When a student has not met all of their goals, schools can now either simply extend the timeline or lower the expectations on a goal. This is another well-intentioned plan that does not actually provide quality education to students with disabilities but rather provides a profile that reflects relative progress (Caruso 2010, Kalaei 2008, McGee 2011, Tincani 2007). If social policy has been put in place to ensure children with disabilities receive quality education, these arrangements no doubt undermine that goal.

As these policies impose upon public education, the trickle down creates a challenging context for families of children with autism. The environment, then, certainly elicits a response of some type from parents. Arguing that many parents would have concern with how a response might impact their child’s education, successful navigation and negotiation of special education requires knowledge of policy/law and how it can provide both impositions and aids to the educational goals of students with autism as well as to public schools (Caruso 2010, Itkonen and Ream 2013, Kalaei 2008, Ong-Dean 2009, Tincani 2007).

Impacts of Class on parent-professional relationships

As autism has been diagnosed in children from all backgrounds, families from a wide range of SES are attempting to navigate special education. The heterogeneous nature of autism fragments
assessments, treatments and interventions and as such there will be a number of educational professionals who will make up a student’s IEP team and with whom families will need to form and sustain relationships. However, specifically within the context of autism, forming parent professional relationships is historically rooted in upper-middle class privilege. In other words, positive and productive parent-professional relationship have been contingent on class (Eyal 2013). With a Bourdieusian resonance, parent advocates who are upper-middle class possess the cultural capital preferable within the field of education. Their own cultural background, milieu, and habitus allows them to permeate the boundaries of the professional field more successfully than others. As such, said capital allows them to practice a form of “privileged advocacy” (Ong-Dean 2009). This is not to say that parents who are not upper-middle class do not possess relevant and important information in regards to their child’s education. They do. However, having a lower SES may not be viewed as culturally appropriate and may not harmonize and fit in with the dominating culture’s view of what is considered valuable in terms of being objective and scientific (Ong-Dean 2009). It can be argued then, a lower SES parent advocating, navigating and negotiating the field of special education will be exceptionally laborious, frustrating, confusing, and potentially unsuccessful.

With the democratization of special education came a rise in the involvement, interpersonal communication and collaboration of parents with children on the autism spectrum (Ong-Dean 2009). And since families of all backgrounds are needing to advocate, poor and working class families are likely to face disadvantages because they have minimal experiences communicating and collaborating with the dominating education system. Middle and upper class parents are known for increased participation in their children’s education (Lareau 1987, Lareau 2003, Ong-Dean 2009). Further, since the institution of education values the practices and habits of middle
and upper class capital, families of a lower SES may be viewed as having a lesser status and be undervalued. Since many poor and working class folks have been socialized not to form working relationships with professionals of dominant institutions, many parents from a lower SES background may want to take an active role in educational advocacy but may defer to educational professionals to decide what is best for their child (Lareau 1987, Lareau 2003). Many poor or working class parents may withdraw from collaboration altogether as they believe the school’s professionals would really do a better job. In contrast, middle and upper class adults will have an extended knowledge of how to navigate complex social institutions, how to form relationships with their associated professionals, and will actually feel more entitled to receiving help and services (Lareau 1987, Lareau and Weininger 2003, Lareau 2015).

THEORETICAL FRAMEWORK

Cultural Capital

Bourdieu’s (1986) cultural capital theory, in the embodied state, is used here as a theoretical guide. Bourdieu’s theory defines the embodied state of cultural capital as one’s predisposition specifically of one’s body and mind which includes perceptions, behaviors, beliefs, appreciations, etc. It includes one’s particular set of skills and resources as “people’s symbolic and informational resources for action.” These skills and resources are acquired through socialization according to one’s habitus or, “external wealth converted into an integral part of the person, into habitus…” (p. 83.) This specialized set of cultural currency can be seen as something that is exchangeable for profit and has the ability to evolve. Although cultural capital is not static it is not something that is available to be infused, transferred or purchased into the mind or body immediately. Rather, the acquisition of capital is a process that requires the investment of time. Having the ability to evolve, the particular arrangements of cultural capital, both in terms of power
and politics, favor the educated, middle and upper classes as the dominant class holds the power to determine what kinds of cultural capital is valued. These values then shape the arrangements of social institutions. The disparities in cultural capital contribute to inequity in education, social stratification and the reproduction of social hierarchies as certain cultural characteristics are either sanctioned or rewarded (Bourdieu 1986).

Cultural capital is very similar to the capital necessary for successful educational advocacy. As families of all social class backgrounds and racial groups attempt to navigate the field of special education, Bourdieu’s cultural capital theory can be observed as intricately interwoven in educational advocacy methods. When parents are able to draw on this capital, navigating and negotiating special education will be remarkably more favorable and will create opportunities to experience what Gengler (2014) calls “microadvantages.” Microadvantages are small dignities experienced that make interpersonal interactions with teachers, specialists and providers more advantageous and successful in reducing the potential for additional stress and conflict. In addition, successfully drawing on privileged capital can influence a professional’s perception of the family and the child creating a climate that promotes a working relationship as well as easier access to services (Abel 2008, Bourdieu 1984, Brookman-Frazee and Koegel 2004, Dempsey et al. 2009, Dubbin, Chang and Shim 2013, Dyches et al. 2004, Foster, Rude and Grannan 2012, Gengler 2014, Lareau 2003, Shim 2010)

**INEQUALITY IN ASD**

*A Unique Skill Set*

There is a unique skill set required for educational advocacy and may include, but is not limited to: in depth knowledge of special education law and rights, literacy to interpret special education law, in depth knowledge of criteria for qualifying for services, knowledge of evidence
based practices available to the district, knowledge of assessments available to the child, knowledge of in-class modifications, ability to participate in the creation of IEP goals, ability to track own set of data relating to IEP goals, ability to communicate this information effectively, extensive management of health records, ability to interpret the school’s own set of data, ability to engage in proactive conflict resolution with members of the IEP team, and the ability to hold members of the IEP accountable (Angell and Solomon 2014, Brookman-Frazee and Koegel 2004, Dempsey et al. 2009, Durkin et al. 2010, Dyches et al. 2004, Foster, Rude and Grannan 2012, Litt 2004, Ong-Dean 2009, Tincani 2007). However, this skill set is not equally distributed among all families (Bourdieu 1984, Caruso 2010, Itkonen and Ream 2013, Lareau 2003, Ong-Dean 2009, Tincani 2007). The cumbersome task of advocating will require time, time management skills, interpersonal skills and organizational skills to be able to secure this particular set of capital which is rooted in class advantage.

