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‘If I was a different ethnicity, would she treat me the same?’: Latino parents’ experiences obtaining autism services

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Abstract

This article reports on an ethnographic study with 12 Latino families of children on the autism spectrum related to obtaining autism services in Los Angeles County. Using critical discourse analysis of interviews, observations, and records, we consider the experiences of the Latino families in relation to: 1) A discursively constructed ‘autism parent’ subject position that mandates ‘fighting’ service systems to ‘win’ autism services for children, originating from White middle-class parents’ socio-economic resources and social capital; 2) A neoliberal social services climate that assumes scarcity of available resources and prioritizes austerity in their authorization; and 3) A media and institutional ‘cultural deficit’ discourse that attributes disparities in autism services for Latino children to their parents’ presumed culturally-based ‘passivity.’ We argue that parental discourse about fighting, or not fighting, for autism services is engendered by a tension between a parental logic of care, and the logic of competition of the economic market.

Keywords

Autism; critical discourse analysis; services; disparities; public school; special education

Introduction

As the prevalence of autism diagnosis in children has increased globally[1](Elsabbagh et al. 2012), so has the notion of an ‘autism parent’ (Silverman 2013; de Wolfe 2014; Lilley 2011; Runswick-Cole 2016; Sousa 2011). The term ‘autism parent’ conjures the image of a White, middle-class mother[2], a self-described ‘warrior’ who fights to ‘win’ autism treatments for her child. In an interview conducted for an ethnographic study with bilingual Latino families of children on the autism spectrum in Los Angeles County (Angell 2016), Sofia[3], a research

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[1] We note arguments that the increased visibility of autism diagnoses in high-income countries is related to sociocultural norms, economic resources, the influence of the biomedical model, and particular diagnostic, clinical, and research practices. Our interest here is primarily in autism as a sociocultural phenomenon (Nadesan 2005; Solomon 2010; Solomon and Bagatell 2010).

[2] Runswick-Cole (2016) uses the term ‘autism mom’ because a great number of autism parents are mothers. However, we use the term ‘autism parent’ because it was used by parents in our study, and because a number of fathers in our study were closely involved in their children’s autism services.

[3] We use pseudonyms for all research participants.

participant, described how she discovered online what it meant to be an ‘autism parent.’ Searching the Internet to learn from parents of children with autism who ‘made it,’ i.e. who were able to attend college and live independently, she noticed that:

> It’s all the same. It’s a pattern. Parents are very involved. It doesn’t necessarily have to be two parents, but it helps when it’s two. One parent needs to be completely involved with hands-on therapy, and the therapy needs to extend all day long. (…) I read these books and research about children who made it who have autism, and they’re Caucasian parents. Most of these kids are Caucasian. I rarely see Latino autistic kids making it, or succeeding. And I’m like, ‘That’s bizarre!’

Similarly to the social media discourse of ‘autism parents,’ the Latino parents in our study used warfare terms (e.g. ‘Everything is a fight,’ ‘You have to be ready for battle’) to describe the adversarial position they felt forced to take against public school officials to obtain services for their children. The experiences of these parents, however, differed from the dominant ‘autism parent’ discourse, which we argue originated in White middle-class parents’ socio-economic status and social capital (Silverman 2013). Having emerged in a global neoliberal context where public services are increasingly defunded (Timimi 2010), the ‘autism parent’ discourse implicitly conveys an institutionally ratified story that low-income parents of color do not know how to fight for autism services for their children, resulting in disparities in autism services utilization among Latinos (Zarembo, 2011).

Our ethnographic data contradicts this story. Drawing upon interviews, observations, and children’s health and educational records, we will characterize the ways in which some Latino parents in our study adopted the ‘autism parent’ identity, while others articulated in deliberate and nuanced ways why and how they rejected, altered, or departed from it (Goodley 2007). In the following sections, we outline the history of autism as a contested diagnostic category, situating the notion of an ‘autism parent’ within this context. We will then show how the ‘autism parent’ discourse implies a socio-economically privileged, White parent, excluding low-income Latino parents via a tacit assumption that they are incapable of fighting.

Autism: A history of contestation

Leo Kanner (1943), an Austrian-born psychiatrist at Johns Hopkins Hospital, was the first to use ‘autism’ to describe a group of ‘blue eyed’ White children whose parents sought him out to contest their children’s diagnoses of ‘feeblemindedness’ and ‘idiocy,’ signifying at that time ‘nonrestorative’ mental deficiencies that warranted institutionalization (Eyal 2013; Rothenberg 2003). Many of these parents, professionals in psychology, psychiatry, special education, and nursing, insisted that their children’s condition should be viewed as a treatable ‘mental illness.’ These White middle-class parents played a central role in the development of autism as a more ‘accepted,’ even ‘desirable,’ diagnosis (Eyal 2013; cf. Ong-Dean 2006).

In the following decades, parents of children with autism fought against the psychogenic theory of autism, which posited that unaffectionate ‘refrigerator mothers’ caused their children to withdraw from the world (Bettelheim 1967; Silverman 2013). Dominant cultural models of parenting have long designated certain kinds of mothers of children with disabilities as 'good' and others as 'unfit' or even responsible for their children's lack of normative developmental progress (Blum 2007; Landsman 2009; Rapp and Ginsburg 2001). Sousa (2011) shows how some 'autism mother' memoirs present 'warrior hero'[4] narratives, which serve to 'alleviate mothers' historic accountability for the cause of disabilities by elevating the discourse to heroism' (228).

