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Understanding parents' concerns about their children with autism taking public school transportation in Los Angeles County

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Abstract

There are a number of recent US news media reports of children and youth with autism becoming lost, injured, or even dying while taking public school transportation, yet research on this problem is scarce. This ethnographic study examines the experiences of 14 parents whose children with autism take public school transportation in Los Angeles County. We present two case studies of children with autism being 'lost' while in transit from school to home on the bus to 1) describe how the situation was experienced, responded to, and managed by the parents; 2) consider three interrelated themes that emerged from interviews with 14 parents, related to children's *safety, independence, and participation*, across multiple contexts and analytic levels; and 3) discuss the findings in relation to US news media reports of incidents involving children with autism on school buses to identify specific weaknesses in school transportation infrastructure, particularly in the context of privatization, that create conditions in which children with autism can 'fall through the cracks' in potentially life-threatening ways. We argue that there is a critical need to address transportation accessibility for individuals on the autism spectrum to ensure their safety and support their independence and community participation.

Introduction

The Americans with Disabilities Act (ADA; US Department of Justice, 2009) mandates that public transportation is made accessible to individuals with disabilities, most commonly achieved through environmental adaptations that aide individuals with physical disabilities to safely enter, exit, and travel in vehicles. Transportation accessibility for individuals with autism spectrum disorder (American Psychiatric Association, 2013), however, has not been clearly defined (Falkmer et al., 2004). Moreover, while local and national news increasingly report instances of children and youth on the autism spectrum becoming lost, injured, or even dying while taking school transportation, there is a lack of research on this topic.

The situation is reminiscent of a previously obscure problem, elopement and wandering in children with autism, when it first came to the attention of researchers (Anderson et al.,

2012; Solomon and Lawlor, 2013). The problem gained the attention of the US research community only after relentless parental advocacy efforts led by the National Autism Association (McIlwain and Fournier, 2012) that were eventually supported by the Interagency Autism Coordinating Committee (IACC, 2011), the Centers for Disease Control and Prevention (CDC, 2011), and the American Academy of Pediatrics (AAP, 2012). The Interactive Autism Network (IAN) published survey results on elopement (Law and Anderson, 2011), which were followed by an analysis published in *Pediatrics* (Anderson et al., 2012), showing the scope of this problem: Almost half of participants reported that their child with autism had attempted to elope at least once after four years of age, and half also reported that they received no guidance from professionals on preventing or addressing elopement behavior. An ethnographic study of African American mothers' experiences of their children with autism in Los Angeles County also showed that the mothers did not receive services, supports, or advice from practitioners or case managers about how to address and prevent elopement and wandering, even when such assistance was directly requested (Solomon and Lawlor, 2013).

To bring a similarly overlooked problem to the attention of the research community, this article examines parents' experiences of their children with autism taking school transportation in Los Angeles County. We draw upon ethnographic narrative interviews with parents to analyze two families' descriptions of situations when their children were temporarily unaccounted for while in transit from school to home. Our analysis aims, first, to glean from these interviews how the problem, i.e. the terrifying fact that one's child became lost while taking the school bus, was experienced, responded to, and managed by the parents; and how the parents described the often inadequate responses of the school and transportation personnel who were tasked to monitor their child while in transit. Second, we consider the themes that emerged from interviews with 14 parents about their experiences with school transportation, themes which are clustered around the children's developmental needs for *safety, independence, and participation*. We are especially interested in the transactional interplay of the children's *safety, independence, and participation* across multiple, interlinked contexts (i.e. the child's home, the school, and the bus), as seen by the family, the school, and the transportation company personnel, across temporal, development-relevant frames (i.e. the child's past, present, and future). The strength of ethnographic methodology is in revealing and naming these patterns found in the interview and observational data. Third, we draw upon US news media reports of incidents involving children with autism on school buses (see Supplemental Table 1¹) to identify specific