Premised on the literature review, it is argued that advocating for an ASD child’s education is a complicated and cumbersome task because of the multitude of variables to manage within the education system and because of the nature of an ASD impacting more than one area of a child’s development. However, this is still mainly speculative. We don’t know exactly how these factors impact parent-educator relationships. We don’t know which factors will present themselves as aids to parent-educator relationships or which factors will create more of an imposition. We also don’t know if and how these factors interact with each other and if and how these factors influence what types of advocacy styles parents adopt. Lastly, we don’t know if certain aspects of an ASD become more problematic than others in terms of parent-educator relationships. This research will be the first to link the macro level constraints imposed on public schools with parent-educator relationships.
AUTISM AND EDUCATION IN AN AGE OF ECONOMIC AUSTERITY

As a multitude of policy constraints have been identified, public schools must also balance these constraints with the current era of austerity. Defunding education has become common and is yet another substantial factor to negotiate and balance. Funding impacts how much training school staff receives, the individual school’s resources, staff ratios, access to outside consultations, shifts at the individual and classroom levels to implement the most effective and appropriate accommodations, attitudes and beliefs of both school staff and parents, behavioral and educational impacts on other students in the classroom and the demands of managing special education with very limited resources (Dingfelder and Dingfelder 2011, Itkonen and Ream 2013, Koenig et al. 2014, McLeskey 2004, Moores-Abdool 2010, Morrier, Hess and Hefflin 2011, Noland 2004, Ong-Dean 2009, Palmer et al. 2005, Sullivan 2013, Tinca 2007, Whitby, Travers and Harnik 2009).

In contrast, parents’/caretakers’ primary concern is the education of their child. This can breed conflict when negotiating a child’s education. Parents/caretakers often find themselves either unaware of or unsympathetic to the constraints faced by public schools. It appears as if the factors that influence the delivery of these students’ education are complex and juxtaposed against the families who are advocating. Institutional arrangements are organized in such a way that sets a stage of conflict between public school and the families of students with a spectrum disorder. (Caruso 2010, Itkonen and Ream 2013, Kalaei 2008, Tinca 2007) This illuminates a macro-level problem as the strains of educational advocacy may very well exceed the issue of fragmented abilities.

Using Bourdieu’s Cultural Capital theory as a guide, the purpose of this research is to gain a deeper understanding of how parents of children with autism manage parent-educator relationships through IEPs in an age of economic austerity? What types of parent-educator
relationships exist between parents of children with autism and IEP teams? What factors influence parents’ advocacy styles?

METHODS

The research question herein is designed to illicit rich and detailed responses that provide “examples, experiences, narratives and stories,” (Rubin and Rubin 2005:29). The use of interviewing allowed for open ended answers in a way that allowed the interviewee to respond however he/she chose. Within this process, the interviewee had an opportunity to elaborate on certain answers, disagree with certain questions and contribute to the process of creating new ones (Rubin and Rubin 2005). Considering the research questions, “what type of parent-educator relationships,” and “influential factors,” are qualitative terms and just could not be captured and analyzed with quantitative methods. In addition, micro level details of how parents manage their child’s education with the myriad of other factors is also something that would be best understood using qualitative methods. The journeys of these families were detailed and could have truly only been captured by in-depth interviews, with open ended answers. The nuances of this research is most appropriately assessed and analyzed with qualitative tools (Creswell 2014, Warren and Karner 2015).

Sampling

Recruiting parents of children with ASD can be difficult for several reasons. Many parents and caretakers who have children on the autism spectrum experience substantial isolation and limited visibility as a result from stigma that accompanies an autism diagnoses. In addition, this population experiences time constraints and resulting fatigue associated with managing the daily logistics of caring for a child with autism (Cashin 2004, Duarte et al. 2005, Giallo et al. 2013, Gray 1993, Gray 1994, Gray 2002, Seymour et al. 2013). Due to these factors, as well as the inability to
access this population through existing databases, convenience sampling or nonprobability sampling and snowball sampling was applied. Because I am not a Kansas native but am a parent with children on the autism spectrum, I immediately identified an advocacy organization and started attending disability rights workshops, IEP workshops and anything else that was relevant to autism advocacy and used that as a networking opportunity. From there I was invited to join an online autism support group, which I accepted and then frequented, which provided a pool of willing participants as well as an additional opportunity to establish myself as a fellow autism parent. In addition, there is a special needs family night held once per month at a local indoor play center. I attended that event for several months, along with my special needs children, and quickly started networking with board members of a local Autism Society. From there, I gained access to another local online support group and began consistently interacting with participants. I also received invitations to attended picnics and other events sponsored by the local Autism Society and was able to successfully recruit participants from there. Again, it was helpful to consistently interact as a fellow “autism parent” in an effort to develop trust and rapport with potential recruits. Once a rapport was developed I then introduced my research and asked participants for an interview. Lastly, at the end of interviews I always asked participants if they knew of any other parents who might be willing to interview with me. In the event participants knew of somebody, participants always spoke with their contact first before providing any contact information.