Rooted in ideologies of 'intensive mothering' (Hays 1996) and 'concerted cultivation' (Lareau 2011), the expectation for 'autism parents' is that they will be *'aggressively'* involved in their child's development (Sousa 2011; Lilley 2011): They must secure cutting-edge treatments; access advice from professionals while also challenging their expertise; and 'activate' their social and cultural capital (Lareau 2011) on behalf of their child. How some parents experience these expectations can be seen on social media. For example, a mother of two children on the autism spectrum in the UK published on her blog a mock job description,[5] beginning with 'Dear Parent: Congratulations on your successful appointment to the position of Autism Parent' (@catonatrampoline 2014). It is written to other 'autism parents' who 'never actually applied for the post' but have nevertheless signed a 'Lifetime contract.' The on-the-job training of this 'mandatory' position includes 'advocating for your child,' 'networking within the multi-disciplinary team,' 'arguing constructively with professionals,' and 'fighting like a bear to protect your child and their interests.' Similarly, an Australian mother of a child on the autism spectrum blogs about the autism parent experience (@michaelsmum88 2016): The 'sleep deprivation and constant stress' of 'slugging it out at therapy all day every day,' spending 'hours every week on making flashcards, printing out programs, and organizing therapists.' In both blog posts, the stakes are clear: Echoing a belief widely touted by professionals and researchers (yet questioned by critical autism scholars; see Russell 2016), the mothers directly link their hard work with their child's chances of a bright future. British disability studies scholar and parent of a child with autism Runswick-Cole (2016) notes the influence of celebrity 'autism mothers' like Jenny McCarthy (US) and Sally Bercow (UK), who declare that it is mothers' *'duty* to free their sons[6] from the autism that is holding them hostage' (24; emphasis added).

The 'autism parent' discourse emerged most prominently in high-income, English-speaking countries, perhaps because it spread most easily through English-language social networks and social media platforms, and because similarities in the countries' service systems and civil rights laws may have made advice about fighting for services more translatable. Perhaps not incidentally, these countries, particularly the US and the UK, were leading the way toward a global economic shift, promoting the conservative economic agenda referred to as neoliberalism, characterized by austerity and the defunding of public services (Harvey 2005). Under the guise of 'family-centered care' and of healthcare and education 'reform,' a neoliberal discourse of 'no legitimate dependency' (Peacock, Bissell, and Owen 2014) shifts the burden of responsibility to parents to facilitate their children's development, which is

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[4] The term 'warrior' is by no means a unified or uncontested term when used to describe autism mothers. Jenny McCarthy's (2008) anti-vaccine 'crusade,' reflected in her book, *Mother Warriors: A Nation of Parents Healing Autism Against All Odds*, is an example of a deeply divisive ideology of motherly warfare.

[5] The job description was reprinted in the *Queensland Autism Parents' Handbook* (Heeman 2015), showing how the autism parent identity moves through time and space.

[6] Runswick-Cole (2016) previously notes that it is most often sons with autism due to higher rates of diagnosis in boys; and mothers are frequently primary caregivers, so the 'duty' is most often theirs.

used to justify reducing formal support from professionals (Hodgetts et al. 2013; Douglas 2010; Ytterhus, Wendelborg, and Lundeby 2008).

Yet another struggle was led by individuals on the autism spectrum themselves. The ‘neurodiversity’ movement challenges the biomedical view of autism, protesting efforts to ‘cure’ it and fighting for equal rights as a minority group (Bagatell 2010; Ward and Meyer 1999; Runswick-Cole 2014). Some autistic self-advocates have spoken against the autism treatments that parents often fight for their children to receive (Hurlbutt and Chalmers 2002; Connor and Ferri 2007). In the new field of critical autism studies, scholars argue for a departure from not only the biomedical view of autism but even from the use of the diagnostic label itself, attempting to open up spaces for imagining new ways of supporting people labelled as autistic (Runswick-Cole, Mallett, and Timimi 2016).

We aim to contribute to critical autism studies by examining how race, ethnicity, and class influence the ‘autism parent’ discourse, both how it emerged from the experiences of middle-class White parents, and how the experiences of low-income parents from racial and ethnic minority groups differ. We build from critical disability studies literature that understands parents of children with disabilities as ‘deconstructing or (re)deterritorializing the areas of policy, politics, practice, theory and activism’ (Goodley 2007, 145), viewing these parents not as definitive subjects but as people who ‘defy categorization,’ challenge boundaries, and are *always becoming* (Goodley 2007; Fisher and Goodley 2007; Ryan and Runswick-Cole 2008). We will explore the ways that the Latino parents in our study were, and were not, *becoming* ‘autism parents.’

The ‘autism parent’ as tacitly White and middle-class

Although a seemingly gender-, race-, and socioeconomic-neutral term, ‘autism parent’ conjures an image of a White, middle- or upper-class, college educated mother who gives up her professional career to oversee her child’s services (de Wolfe 2014; Silverman 2013; Sousa 2011; Singh 2016). The previously described Australian ‘autism mother’ @michaelsmum (2016) blogs about her transition from successful tax lawyer to full-time caregiver for her son, claiming her newly acquired expertise by describing herself as a ‘qualified ABA therapist and full time autism researcher ’

Implicit, however, in the ‘autism parent’ discourse is that parents’ tireless efforts are rewarded with an abundance of services. An excerpt from a *Los Angeles Times* article exemplifies this narrative (Zarembo 2011):

> From the day her son was diagnosed with autism nine years ago, [mother’s name][7] has made it her full-time job to find him the best possible help. Hiring lawyers and experts to press her case, she established herself as a mother whose demands could not easily be dismissed. The result has been a bounty of assistance for [child’s name]: A behavioral therapist who works with him at home and comes along on family outings, a personal aide at school and specialists to design his curriculum, improve his speech and refine his motor skills. So far, the state of California and the

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[7] To be considerate of this family’s privacy, we have omitted their names used in the article.