¹Supplemental Table 1 was compiled via online searches using a combination of terms: autism, developmental disability, school bus, bus, public transit, and public transportation. We initially identified 63 incidents. We eliminated duplicate reports and those outside the U.S.; reports without a specified autism diagnosis (i.e. reports where the student was described only as having "special needs"); and incidents involving public transportation or paratransit (as there were very few compared to incidents involving school buses). We then combined reports of related incidents (e.g. item 10) and selected the most reputable sources available (e.g. local news websites). This yielded 35 incidents. The majority (81%) occurred in the past five years, which could be due to an increase in online news media presence, changes in documenting and reporting of school transportation incidents, or a true increase in incidence. We then used a qualitative coding approach to create a nomenclature of risk categories related to school transportation use by children with autism (see Table 1). The risk categories were based only on information explicitly given in the news reports. (e.g. Some reports indicated that when a student was absent because he/she was left on a bus, the parents were not contacted, which delayed the finding of the student. Other reports did not mention whether parents were called but simply indicated that the student was found on the bus at the end of the school day. In keeping with only coding information present in the reports, we coded the former, but not the latter, as "Failure to notify parent/guardian of student absence.")

weaknesses of the school transportation infrastructure that create such conditions of risk where children with autism ‘fall through the cracks’ in disturbing, and often life-threatening, ways. The analysis of ethnographic data, complemented by the news media reports, allows us to move within and across three analytic levels: the micro-level of the child and family; the institutional, meso-level of school districts and school transportation companies; and the macro-level US neoliberal climate that leads to an increasing privatization of human services (Harvey, 2005; Peacock et al., 2014).

School buses are believed to be the safest way for children to travel to and from school because they are less likely to be involved in a traffic collision compared to riding in cars (NSTA, 2013). However, news media increasingly report that while on school buses, children with autism encounter other kinds of risks besides a traffic collision, e.g. being dropped off at the wrong stop; facing verbal, physical, and sexual abuse by other students, bus drivers, or aides; being left behind on empty buses in extreme heat or cold; and even dying while on a school bus (see Supplemental Table 1). The scale of such abuse and neglect, i.e. what percentage of students with autism taking school transportation have experienced any – or several – such situations, is impossible to estimate from news reports alone, and would warrant the attention of the autism research community. These reports, however, can serve as a starting point to assemble a nomenclature of risk categories associated with the use of school transportation by students on the autism spectrum, as summarized in Table 1.

“The transport situation” for individuals on the autism spectrum

Although transportation to school, work, healthcare appointments, and social activities is a daily necessity for individuals on the autism spectrum, there is little empirical research on “the transport situation” (Falkmer et al., 2001) for these individuals and their families (Dudley et al., 2012; Lindsay, 2016). Swedish studies found that parents of children with autism were more worried than parents of children with other disabilities about their children taking school transportation because they felt that drivers had inadequate knowledge about autism and were not trained to effectively communicate with their children (Falkmer and Gregersen, 2002; Falkmer et al., 2004). This was particularly problematic because the children often rode in vehicles with unfamiliar drivers rather than having one consistent driver. In a US survey, school administrators reported that the top challenges faced by transporters of children with disabilities were the children's emotional or behavioral difficulties (51%), children being resistant to safety restraints (32%), and drivers needing additional personnel to assist them (31%) (Stout-Everyly et al., 1994). Occupational therapists conducting transportation evaluations of children with autism in the US found that 74% of the children with autism escaped their safety restraints and 21% demonstrated unsafe behavior during travel, such as aggressive behavior toward drivers, self-injurious behavior, or opening vehicle doors (Yonkman et al., 2013).