Eligibility criteria included the parents/caretakers of children diagnosed with an autism spectrum disorder who are enrolled or have been enrolled in 1st through 12th grade at a public school and who have or had an individual education plan (IEP) in place. The criteria for an existing autism diagnosis was not only premised on the population of interest but assisted in determining why parents pursued the diagnosis, whether the pursuit for the diagnosis was school-related or
otherwise, what the diagnostic process encompassed and how the attainment of a diagnosis impacted educational advocacy. The reason for excluding families with students in preschool and kindergarten is based on their shorter period of time advocating. I found previously that conducting previous interviews with parents of younger students was not extracting as rich of a narrative as parents who had been advocating for a longer time period. No gender preference was applied so long as the participant identified as the primary person who possessed the extensive and ongoing knowledge of the child’s behavioral, medical and educational history and who facilitates and manages the child’s public education. The facilitation and management of the child’s education included, but was not limited to: attending IEP meetings, managing and maintaining parent-professional relationships, conflict resolution, development of IEP goals, tracking IEP goals, data collection, ongoing research of special education law and knowledge of the family’s rights, ongoing research about the school’s use of evidence based practices, regular communication with the school about the child’s needs and progress.

Sample Description

The sample size includes twelve (12) participants. Twelve (12) interviews were conducted over the summer of 2016 in East Kansans. The sample includes eleven (11) female participants and 1 male; one couple was interviewed, although the mother did the majority of the interview. Ten participants identify as White, 1 as Latino and 1 as Native American. See Appendix for additional sample demographics.

Interviews

The in-depth interviews were conducted in person. I allowed the participant to choose a date, time and location that was preferable and most convenient for them. I only chose the date, time and location at the request of the participant. Most of the interviews were conducted without
the presence of children so as not to influence what types of information was or was not appropriate to reveal. Although I made no efforts to seek a gender balance, 1 participant was male and 1 interview was done with a couple, although the mother participated more than the father.

During the in-person interviews the participants were given an informed consent form that was previously approved by the University of Kansas IRB. The participants took as long as they needed to read the informed consent, ask any questions, sign and date the informed consent and choose a pseudonym for themselves and for their child.

At the beginning of the interview, participants were given a demographic questionnaire to fill out. An interview guide was used to lead the interview and prompt participants to elaborate on their responses. The guide was comprehensive with open-ended questions and was used as a tool to extract rich details in narratives that revealed the nuances associated with exploratory research. Further, the semi structured interview guide provided room for adjustments when needed both during and after the interview process (Locke, Spirduso and Silverman 2014). The interviews were digitally recorded and lasted between 1- 1.5 hours. Only a few times did the interviews exceed 1.5 hours. The digital file was transferred onto my password protected computer and the files then encrypted for privacy. When the interview was interrupted by another person who did not provide informed consent the recorder was turned off for the duration of the interaction and then turned back on once the interaction ended. I took minimal notes as needed throughout the interview so as to provide the maximum amount of attention to the participants and their narratives. After I exited the interview, I immediately drafted memos to provide an appropriate time to record my observations, reactions and any relevant thoughts about the interview at a pace that was conducive to my thought process. In order to manage my past and ongoing personal experiences as an autism parent and educational advocate, I noted any personal events that may have occurred prior to the
interview that could have potentially influenced the direction of the interview or the interpretation of the interview. The memos were used for critical review in between interviews and in the data analysis stage. “Analytic memos are an important tool for researchers to develop thoughts, track reflexivity, collect data and analyze data,” (Locke, Spirduso and Silverman 2014:292). After an interview and before the next interview, I reviewed any interview notes and memos drafted to determine if I should amend the interview guide, which I did frequently. Amendments included removal or addition of questions, removal or addition of prompts or rearranging the order in which the questions were asked.

Data Analysis

The first step of data analysis was to critically review my interview notes and memos. Although an ongoing process, the purpose of the critical review was to reorient myself with the participants and the data provided. While analyzing the interview notes and memos I applied a constant comparison approach to search for potential connections. The connections were recorded in a supplemental set of notes to help identify emerging codes based in the data (emic) and emerging codes based in the literature (etic) (Locke, Spirduso and Silverman 2014).

The second step in data analysis was to personally transcribe the interviews verbatim. During the transcription process, I continued to add to the supplemental notes created in Step 1 which illuminated emerging codes.

The third step in data analysis was to code the interview transcripts. Reading through each interview transcript entirely, I assigned a code to chunks of the text. Appearing in the margins, the code assigned was representative of what that specific text means. This strategy was applied to the entire transcript and to the entire collection of transcripts so that I could compare the emerging
codes. The use of the supplemental notes assisted me in this process. Next, I made a list of all of the codes created in preparation for consolidation. The logic in this step was to start reducing the amount of codes by consolidating similar codes together which results in more efficient organization of the codes. For example, I may have assigned a piece of data different codes that have the same meaning. After consolidation, I reviewed which codes were left over and discovered which codes were emerging more frequently. The next step was to organize the codes into broader themes. This required constant comparison and analysis as to which codes were interrelated. After assigning themes, another consolidation was applied in an effort to narrow my analysis even further and maximize organization. Next, I decided on final themes and put them in alphabetical order. Throughout this process, I coded, recoded, threw out original codes and developed new codes, and reorganized any number of times. While a number of illuminating themes emerged from the data, this paper focuses on just three main themes.

Validity

A number of validity strategies were incorporated. One was the use of thick descriptions to transmit the findings: Creswell (2014) states “When qualitative researchers provide detailed descriptions of the setting, for example, or offer many perspectives about a theme, the results become more realistic and richer. This procedure can add to the validity of findings” (p. 202). I also clarified my research bias. An honest, self-reflexive explanation of my interpretation of the findings was provided and accounted for in the data analysis. I kept a working journal of circumstances and events that were occurring in my personal life regarding my own children with autism and reflected on how those circumstances and events could potentially influence findings. Lastly, member checking was used to help determine the accuracy of the findings. A final report of themes was transmitted back to participants to determine whether the participants felt the themes
are accurately represented. After participants had an opportunity to review the themes, we held a brief discussion regarding any areas that may need attention and participants felt there were none as the findings from the research held resonance with them.