> Los Angeles Unified School District have spent at least $300,000 on specialized services for [child's name] (…) Getting a wide array of help for an autistic child can require waging a small war with the gatekeepers of state and school district services.

Adding to the story, a photograph of the child in his classroom, his aide and the teacher by his side, and the city where the family lived, convey their upper-middle class status and Whiteness.

Even socio-economically privileged 'autism parents' face challenges in obtaining services for their children in the current climate of austerity. For example, Matthew Asner, executive director of corporate development for Autism Speaks Southern California and the father of a son on the autism spectrum, said in an interview: 'You have to be a squeaky wheel in order to get the services that you need. This was a revelation to me. It's just bizarre, and unfortunate' (Interacting with Autism 2016). Implicit in this statement is a seemingly straightforward story: If you are able to 'be a squeaky wheel,' you can obtain 'the services you need.'

Low-income parents of color, however, face even greater challenges 'being a squeaky wheel' to successfully obtain services. In the US, children with autism 3 years of age and older receive most services through the public school system (Bilaver, Cushing, and Cutler 2016), which is ridden with documented disparities in allocation of funding for children of color (Harstad et al. 2013; Bruce and Venkatesh 2014). Autism is a unique diagnostic category in the US for which White children are overrepresented and racial and ethnic minority children from low-income families are underrepresented (CDC 2014; Mandell et al. 2009). White children diagnosed with autism receive more high-quality services than Latino children with the same diagnosis (Magaña et al. 2013; Leigh et al. 2016; Broder-Fingert et al. 2013). Institutional discourse reported in news media reflects an underlying assumption that these disparities are caused by a 'cultural deficit' whereby Latino parents do not have the knowledge or ability to fight for services (Zarembo 2011; cf. Angell, Frank, and Solomon 2016).

For example, a Los Angeles Regional Center official, responding to statistics on vast disparities in California state spending on services for Latino children with autism compared to White children, told the *Los Angeles Times* that Latino and African American families often feel stigmatized by an autism diagnosis and take minimal advantage of available services: 'Even though they have the diagnosis, they still aren't coming to terms with it' (Zarembo 2011). A statement in the article from the California Department of Developmental Services echoes this, attributing the disparities to 'language and cultural barriers' (2011), without acknowledgement of structural barriers.

In this article, we draw upon an ethnographic data corpus to examine from a critical discourse-analytic perspective (Laliberte Rudman 2013; Wodak 2004) the tension between the 'cultural deficit' account of disparities in autism services experienced by families of color, and the master narrative of parental engagement with systems of care signified by the term 'autism parent.' The description of the study is outlined below.

Methodology

Participants

The children in the study were 8 years of age or younger and had a documented autism diagnosis by a licensed professional. At least one parent was bilingual (English/Spanish) and self-identified as Latino or Hispanic. Participants included 13 children on the autism spectrum from 12 families; 12 mothers; eight fathers; and one grandmother. The socioeconomic status was left open, but the median income and average household size for the cities where the families lived indicate that most would likely be considered earners from the 'lower income tier,' and several from the 'middle income tier.'[8]

Ethical approval was obtained from the University of Southern California Institutional Review Board and the study site, a regional center in Los Angeles County. The regional center staff mailed recruitment letters to a random computer-generated list of eligible children's addresses. Interested families contacted the first author by phone or email. Because we aimed to gain multiple perspectives, we planned to recruit professionals who provided services for the children, via invitation by participating families. Only two professionals, however, were successfully recruited.[9]

All adult participants signed IRB-approved informed consent forms. Parents who shared their children's health records also signed Health Insurance Portability and Accountability Act (HIPAA) forms. Parents gave assent on behalf of their children because none were able to give written consent.

Data collection

The first author collected all data between May 2014 and May 2015, in two phases. Phase 1 (3 months) consisted of two audio-recorded narrative interviews with 12 families (20 parents, one grandmother) about how they obtained services for their children. Next, six of these families were recruited using heterogeneity sampling to represent a range of experiences (Patton 2014) to continue to Phase 2. Phase 2 (9 months) consisted of audio-recorded interviews with parents and practitioners; video-recorded observations in home, community, clinic, and school settings; and collecting children's health records (i.e., medical and educational documents related to the child's services; Angell and Solomon 2014). The data corpus consists of almost 80 hours of audio and video data (40 interviews, 10 observations, and 60 fieldnotes) and 333 health records.

Data analysis

After the first interview, the first author created visual timelines for each child, with uniform color- and pattern-coding of events related to autism services. During the second interview, the timelines were used as an interview guide and member checking strategy (Patton 2014). All interviews were transcribed verbatim and thematically coded using NVivo10 software.

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[8] This assessment uses a recent Pew Research Center analysis of lower, middle, and upper income tiers in the US (http://www.pewresearch.org/fact-tank/2016/05/11/are-you-in-the-american-middle-class/). One family's city median household income was $80,000 USD; all others ranged from $30,000 to $60,000. City average household sizes were slightly larger than the Los Angeles County average.

[9] One therapist and one therapy supervisor were recruited; see Angell (2016) for details about recruitment challenges.

Building upon our prior work (Angell and Solomon 2014), we used a critical discourse analytic approach (Laliberte Rudman 2013; Wodak 2004). The term ‘discourse’ refers to ‘a form of social action that shapes how phenomena…are understood within particular socio-historical contexts’ (Laliberte Rudman 2013, 170). We considered how the subjectivities of the parents were shaped, maintained, or resisted, iteratively moving between three kinds of discursive data: 1) Parents’ stories about obtaining services; 2) Chronologically-extended family narratives represented in the timelines; and 3) Review of health records, which often represented professionals’ or institutional perspectives, examining how these intersected with the ‘autism parent’ discourse.

Findings

Of the twelve families in the study, five fought their child’s school district at some point (see Table 1). Several of these parents proudly identified as ‘autism parents,’ while others fought reluctantly. Because of the longitudinal nature of the study, we had the opportunity to observe the transformation of two families (the parents of Jayden and of Mateo Jr. and Isabella) who initially preferred to be cooperative but began fighting their school district after an event that caused them to question how well their child was being cared for (Angell and Solomon 2017).

Five other families (see Table 1) chose not to fight, despite having concerns about their children’s services. These parents did not embrace a ‘warrior’ identity because they feared that it would cause professionals to retaliate by mistreating their child in their absence; or because, based on previous experience, they felt that they would not be heard anyway. Finally, two families, both living in higher-income areas and with young children who had only recently begun receiving services from their school district, did not have to fight to receive services. These families felt fortunate because they were aware, from social media, of other parents’ stories of having to fight.

Becoming ‘autism parents’

The five families who fought with their school district described their gradual realization that previously trusted professionals were not acting in their child’s best interests. Learning to fight was a prominent marker of *becoming* an ‘autism parent’: Sofia, mother of Danny, said, ‘We’re your typical autism parents, you know? We’ve learned how to fight.’

For many, the change from being *parents of a child with autism* to *becoming ‘autism parents’* began when they observed that school administrators seemed financially motivated to *not* provide services to their child, instead investing extensive time, energy, and resources resisting parents’ requests for services. For example, Daniel (father of Danny) and Elizabeth (mother of Tanok) noticed that their school districts claimed they did not have money for services but spent money to hire attorneys to be present at Individualized Education Program (IEP) meetings, which are held annually for US special education students to determine their needed services and supports (US Department of Education 2004). Daniel said, ‘You have money in the books for an attorney, but you don’t want to spend money on kids.’

The disillusionment that led parents to fight occurred after they initially approached their child’s special education services using a ‘logic of care’ (Mol 2008; see also Singh 2016;

Scott and Doughty 2012; Kroger 2009), only to find that the school officials approached special education as a ‘business’ where saving money – rather than educating and caring for children – was a prevailing goal. Sofia discovered this when she, a regular education teacher in a different school district than the one her son Danny attended, attended an autism training for special education teachers. During the training, the instructor told special education teachers that if a child in their classroom was provided with a one-to-one aide per their IEP, ‘that person can help with other kids [in the classroom] as well.’ The instructor also told teachers to never mention that a child might need ‘electronics’ (an electronic communication device), because if parents learned they could ask for one, the district would be required to assess and potentially provide the device for the child. In response to such instruction, Sofia said:

> I raised my hand and I’m like, ‘I want you to know that I’m here as a parent, and I don’t appreciate you training these teachers in that way. I think that’s very unethical and unprofessional.’ She went like, ‘I’m just letting them know what their rights are.’ I go, ‘That’s not their rights. What about parental rights? Did you forget about that? Because we’re here for the children, and we’re here for those families. We’re not here to make *us* look good…and get money for the district…What *side* are *you* on?’

Fabiana felt similarly after her son Mateo Jr. was ‘lost’ on a school bus, unaccounted for by the transportation department for an hour (Angell and Solomon 2017). When her request for a bus aide to ensure his safety was met with resistance, Fabiana said to the first author, ‘They may say, “I understand as a parent,” but I don’t think they do. I think they’re looking at it as a business…It’s all about the dollars.’

Sofia and Fabiana’s observations are supported by the literature. A shift in public education in the 1980s brought about legislation and policy ‘underpinned by a market-place philosophy based on principles of academic excellence, choice and competition’ (Rouse and Florian 1998, 324). This logic of competition, seen as the imperative to ration and assign market value to public services, was in direct opposition to parents’ emotionally vulnerable, interpersonally collaborative logic and ethics of care (Kröger 2009; Mol 2008). This tension led the parents to abandon emotional vulnerability for a metaphorical ‘suit of armor,’ taking an adversarial stance. Parents were still motivated by a logic of care, as is evident in spaces where ‘autism parents’ speak to one another. For example, in the previously described blog ‘job description,’ autism mother @catonatrampoline (2014) warns parents of the necessity to ‘[fight] like a bear to protect your child and their interests.’ It becomes clear to parents that vulnerability in IEP encounters is a liability (Sousa 2015). Caring for one’s child in this context means responding to administrators with emotional distance, vigilance, and force. Nicole, mother of Rafael Jr., said that in IEP meetings:

> If [Rafael Sr.] feels that I’m getting emotional, or I’m getting rattled, or I’m going to snap, he’ll take over for me. I’ve actually gotten into arguments with [therapy] supervisors before and he has to step in like, ‘Go outside, I’ve got this, because they’re no longer respecting you. They’re looking at you as an emotional parent… Let me handle it.’

For the five families that fought their district, *becoming* an 'autism parent' was initiated by the discovery that in order to get services or support for their children, their vulnerable logic of care (Mol 2008) had to be disguised, meeting administrators' market logic with equal force and distance.

Becoming Latino 'autism parents'

Danny's and Tanok's parents described long, arduous journeys to becoming 'autism parents' after constant resistance from school administrators to provide services for their children, which the parents felt was not simply to save money but to make a statement. Elizabeth said, 'All I'm asking for is more support for my son, little services. I'm like, "It's much cheaper to give me this than for me to fight you."' These families linked their Latino ethnicity to school administrators' seeming efforts to resist at all costs.