FINDINGS

Regardless of cultural capital or educational attainment, all interviewees developed an advocacy style. During the coding process, three main themes relating to styles emerged from the data – Playing Nicely, Giving Up and Passive Acceptance. Playing Nicely was a style that indicated premeditation with a concerted effort; a very conscious and purposeful act which represented leveling the power distribution between parent and school in an attempt to exploit the maximum educational benefit through cultivating and nurturing a productive, working relationship with an IEP team. Playing nicely had three sub-themes: *It’s Nothing Personal*, *To Due or Not to Due* and *Gift Giving*. Giving up was also a conscious act that sought to nurture a team-oriented relationship with the school but was not an attempt to democratize the power distribution as these parents relinquished control over their child’s academics by letting go of that piece of their child’s education. Passive acceptance was a theme in which participants’ advocacy was not premeditated or conscious and represented an acceptance of the unequal power distribution between parent and school. See chart below for a visual orientation of themes and sub-themes. These themes and their sub-themes were not necessarily mutually exclusive and certainly were not static. Participants were found to have implemented any one of these styles in combination with others and at different time periods throughout their journeys as their circumstances and their subjective realities shifted.
Figure 1: 

PARENTAL ADVOCACY STYLES

- ADVOCACY STYLES
  - PLAYING NICELY
    - It’s Nothing Personal
    - To Due or not to due
  - GIVING UP
    - Gift Giving
    - Academics v. Social Skills
  - PASSIVE ACCEPTANCE
    - With Unease
    - Without Unease
PLAYING NICELY

Parental advocates who adopted the played nicely were those parents who made a very conscious attempt to develop collaborative, working relationships with their child’s school. While these parents saw the value in cultivating and sustaining a healthy relationship with their child’s team, they didn’t always necessarily want to do so for the sake of doing so. But rather, playing nicely was a way to level out the power distribution so their child would receive the maximum amount of educational benefit from nurturing this relationship. Especially in times of conflict, parents would purposefully manipulate their interactions with the school so that they would be viewed as diplomatic negotiators who were sympathetic to the constraints that schools are faced with and willing to be flexible in their expectations and requests. While there were a myriad of ways a parent could facilitate playing nicely three sub-themes are identified here: “It’s Nothing Personal,” “To Due or not to Due,” and “Gift Giving.” Included in the playing nicely repertoire was demonstrating an interest in the lives of IEP team members; many parents would inquire about how someone’s sick family member was doing or asked about a child about to leave for college or made an effort to bring up the most recent box office hit. Further, what Playing Nicely embraced the most was a communicable sense of gratuity and humility on the parent’s behalf. Letting schools know that as a parent they were grateful for the effort the school and team put forth, especially in the presence of conflict. This had no correlation to any authentic feelings of gratuity. In fact, many parents down right resented many of the people on their child’s team but saw this style as a pathway to maximum success and a higher probability of achieving their specific goal. What this really comes down to is managing negative emotions for the sake of being team-oriented.
Lilly’s interview illuminated the idea of being team oriented as she described how she manages her relationship with her son’s IEP team. Lilly was 36 years old and a single mother of 7 year old son Austin, diagnosed with autism and in public school. She also happened to be a special education teacher for high school students with autism at a local public high school. When asked about her experiences so far, what was hardest about advocacy for her and what she thought worked best, she replied:

P: Trying to not get emotional about it, trying to stay positive and not get angry - I try not to repeat what I have seen some of the parents I have do, where they just come in overly aggressive.
I: What do you think works?
P: You have to stay calm and yes it is ok to get emotional and cry and be angry. But it’s how you present what you are wanting and the calmer you are, the more team-oriented you are, the more willing you are the more it is likely you are going to get the buy-in of what you need. The more team approach you have, the consistency of that.

Clearly, it’s not the absence of negative emotions or even really an authentic desire to establish and maintain a relationship with the school but to equalize that power distribution to get “the buy-in of what you need,” that was at the core of Playing Nicely.

*It’s Nothing Personal*

While Playing Nicely includes aspects that may seem contradicting to the sub-theme “*It’s Nothing Personal,*” such as inquiring about the personal lives of school professionals, Amy demonstrates that active advocacy is nothing personal quite nicely by acknowledging that there is a balance between push-back and niceities that should be maintained. Amy is a 38 year old married mother of 3. At the time of the interview, her son Bret, diagnosed with autism, was 16 and in public high school. While Amy attended some college she never finished with a degree and was employed as a clerical worker at the time of the interview. When asked about what advice she would give to parents navigating special education she stated:

I think the hardest part is keeping the relationship with the school and being able to shut the door after the IEP and smile and shake hands and talk to them about their kids and their day. That way
they know there was nothing personal in that room. There was nothing personal at that table. Sometimes it’s hard because I, 100%, have that intention…..It wasn’t hard for me to do but it seemed like they didn’t think I was sincere when I would try to ask them how their day was. That’s the hardest thing, or was the hardest thing for everybody to understand it’s not personal. And we need to like each other so that you like my kid. And I think that was the hardest thing to learn was how to do that. Because you have to do that year round, not just in the IEP. You do that year round……. I think that you have to push. Even if you think you’re going to upset somebody. And then balance that out with niceities. And actually caring about your kid’s staff as much as you want them to care about your kid…..You have to push but you can’t be mean, you know. You don’t want them to be mean to your kid. There’s a difference between aggression and anger. It took me a long time. The reason I can say that was because I was angry. And it got me nowhere. You know we battled. And I had to learn to do it differently.”

Amy describes several important points here. One, is that “playing nicely” as a tactic isn’t something that occurred organically but rather was intentionally planned out, was strategically executed and was something she felt she had to be engaged in during the entire school year, not just during an IEP meeting so that her child would receive some sort of benefit. Amy also emphasized the importance of actively advocating if and when that became necessary but also openly acknowledged the specific demeanor preferred by IEP teams and she felt that not adopting this demeanor would only work against Bret’s best interest. Although Amy adopted and wholeheartedly believed this tactic was what was best for her son, she also explained the difficulty of maintaining this style. She also points out that pushing-back has to be managed by balancing that out with pleasantries.

To Due or Not to Due

One of the stipulations of playing nicely meant that there would be no consideration of exercising a parents’ right to due process. Filing due process to take your district to Court was absolutely out of the question. Due process was something that “you just didn’t do,” even when circumstances were ripe. Bringing in an outside advocate was also considered a negative course of action. Either one of those choices, while a legally viable right rooted in federal policy, would compromise the integrity of the team’s relationship. Many parents expressed not wanting to be labeled as “that one parent” for fear of being discredited by the school and labeled as emotional,
irrational and/or outright crazy. When this situation did arise, parents found themselves at an utmost state of vulnerability in terms of advocacy and quite powerless.

Jessa, a 57 year old mother of 17 year old Kyle and a board member of a local autism group started by parents, describes the experience she had after considering having to file for due process after her son’s school decided to discontinue his occupational therapy without providing the supporting data:

P: When I asked for the report that would be the reason why he did not need any occupational therapy anymore, I never saw and never got a real good explanation. But I did get the hate look right up close from my friend from junior high school here who was Kyle’s resource teacher and she said “don’t you dare.” I said I really wanna know what’s going on. And she’s like “don’t you dare do anything.”
I: Why?
P: Because I was questioning why they were taking his occupational therapy away. And I wanted a report, I wanna know what’s going on. Why are they taking it away from him. I was asking for a copy of my IEP and the report.
I: And she said don’t you dare?
P: Yeah. Marissa and Carol (fellow society board members) were so freaked out when I told them what happened with Kyle and that I might have to sue. They’re like “no you can’t sue, don’t sue,” when we’d have one of our get-togethers. “No you can’t sue it won’t work, you don’t do that. Don’t sue.” I think they were afraid it would reflect badly on them if I were one of the board members and then they would end up having trouble with their child at their school. They were afraid.

Jessa’s statement here is a reflection of a hidden protocol of sorts; an unspoken rule that exercising a parent’s right to due process would be unacceptable. What’s striking is that this idea that one shouldn’t sue a school district has been adopted by not just the districts, but by other fellow autism parents. Jessa did actually make an attempt to organize some supports in preparation of filing due process, at which her attempt was unsuccessful:

There’s no way to move forward. I mean I know better than to go above them (the school district) really. Anyway, working silence just like a conspiracy of intimidation whenever there’s a problem because of the way the groups (schools and Partners Together) have been. I want to say, there’s been somebody for the school district in any of the parent advocacy groups so that being able to really fully form, we (parents) aren’t able to have anything. There’s been enough conflicting interests. And then when we figured out that Partners Together lost their private funding, or their grants they were getting and then they were just only State funded. So once they became only state funded there was only so much help they could be.
When Jessa says here that she “knows better than to go above the school district,” it is a blatant demonstration that she learned very quickly that due process, while a legal right won by a tough, long battle on behalf of parental activists, was no longer a viable option to negotiate Kyle’s education.

Gift Giving

Gift giving was a common practice among those parents who were playing nicely with their child’s IEP team. Bestowing gifts such as homemade baked goods, other foods, wine and supplying treats for IEP meetings was all part of the playing nicely repertoire. These gestures, too, were done in an effort to maximize a benefit of sorts through maintaining a friendly, sociable relationship that reflected being on good terms. Many parents would engage in gift giving so that a particular teacher or educator would find working with a child much more pleasurable and would, perhaps, make a concerted effort to be kind or sympathetic to the child. Secondly, many parents felt that gift giving represents that spoonful of sugar to help the medicine go down when it came to working together and negotiating certain aspects of their child’s education.

Anne, a 37 year old married mother of 8 year old Christopher, discusses this very idea. Anne, just like Lilly, also worked for a public school district. Anne did not work in the same district her child attended school and was teaching Kindergarten at the time of the interview. She explains:

P: I always felt like I wanted to go in and be super nice. If I was really nice and brought snacks and did all these things that they would be nicer to him.
I: So are you afraid then that if you went the other direction that they would take it out on Christopher?
P: I would be yeah. I would think that they would make it feel like he was more of a chore to work with and not find something that they would enjoy working with him. They would be like god his mom’s a bitch. I’d just be afraid they’d treat him differently.
I: Right. Now what makes you think that?
P: That’s just from hearing teachers in special education. Not where I work now, but just teaching and hearing some things. Just hearing special education talk like ugh I’m not looking forward to
this IEP meeting. This mom all she wants is, she’s always asking for this and this and this. I say well but think how lucky he’s gonna be to have somebody looking out for him. And then the special ed teacher then goes on about well we don’t have time and they don’t have this and they don’t. Like I get it. I feel like I’m caught in between. I understand if I advocate for two more hours of time for him, he may not even get it.

Here, Anne explains a couple of things; how Christopher may be more likely to get preferential treatment by his educators if she brought treats to an IEP meeting and also how if she was pleasing in her ways neither she nor Christopher would be seen as unpleasant to work with.

In alignment with Anne, when Jessa was asked about how she secures certain treatment for Kyle she explained, “I have sent in trays of homemade brownies, bottles or whole cases of wine, gift certificates, holiday gifts, drinks at the club, whatever it takes.”

Additionally, it was found the more educated a parental advocate was and the longer they had been advocating, the more likely they were to engage in Playing Nicely and one or all of the sub-themes, since themes weren’t mutually exclusive or static. And lastly, there was a strong association with those parents who had consulted with the advocacy organization, Parents as Partners, for advocacy advice and the use of Playing Nicely.