Elizabeth thought that the resistance she and her husband met was because administrators initially assumed that they were not a 'threat' based on 'cultural deficit'-based stereotypes about Latinos:

> I think, it sounds horrible, but if you see our names on paper, we're Mexican. But I was like, 'I don't care. This is my fight. This is my job. I'm not going to back down.' And I don't think they were expecting that (laughs).

Daniel and Sofia found themselves in a year-long battle over a classroom placement with Deborah Rutgers,[10] a district representative with a reputation as a 'bulldog' who caused parents to leave IEP meetings in tears. Deborah Rutgers maintained the position that Danny should be in a Los Angeles County classroom, where children with more 'severe' disabilities are placed. The parents argued that this recommendation was based on flawed standardized intelligence tests that did not reflect Danny's many abilities, such as teaching himself advanced geometry and Russian by watching YouTube videos. Sofia remembered, 'That was the worst year in my life. The *worst*.' Daniel and Sofia thought that Deborah Rutgers' efforts to place Danny in a county classroom were financially motivated, because the district would have to provide Danny with more supports if he was in a more educationally challenging classroom.

They also felt that the district's fierce resistance to their classroom placement request for Danny was an attempt to send a message to all Latino parents in the district. Sofia said, 'It was like a vendetta for her. She was like, "That's *it*…I'm gonna *squash* you."' Their son's behavior therapy supervisor agreed with this assessment; he attended one of Danny's contentious IEP meetings and told the first author it was the worst he had seen: '[The school district] needed to make it clear that they were going to be ahead no matter what…They don't want to set a precedent, so that the community understands that they're the boss, they're the gatekeepers.'

Contrary to the dominant discourse that 'autism parents' get more services because they 'wage a small war' (Zarembo 2011), the Latino 'autism parents' in this study attended parent advocacy trainings, consulted with lawyers, spoke at school board meetings, wrote

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[10] Deborah Rutgers is a pseudonym. We use a full name because Sofia and Daniel always referred to her by her full name.

formal letters to administrators, and went to IEP meetings knowledgeable about their children's rights, wielding thick binders with their children's service-related documents as evidence of this knowledge (see Angell and Solomon 2014). Unlike the mother described in the *Los Angeles Times* article who 'established herself as a mother whose demands could not easily be dismissed,' resulting in 'a bounty of assistance' for her child (Zarembo 2011), Sofia's use of 'autism parent' strategies seemed to achieve quite the opposite. When she finally 'won' the battle simply to be permitted to observe classrooms other than the one that the district recommended for Danny, Sofia, who had a master's degree in education, created an observation tool and recorded data on the number and types of verbal interactions of children in each classroom. At the IEP, Sofia presented graphs of the data to Deborah Rutgers to justify her position that Danny would have greater opportunity for verbal peer interactions in a different classroom. Sofia said, 'Her mouth just dropped and her *eyes…*and that's when I realized, "This is a *personal* thing for you."' This strategy, which revealed Sofia's expertise, did not intimidate Deborah Rutgers or cause her to respect Sofia. Instead, Sofia said that Deborah Rutgers continued to treat her as uninformed and inferior:

> It's like a shark versus a fish. You have *no* chance. And even though I'm an educated person, and I'm very knowledgeable of what [the] least restrictive environment is, and I knew all the lingo, she still spoke to me as if I was an *idiot*! Like I didn't know what I was talking about. Like I had no idea!

Sofia wondered:

> If I went in there and I was just a different ethnicity, would she have treated me the same? If I was a White woman, fighting for my children, with all the credentials that I have, would you still have treated me the same? Would you have spoken to me the same way? And *blocked* me from the services that I want?

Speaking to the first author, a White woman, Sophia suddenly stops referring to Deborah Rutgers in the third person, as 'she,' and starts referring to her in the second person, as 'you.' Instead of telling a story to the first author *about* her experiences of being discriminated against by Deborah Rutgers, Sofia is now directly confronting Deborah Rutgers about this discrimination, something she was not able to do during the actual IEP meeting. The striking shift in how Sofia discursively marks her positionality during this ethnographic interview evinces not only her despair and outrage, but also her trust that she will be heard and understood by her interviewer.

Sofia's poignant questions are underscored by the IEP meeting record: Deborah Rutgers, acting out her adversarial attitude and determination *not* to be influenced by Sofia's 'autism parent' expertise, walked out of the meeting. The meeting notes, previously typed, are now handwritten: 'School district personnel directed the parents to add their comments to the IEP. The district personnel said the meeting was over and proceeded to leave the room.' The handwritten notes list the parents' disagreement with specific claims made by the district, ending with, 'Parents do not feel they have been involved in the decision-making process of [the classroom] placement since the initial IEP.' These ethnographic data problematize the notion that parental fighting alone 'wins' services for children, suggesting that Latino 'autism parents,' despite high-level expertise, may encounter vastly unequal treatment from administrators compared to White middle-class 'autism parents.'

The making and un-making of Latino 'autism parents'

We have described how the necessity to respond to the adversarial stance of administrators tasked to authorize their children's services turns *parents of children on the autism spectrum* into *'autism parents'* The previous section was based on narrative interviews with parents reflecting upon their previous battles. Our ethnographic observation data allow us to also understand ways in which interactions between parents and professionals in the neoliberal human services context engender the subject position of an 'autism parent.'

Administrators used education law to exert authority over parents, most commonly observed as administrators attempted to legitimate their denial of parents' requests for one-to-one aides, highly desirable supports in the school system for children with attention difficulties (Kang-Yi et al. 2016). Under the Individuals with Disabilities Education Act (IDEA), children with disabilities have a legal right to the 'least restrictive environment' (LRE), meaning that they must be educated alongside non-disabled peers, rather than in separate classrooms, 'to the maximum extent appropriate' (U.S. Department of Education 2004, p. 118, STAT. 2677).

The notion of the LRE was brought up during an IEP meeting that the first author attended with Nicole (mother of Rafael Jr.). Nicole asked the IEP team, 'Do you think [Rafael Jr.] would benefit from a one-to-one aide?' The first author's fieldnote documents how charged the atmosphere in the room immediately became:

> Everyone's attention quickly goes to her and this question…The teacher says, No. We have a lot of help, and we don't want more adults for him to rely on.' The principal quickly says, 'That's more restrictive. We don't want him in a more restrictive environment.' Nicole says, 'Well, I just ask because he's 6, almost 7, and you were saying he's at like a 2-year age-range, right?' The teacher says, 'Well, he's developmentally low [*sic*], but another adult won't necessarily make him catch up faster.' Everyone's nodding. The principal says, 'Yeah, and he's not a danger to himself or others.' And everyone says, 'No.'…Everyone really picked up on their cue to chime in and agree.

During this exchange, Nicole drew upon 'evidence' from Rafael Jr.'s recent evaluation, which placed him at a 2-year-old developmental level. Test scores are often reported to parents in age ranges for particular normative skills, which can be painful for parents to hear, as it fails to capture the child's strengths (Angell and Solomon 2014). Nicole adeptly wielded this as evidence that the IEP team should consider whether a one-to-one aide might be appropriate for Rafael Jr., reasoning that if he is so far behind, he needs more support. Everyone in the room (the teacher and three therapists), however, took their cue from the principal to argue that having an aide would be 'more restrictive.' The *Los Angeles Times* reported that in the Los Angeles Unified School District, children in higher-income areas with a larger proportion of White students had one-to-one aides at more than 10 times the rate of children in low-income areas, making the claims about one-to-one assistance being 'more restrictive' clearly dubious (Zarembo 2011). These statistics support the notion that parents living in different geographical areas within the same district might receive different answers from professionals in response to the request of a school aide for their child with autism, a difference strongly demarcated by locally- and institutionally-defined notions of personhood linked to parents' class, race, and ethnicity.

Another example of professionals using legal terminology to exert institutional decision-making power regarding authorization of autism services is seen in Daniel and Sofia's story. Under IDEA, all children with disabilities are entitled to a 'free appropriate public education' (FAPE), defined as 'special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living' (U.S. Department of Education 2004, p. 118 STAT. 2651). When the parents and the district could not agree on a classroom placement, the district filed a lawsuit against Daniel and Sofia for 'parental rights.' Sofia said, 'They were telling us we were not giving our child the opportunity to have a free, appropriate- a FAPE. So they were suing us for that.' This last sentence is striking in its deceptive matter-of-factness: The school district was attempting to take away these parents' legal rights to make decisions regarding their child's educational placement, essentially 'unmaking' them as 'autism parents.'

Exhausted from the fight and worried that the district may win the lawsuit, Sofia and Daniel took Danny out of the public school system and put him into a private preschool for a year, using money they had been saving for an education lawyer. Daniel, an avid American football fan, used a story about the Buffalo Bills team to describe the defeat he felt: After being beat at the Super Bowl for the third year in a row, 'The coach quoted some poem, "Let me lie here wounded for a while. I'll get up again and fight later." And that's what it felt like.' A year later, Daniel and Sofia's neighborhood had been re-zoned, putting them in the catchment area of a different school district. They enrolled Danny in this district so they would never have to face Deborah Rutgers again.

Becoming reluctant 'autism parents'

The families of Jayden and of Mateo Jr. and Isabella did not want to be 'difficult' or 'take it that far.' However, during data collection, they reluctantly began fighting after they felt their child was not receiving adequate attention and care (Angell and Solomon 2017). Our longitudinal study provided the opportunity to observe the process unfolding. The first author's fieldnotes initially document that these families were highly collaborative, explicitly distinguishing themselves from parents who fought. For example, Sabine observed that the mothers in a support group she attended seemed 'very angry,' always fighting their school districts. She wondered if they simply did not know how to communicate differently. In the course of a year, however, she and Kyle came to feel that fighting, although undesirable, was necessary.

Initially Kyle and Sabine tried to develop a 'friendship' with Jayden's IEP team because they felt that a 'wall of professionalism' hindered communication. They eventually became frustrated, however, with a school speech therapist who used 'super old school' therapy techniques; they felt she was not putting forth her best effort with Jayden. A trusted former speech therapist of Jayden's told the parents that Jayden should have made more progress in the year that the school speech therapist had been working with him. This prompted the parents to question the school speech therapist's techniques:

> We were able to press her a little bit more during the IEPs and were very disappointed in her philosophy. She was like, 'Well this works for 99% of my children.' Well, this is *special* needs, you know, you're crazy! (laughs)…We wanted to fight that, but at the same time these are the people that spend an awful lot of time with our child. Do we really want to make enemies within a district?
>
> Well, no…We found out that she was retiring this year and it's like, 'Okay, so we just have to wait her out'…God, can you just imagine having to wait out an educator? It's the hardest thing (sighs).