GIVING UP

Another style used in managing parent-educator relationships was giving up. What these parents decided to give up on was managing the academic piece of their child’s education. As identified in the literature review there are multiple factors that impede academic success for children with autism. Schools have multiple interests that need to be managed in addition to the best interest of the child, including diminishing resources, conflicting special education policy that has unintended consequences for disabled students, and certain attitudes among educators regarding where disabled students belong and how much accommodation should be provided to ensure students with autism have access to a general education curriculum. Some parents went into
role of advocacy believing that with diligence their children could possibly have a future filled with opportunities that were the same as neurotypically developing children, starting with access to the educational curriculum and meeting both academic and social goals. They went into advocacy thinking that they wouldn’t be faced with idea of having to give up academic goals for social ones. At the end of the interviews, participants were asked if there was anything that made advocacy easier. Surprisingly, some parents confessed that giving up on the academic piece of their child’s education made advocacy easier, especially in terms of developing and maintaining relationships with their child’s IEP team. Once the challenge of providing appropriate academics was removed, then advocacy was much more manageable.

Revisiting Amy and Bret is a good example of giving up. Here, Amy describes how giving up academic expectations/goals for Bret helped her advocacy and negotiation of the rest of his education much easier:

I: Is there any part of advocacy that you felt was easy or that went smoothly?

P: Was when I let go of education as far as gen ed education. And I remember saying, reading the local school paper, and I was like they sent these kids to an Olympics to stuff envelopes. I’m not going to have my kid spend his school day stuffing envelopes. He needs to learn how to have a better job. Mind you, this was years ago. But I had that, I wanted so much more for him. And now I’m like, stuffing envelopes are the best thing ever. This is great. If that’s all he can do that’s all he can do. But I had to let go of my dreams for my kid and that was the hardest part. Once I did that and realized it’s a totally different life but it can still be good, things got easier.

What Amy is letting go of exactly are certain parts of Bret’s academic planning and future. What is demonstrated here is Amy’s indirect knowledge that education or academics is actually a mechanism for employment. She is indirectly aware that without proper academics Bret’s future employment options would be limited to something like stuffing envelopes. When she states that advocacy became easier after she de-emphasized the academic piece, what she is communicating is that academics is so difficult to negotiate in public schools in order to reconcile that educational deficit, she had to let go of certain hopes and expectations for Bret’s future. When the school was
not able to provide sufficient supports to achieve Bret’s academic goals it become a key point in
Amy’s advocacy as it changed her hopes and dreams for her son’s future.

Mary experienced something similar with her son David. At the time we interviewed, Mary
was a 46 year old married mother of two. Mary was working on her Ph.d. in Social Work and
David was a student in a public junior high school. Although Mary was an active advocate, she
too had to find a way to reconcile this deficit between what she originally wanted for David
academically and what she thought public school was realistically able to provide. Mary goes on
to explain:

P: Honestly, I think I gave up at some point.
I: In what aspect?
P: Well in school for one.
I: Do you mean the academic piece?
P: Well yeah. I tried to push that when we started school but then he doesn’t get the kind of
support he needs to be able to do.
I: To access the curriculum?
P: To access the curriculum……..He’s doing his science and art and whatever. Social studies,
that kind of stuff. But he’s on the honor roll at school. He makes straight A’s [in a very
condescending, suspicious tone] [laughing] which is a fucking joke. I mean it’s a joke. It doesn’t
exist. I have no idea what he knows or doesn’t know. I have no idea what they’re teaching him at
school because he can’t tell me. They don’t share, now I can’t even go up there now that he’s in
junior high….. and they adapt all of the materials so.
I: So they’re dumbing it down and going, ‘see he’s making progress?’
P: Oh yeah. Yes. He’s happy. But I just know he’s not, the academic piece is not.

Mary’s description here is of making an attempt earlier on in David’s education to secure
the academic piece only to give up on it later on as it became such an overly burdensome factor to
secure. Similar to Amy and Bret, what this demonstrates is the presence of external constraints
faced by public schools that directly impact the experiences of ASD students and how their parents
are having to negotiate their education.

Similar to the factors that influence Playing Nicely, Giving Up was associated with length
of time as an advocate and consultation/interaction with Parents as Partners.
PASSIVE ACCEPTANCE

Passive Acceptance describes how the power is distributed between parents and educators. The school continued to hold much of the power in the relationship, lacking that team oriented context with the parent excluded from decision making and input. In some cases the parent could experience unease about a decision or circumstance and in some cases not. When a parent experienced unease or nervousness, their attempts to reconcile that did not take the form of active resistance or appear as an attempt to level the power distribution. But rather, a mild inquiry into the issue with ultimately ceding control over to the IEP team. These parents were categorized under Passive Acceptance – *With Unease*. When a parent did not experience unease and relinquished control over to the IEP team, they were categorized under Passive Acceptance – *Without Unease*.

Further, parents in both sub-categories were unlikely to recognize a compliance breach, did not realize the full extent of their parental rights, would agree to the suggestions made by the IEP team and would not make much contribution to the development of IEP plans, goals, services and accommodations/modifications. For example, a parent may have been unaware they were not required to sign an IEP if they weren’t in full agreement with any part of it. When these parents attended an IEP meeting much of the outcome of the meeting had already been predetermined by the IEP team and the meetings looked more like an informational session to inform the parent of what the educational plan was going to look like and the decisions that had already been made and deemed as in the best interest of the student. These parents did not ask for any new reports generated from new assessments or current data collected prior to the meetings.

This style proved effective in terms of a positive relationship with the IEP team but only to the extent that this style exempted the school from having to justify the specific arrangements
of the child’s IEP. It wasn’t an act that was necessarily done with a specific intent deliberately to nurture a productive relationship with the child’s IEP team.

These same parents also were likely to have little education, be newer to the role of educational advocate, and have had no interaction with outside advocacy supports such as Parents as Partners.