Kyle, frustrated that the speech therapist did not take an individualized approach to Jayden's therapy, made a spur-of-the-moment decision in the meeting to ask for an Augmentative and Alternative Communication (AAC) assessment, which would determine whether Jayden would benefit from a device like an iPad to help him to communicate. Kyle used the therapist's bleak reporting of Jayden's capacity for speech to ask the district for the AAC evaluation. Kyle said:

> [The speech therapist] was telling us, 'Well, he can't do this, and he can't do that.' …Right then I said, 'Can we have an AAC assessment?' And by that point she had already kind of ruined her case, like she couldn't say no. And it wasn't planned, it just kind of happened that way…And the face on the [special education] director kind of changed a bit. You know, it started out smiles, then it was almost kind of like we defeated them. And we weren't really trying to get anything out of them, we were just trying to find out what would work best…So it kind of made it funky, but I think the main thing for us was to (sighs), to come to the realization that these people spend an awful lot of time with our child. So we want to keep this as amicable as possible. We want to make sure that, you know, they understand that we support what they're doing. So we really didn't try to beat it in, although I know I would have liked to.

Similarly, when Fabiana disagreed with the school district that Mateo Jr.'s autism diagnosis, and subsequently qualification for services, should be taken away, she tempered her position by acknowledging the professionals' expertise: 'I respect, I appreciate all you guys have done, and your views…But I know what I know for my kids.'

Like Goodley's (2007) 'rhizomatic parents,' here *becoming* autism parents was not linear or straightforward. The parents' identities and approach with the district altered slowly, through back-and-forth interactions with professionals in which parents found that expressing anything other than enthusiasm for professionals' recommendations caused the professionals to react defensively, treating the parents as adversaries. Kyle observed, 'They don't like when you challenge them, I guess.' This was reiterated when Sabine and Kyle consulted with an education lawyer after Jayden was 'lost' on a school bus for an hour (Angell and Solomon 2017). Sabine described what the lawyer told her:

> They're going to feel as if you're trying to attack them…Just keep reminding them that you are the parent of…a boy with autism, that your son is nonverbal. Just keep reminding them that…you're not trying to fight them, you're just trying to make things better for your son.

Despite parents' desires to act collaboratively, questioning professionals' authority resulted in being viewed as adversarial, again exemplifying a contrast between parental logic of care and school administrators' market logic (Mol 2008). Despite feeling forced into this position, as the education lawyer's advice shows, parents must simultaneously appear as though they are *not* using a competitive market logic.

Critiquing the need for an autism parent identity

Two families – the parents of Tanok and of Mateo Jr. and Isabella – initiated a fight with their district, only to find that once they gained the attention of someone 'higher up' in the district's hierarchy, their requests were quickly granted. Although both families had the benefit of having a parent who worked in public education and thus had the knowledge of the 'system,' they recognized the unjust way that the system seemed to weed out parents who might not have the time, energy, or resources to fight.

After getting a new school placement for their son Tanok, Elizabeth and her husband were fighting to get reimbursed for mileage for driving him to school because bus services were not offered. She said:

> Once my husband e-mailed the assistant superintendent, in five minutes, we got a phone call from the special ed[ucation] director, 'We're going to go ahead and reimburse you, don't worry. Just come in and sign the addendum.' Like that. After weeks of back and forth calling and e-mailing. Why do they do that? Why do they play games like that if they're going to ultimately…? I guess they want to see if you'll give in and not challenge them. Because it's going to save them money. And that sucks, because it's time and energy wasted.

Similarly, Fabiana said her concerns weren't taken seriously until her husband, a teacher, sent an email to the special education director. They were then immediately given everything that they had been asking for, and had been denied, for months. She said:

> Why couldn't you just say yes from the beginning? We were ready to pay a lawyer. Why do we have to get lawyers involved? Why do we have to get advocates involved? Why do we even have to tell the special education director?

These questions serve as a powerful critique of the system that awards services to only the most competitive parents who have resources to take their fight to higher-ranking authorities.

Resisting the autism parent identity

Five families in the study chose not to fight. None were satisfied with their child's services, but many said that protesting the situation would not help, based on past experiences where they felt that their voices were not heard. Toward the end of data collection, one mother who had just enrolled her child in public school was considering voicing concerns to the district about how well her daughter was being cared for and educated.

As we have shown, the 'autism parent' identity was taken up in varied and complex ways by the parents in the study. Even though the parents of Rafael Jr., Jayden, Mateo Jr., and Isabella at some point engaged in a fight with the school district, analysis of their interviews helps to identify reasons why other parents may choose not to fight.

A primary reason cited by parents for *not* fighting was that they feared professionals would exact retribution on their children. Kyle's story about asking for an AAC assessment for Jayden conveys the dilemma that parents faced: If they were 'difficult' parents, professionals might mistreat their children, most of whom would be unable to report it to their parents. Sabine said:

> It's scary, especially with Jayden. He doesn't speak. So if we…become the mean parents, well, not that they *want* to be mean to Jayden, but they might treat him differently because, 'Oh, he's the kid with the mean parents.'

Nicole reflected on an IEP that the first author attended with her. Initially, she had planned to voice a concern during the meeting; she felt the teacher treated Nicole's husband disrespectfully when he dropped Rafael Jr. off at school. However, Nicole changed her mind, explaining:

> I did want to tell [the teacher] that, but there's a line, because she has my child seven hours of the day. I don't want her to [take] it out on him…I don't *think* she's like that, but then again you can never trust anybody with your kids…Especially someone like him, he can't talk, he can't tell me, 'They were mean to me.'