With Unease

Aubrey’s story is a great example of Passive Acceptance – With Unease. Aubrey’s advocacy reflects a relinquishment of control, in terms of decision making, to the school even in times of unease. At the time we interviewed, Aubrey was a 37 year old single mother to 8 year old son Justin. Aubrey was working as a service administrator and had some college experience but was not degreed. Aubrey stated she’d had a good, working relationship with Justin’s IEP team but describes a situation when she wasn’t in full agreement about Justin’s placement:

I: So it sounds like there was a disagreement at some point. Did you communicate to them or did you just be like, oh well you know, maybe they know best? So how did you deal with the conflict, what did you do to resolve those feelings? Or did you?
P: Well by the time I really got the feeling of what was going on, they brought me into the meeting but it was like they had already made the decision, they were transferring him to this new school. Um, I did say I didn’t know how comfortable I was with that but it didn’t sound like they were really giving me much of a choice. And I got more of a feeling that she was done with it and wanted to fill this other school up. Um, so I didn’t um, I probably should’ve confronted her and told her I don’t think, you know…… But I didn’t.
I: Ok. Did they ever explain to you that you didn’t have to sign an IEP document and that they couldn’t move forward with any of their decisions until you signed that, did they mention any of that to you?
P: No.

While Aubrey had her own feelings of uncertainty and concerns about Justin’s educational placement, she asserted very little push back when it came down to it. She continued to explain how IEP meetings were facilitated:

I: So, who decided that he was going to have so much pull out? Did you guys discuss that at an IEP meeting or did they just send you an email or a note home or a phone call and say hey this is what we’re going to do, how did that come to be decided for all that pull out?
P: They made the decision beforehand to tell me and then they did it. It was kind of like this is where he’s at and this is what we’re doing, like letting me know he spends this amount of time in this class and this amount of time in this class and he’s improved here and, it was already kind of lined out, um, I didn’t have any say in that, um, they’re just basically delivering to me here’s the process, here’s what we’re doing.

Aubrey had established herself as a secondary team member when she stated she felt that other IEP team members had already decided what the details of Justin’s education were going to be and that the team meetings functioned more like an informational session rather than an opportunity for negotiation, collaboration and problem solving.

*Without Unease*

This sub-theme refers to those parents who, from the very beginning, were either unaware that school districts were managing a myriad of interests when negotiating a child’s education and/or believed that an educator or a school would automatically want to do what is best for their students and were able to do so. They had the utmost trust in their child’s educators and so would not think to even question how an educator handled or responded to an IEP related issue.

41 year old Tiffany is a married mother to 10 year old Jordan and had an associates degree at the time she interviewed. She worked from home as her husband’s secretary and describes here a scenario when her advocacy journey had just begun:

You know they didn’t even try to teach him how to read, it wasn’t even an option. And it was like well are you kidding me?! He’s like 7, 8 years old and it’s not even brought up. And obviously that wasn’t appropriate……and I was like why did I not push? Um and it’s because you think that they are, you know doing what’s best for your kids.

At the time Tiffany was interviewed she had moved away from the passive acceptance without unease stage in her advocacy and was transitioning into a more conscious style. Some parents may or may not evolve from this stage. However, what she is describing is where her advocacy was at a particular point in time that was reflective of the trust she had in educational professionals as justification for relinquishing control to the school. She automatically thought that
the school would do what was best for her son and so she did not question the fact that Jordan was not provided a reading curriculum.

While educational attainment is well known in Sociology for having an association with a higher cultural capital, and while it seems reasonable that the longer a parent advocates the more developed their skill set will become, the research unexpectedly found that there was something particular about the association between parental advocates Playing Nicely and Parents as Partners, an advocacy support organization. All parents who engaged in Playing Nicely and Giving Up had interacted and received advice/information from Parents as Partners.

**DISCUSSION**

From the interviews, the idea that parental advocates have to strategize around their advocacy approaches is illuminated. Although disability rights and the educational rights of the autism community have gained many advances since 1990 when autism was included in the Individuals with Disabilities Education Act, negotiating the education of a child with an autism spectrum disorder has become increasingly difficult as austerity in the U.S. has become heightened and will most likely continue under the Trump administration. That combined with problematic and conflicting special education policy has only put the public school system in between a rock and a hard place as they attempt to balance a myriad of interests with what’s best for their students. These structural constraints have only exacerbated an already existing asymmetrical power distribution between parents and school districts which has created a heightened state of conflict.

Regardless of educational attainment or family income and consistent with the Fish (2006) case study of parents of students with autism and their perceptions towards IEP meetings, conflict was a major over-arching concept that was apparent from the first handful of interviews
conducted and remained a significant topic of conversation among many interviewees. As a result of this conflict, parents have had no choice but to develop advocacy styles when attempting to manage the relationships with their child’s educators. And while the development of advocacy styles illuminated cultural capital as a guiding theory, educational attainment became teased out of cultural capital/SES as a separate factor aside from income that influenced advocacy styles. The educational attainment of parents works as a premise to how parent-educator relationships are formed and determines the nuances of these micro-level interpersonal interactions and is influential over how the power between parents and educators is distributed. While both educational attainment and income are included in SES, this study suggests that SES may be too broad in this instance suggests that the effects of education and income may vary across settings.