One way that parents managed this fear was by using a 'good cop-bad cop' strategy during IEP meetings to maintain the delicate balance between being firm enough to be taken seriously, but congenial enough that professionals 'liked' them. Early in Jayden's education, before Sabine and Kyle felt forced to fight, they engaged in sophisticated intersubjective work during IEPs to calibrate the overall impression they presented as a couple, based on a moment-to-moment reading of each other's behavior and the overall tone of the meeting:

Sabine:	Kyle and I work really well as far as good cop-bad cop. (Kyle laughs)…
First Author:	Who's which?
Kyle:	It just depends.
Sabine:	I think we just catch on, and we switch (laughs)… I can be a massive B-I-T-C-H-
Kyle:	Mid-conversation we'll switch.
Sabine:	And then all of a sudden, Kyle's like, (diplomatic tone) 'Okay, well, no, what she *meant* is this, (as if trying to calm Sabine) sweetheart, sweetheart, *sweetheart!* (Kyle and first author laugh) And then he goes ahead and explains my rage.

The reasons that some parents resisted the 'autism parent' identity are yet another manifestation of the logic of care (Mol 2008) that drove their actions. Fearing that their children would be mistreated, some skillfully managed the impression they gave to professionals during meetings, while others avoided even the appearance of fighting, at the cost of not being able to express their concerns.

Discussion

We have argued that the 'autism parent' discourse emerges from the experiences and resources of White, middle- and upper-class parents. Our analysis provides a critical look at the emergence of the 'autism parent' discourse through the lens of the experiences of middle- to lower-income Latino parents of children with autism in Los Angeles County. Some of the parents in the study took up and embraced the identity after meeting resistance from school administrators at every turn. Initially assuming professionals were 'on their side,' their 'processes of becoming' (Goodley 2007) were in response to discovering the market logic that drove school administrators' rationing of services. Contrary to the 'autism parent' discourse, some of these parents faced resistance even in the face of their expertise, leaving them to question how their ethnicity influenced administrators' responses.

Other parents began to enact the 'autism parent' identity only after a significant loss of trust and fear that their children were not being well cared for. We observed this shift for two families, where parents transformed from being distinctively collaborative to reluctantly fighting when they found it was the only way to get their child's needs met. Still other families opted not to fight, determining that being amicable, or at least quiet, would ensure that their children were treated well at school.

Rather than using an overarching, culturally-determined approach to engaging with special education systems and personnel, the Latino parents in the study responded to their child's autism in varying ways. In trying to meet their child's needs, the parents faced expectations, reactions, and assumptions from professionals that differ from those implicit in the 'autism parent' discourse. Contrary to the flawed and simplistic 'cultural deficit' explanation for autism services disparities, these data reveal structural barriers to services, as well as the ways that parents' assessments of how best to care for their children lead them to make different decisions. These parents are faced with a dilemma: They must ensure that professionals 'like' their children while also aggressively fighting to prove their children to be 'service-worthy' (Hansen, Bourgois, and Drucker 2014; Marvasti 2002), even as they are positioned in opposition to gatekeeping administrators who ration services according to fiscal pressures rather than children's needs. The dilemma is rooted in the conflicting logic of competition, seen in the imperative to fight for rationed public services, and logic of care (Mol 2008), visible in the parents' concerns about their children's wellbeing. By protesting the tacitly normative processes whereby parents must fight for services for their children, the parents' stories and actions make a case against the logic of competition and for an ethics of care.

Conclusion

As the 'autism parent' discourse spreads globally through social networks and social media platforms, this article aims to understand a missing voice, that of Latino autism parents, and to show that their positionality results in different experiences than White middle-class autism parents. Despite being the largest ethnic minority in the US,[11] Latino families face not only the same resource-scarce climate as 'autism parents' around the world, but they may also face resistance from professionals despite their skillful use of 'autism parent' strategies. Although the parents in this study took different courses of action in their efforts to meet their child's needs, they were driven by a logic of care (Mol 2008). These findings problematize prominent 'cultural deficit' explanations of disparities and reveal the rich, complex, and varied processes of *becoming* – and not becoming – 'autism parents.'

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[11] As of 2014, the Hispanic/Latino population made up 17 percent of the total population of the US (https://factfmder.census.gov/faces/tableservices/isf/pages/productview.xhtml?src=bkmk).

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Points of Interest

- On social media, the phrase ‘autism parent’ often brings to mind a White, middle-class mother who ‘fights’ with administrators to ‘win’ autism services for her child.
- In our study, some Latino parents told stories about fighting their public school district to receive autism services for their children. Other parents decided not to fight, worrying that the professionals who worked with their children might mistreat them in retaliation.
- News media coverage about ‘autism parents’ make it seem as though lower-income parents from racial and ethnic minority groups are unable or unwilling to fight for services for their children. Our research shows that quite the opposite is true, and that the picture is much more complex.
- The parents in this study developed short- and long-term strategies, and made deliberate decisions about services based on their *care* for their children, but they interacted with school systems that were driven by business principles like *competition.*

Table 1

Parents' experiences of 'fighting'

Participating parents/caregivers	**Participating children on the autism spectrum**	**Parents engaged in a fight**	**Parents chose not to fight**	**Parents did not have to fight**
Sofia and Daniel	Danny	X		
Elizabeth	Tanok	X		
Fabiana and Mateo Sr.	Mateo Jr. and Isabella	X		
Sabine and Kyle	Jayden	X		
Nicole and Rafael Sr.	Rafael Jr.	X		
Jessica and Michael	Mikey		X	
Laura, Felipe, and Maria (Grandmother)	Elijah		X	
Julia	Luke		X	
Christina	Salvador		X	
Sarah	Gabriela		X	
Miriam and Dan	Olivia			X
Lydia and Edward	Ben			X

[1] The highlighted gray rows indicate the families that participated in both phases of the study and for whom we have interview, observation, and health record data.