In regards to participants’ involvement and interaction with the advocacy organization Parents as Partners and the use of the Playing Nicely and Giving Up, a discussion on the matter is warranted. According to their website, the main function of Parents as Partners is to “encourage, educate, and empower” special needs families. This support takes several forms including providing various workshops to special needs families on topics such as IEP management, special education law and the rights of the family and their child; organizing and subsidizing parents’ attendance at conferences, advice hot lines, a family-to-family health information center and parent-to-parent support. Parents as Partners also has had a “parent training and information” (PTI) center since 1986. The website states, Parent Training and Information centers (PTIs) are available in each state. Parents as Partners provides these services by offering individual assistance to families on the phone, by email, or in person at one of our Centers.”
While Parents as Partners certainly provides accurate and empowering information and remains a valuable resource to the special needs community, the narrative is one that does not include when it would be appropriate to consider due process and how to do so. While Parents as Partners is a 501c(3) non-profit organization, much of their funding is received from the Kansas State department of education. After considering this funding source it would seemingly be a conflict of interest if Parents as Partners encouraged using due process as a viable option for families who are faced with diminishing avenues. What has developed is a narrative that has been adopted by Parents as Partners, influenced by State funding, that provides a particular form of social conditioning and dominates over a parents’ agency as an advocate. With the play nicely narrative, Parents as Partners, and any parent advocates who have been “trained” by Parents as Partners, are conditioning families in such a way so their micro-interactions with schools are cooperative and prioritize the constraints that public schools are faced with as much as they prioritize the education of their child. From a macro perspective, “playing nicely” is demonstrative of the influential power that social organizations have over individuals in the never ending dance of agency vs. structure. It is also demonstrative of how inequality can be reproduced through such conditioning.

Consistent with Lareau and Weininger’s macro analysis of education and capital, “playing nicely” reflects the “educational system’s ability to reproduce the social distribution of cultural capital which results from the educational norms of those social classes capable of imposing….the criteria of evaluation which are the most favorable to their products” (2003:578-579). Conditioning parent advocates to play nicely and prioritize cooperation cultivates a climate where the child receives some but not all of their legal rights. Further, this context does not provide a level playing field, particularly when compared to neurotypically developing children.
Just as passive acceptance or “passive participation among parents towards the IEP process is likely to hinder productive planning of a student’s education” (Fish 2006:57) so may playing nicely and giving up. What we know is that children with autism have some of the worst life trajectories compared to any other disability category combined. Adults with autism have persistently high unemployment rates, poverty rates and homelessness rates. If education is a mechanism for these circumstances and the dominating social organization is conditioning advocates for compliance, then this may be a contributing factor to the educational inequality imposed on the autism community.

**SUMMARY AND CONCLUSION**

As the autism community confronts rising prevalence rates, conflicts in special education policy and funding cuts to public education, this project sought to explore how parents of children with autism negotiate their child’s education in an age of economic austerity through the interpersonal interactions with IEP teams. Structural constraints only exacerbate a pre-existing unequal power distribution between families and schools which creates a heightened state of conflict between the two leaving parental advocates to adopt particular styles for advocacy. Both conscious styles and unconscious styles were identified through the data with educational attainment, length of time advocating and interaction with Parents as Partners influencing which style was developed. While advocacy styles weren’t necessarily mutually exclusive or static it was found that conscious styles may maximize educational benefit to an extent through the cultivation and maintenance of positive family-school relationships, with an emphasis on partnership and teamwork. Unconscious styles did not impede or support the development of a positive family-school relationship, nor did they maximize educational benefits. While different styles adopted by different parents in this study were seemingly more effective and less effective in different ways, every single parent
expressed the utmost concern for their child and sincerely wanted to do what they felt was best for their child’s education. While the more conscious styles possessed more advantages than passive acceptance, no parent got everything they asked and hoped for and no parent ever experienced an absolute success. It can be argued then that all advocacy styles may be contributing to the educational inequality and poor life trajectories experienced by children with autism. While all participants in this study were loving and concerned, the constraints placed on public schools exacerbates an already unequal power distribution between parents and educators. This dynamic impacts parent-educator relationships in a way that requires parents to develop an advocacy style.

**Strengths**

Within the field of sociology, much research has been done on the stress, anxiety, emotion management and stigma associated with parenting a child on the autism spectrum. While certainly a research worthy issue, this research looked at a different aspect of parenting a child on the autism spectrum: parent-educator relationships within the context of advocacy and the factors that influence advocacy styles. The literature reviewed revealed an emphasis on economic austerity and conflicts within special education policy.

Further, my status as a parent and educational advocate for children on the autism spectrum provides a deeper insight into the complexity of educational advocacy. I have been advocating for two children diagnosed with autism, both of whom have a different set of educational needs, for the last 8 years. My personal connection to autism and my advocacy experience helped provide entrée into the autism community, has assisted in the development of and future revisions to the interview guide, and assisted in the data analysis phase of the project.
Limitations

This study presents several limitations. The first limitation is the sampling method used. Due to the marginalized status of this study group, I was not able to apply any form of random sampling. And since I found this group unresponsive to the recruitment flyers, successful recruiting was the result of a combination of convenience sampling and snowball sampling. Second, the study lacks racial/ethnic diversity among participants. Applying snowball sampling and recruiting participants through my own social networks within the autism community, the participants recruited were of a higher SES and mostly Caucasian. Further, higher SES and Caucasian individuals are likely the individuals to be connected through support groups, at conferences and parent trainings. Lastly, future research on this matter should include what possible solutions may be needed to alleviate the impacts of educational inequality for children with an autism spectrum disorder. Such solutions could include providing an objective advocacy service, at no cost or low cost, to parents of children with autism vis-à-vis neurotypically developing children or those families with more cultural capital.
APPENDICES
**APPENDIX A**

**SAMPLE DEMOGRAPHICS**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Education</th>
<th>Yearly Family Income</th>
<th>Length of time</th>
<th>PAP Interaction</th>
<th>Advocacy Style</th>
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<tr>
<td>Lilly</td>
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<td>Playing Nicely</td>
</tr>
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<td>Sherry</td>
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<td>4 years</td>
<td>Yes</td>
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</tr>
<tr>
<td>Eric</td>
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</tr>
<tr>
<td>Amy</td>
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<td>12 years</td>
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<td>Playing Nicely/Giving Up</td>
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<tr>
<td>Elizabeth</td>
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<td>6 years</td>
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<tr>
<td>Anne</td>
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<td>5 years</td>
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<td>12 years</td>
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References