There is very little known about how individuals on the autism spectrum themselves experience transportation (Dudley et al., 2012; Falkmer et al., 2001; Lindsay, 2016). An Australian study compared the public transportation experiences of adults with autism to neurotypical adults (Falkmer et al., 2015). Transportation was particularly important for the

individuals with autism in the study because it promoted independent community mobility. They found timetables and train line maps easy to understand but reported that they sometimes felt anxious when vehicles were crowded or services ran late. In another US study, adults on the autism spectrum and their family members emphasized the critical link between transportation and community participation (Feeley et al., 2015). Although the Individuals with Disabilities Education Act website (US Department of Education, 2006) notes that Individualized Education Program² (IEP) teams should consider travel training (e.g., Precin et al., 2012) as part of a student's postsecondary transition plan, such training is not required, and the participants in Feeley et al.'s (2015) study reported that travel training was “minimal to nonexistent” (2015: 10).

Twenty-five years after the enactment of the Americans with Disabilities Act, individuals with disabilities still experience significant disparities in transportation access, which greatly impacts their community participation (Hammel et al., 2015). However, very little is known specifically about transportation access and participation for individuals on the autism spectrum (Lindsay, 2016). Although some of the risk categories presented in Table 1 could be relevant for children with any disabilities, the previously reviewed literature, along with traits that may be shared by individuals on the autism spectrum³, suggest a particular nomenclature of risk categories that individuals with autism may be vulnerable to.

For example, if a driver fails to check the vehicle for remaining passengers, children with autism with limited verbal communication skills, unable to gain the driver's attention, may be left on the bus, a phenomenon that occurs in almost 30% of the reviewed news reports. Both the previously reviewed literature and news reports suggest that staff may lack training in how to effectively manage aggressive or self-injurious behavior; behavior such as escaping safety restraints or opening doors of moving vehicles; and behavior that signals that the child is overstimulated or unable to communicate their needs. Almost half of the reviewed news reports involving physical abuse by staff were in response to student behavior (e.g. kicking the back of a seat, hitting the driver). What is particularly disturbing is that eight of the incidents of abuse by staff were caught on video from a camera mounted to the front of the bus. This indicates that efforts by school districts or transportation companies to improve oversight and accountability by installing video cameras on buses did not prevent staff from abusing students. While taking the school bus, students with autism might face challenges such as being bullied (Zablotsky et al., 2014); having opportunities for elopement and wandering (Anderson et al., 2012; Law and Anderson, 2011; Solomon and Lawlor, 2013); and experiencing overstimulation or anxiety when schedules are not followed (Falkmer et al., 2015).

It would be a mistake, however, to only consider “the transport situation” (Falkmer et al., 2001) of students with autism in terms of risk and harm. Certain traits can be assets for

²The Individualized Education Program (IEP) is a document tailored for each special education student in the US public school system that details their specialized education program, including their current levels of performance, goals, services, and supports. Every child in special education has a legal right to have an IEP, per the Individuals with Disabilities Education Act (IDEA; US Department of Education, 2004).

³We refer here to the autism phenotype as outlined in the Diagnostic and Statistical Manual (DSM-5) diagnostic criteria for autism spectrum disorder (American Psychiatric Association, 2013).

taking buses, such as ease of reading maps and timetables (e.g. Falkmer et al., 2015), and using internet and mobile phone technology. A 2011 *New York Times* article reported that a number of train museums in the US and Britain have designed programs for children with autism capitalizing on their interests and skills related to trains and train schedules (Haughney, 2011). Although children with autism may be vulnerable to certain risks while riding on buses, and more research is needed to understand and mitigate these risks, we assert that such research should avoid essentialization of autism-related traits. Rather, researchers should investigate collaboratively, with individuals on the autism spectrum and their families, what environmental adaptations would enable safe transportation access and promote community participation (e.g., Nicolaidis et al., 2011; Pellicano and Stears, 2011).

Methods

Arguing in support of rigorous qualitative research on autism in a recent editorial, Bölte (2014) wrote that “the main objective of qualitative research is to gain deeper understanding of human behavior and experiences based on (a series of) cases,” and that it “helps to ask the right questions...and can enable a deeper understanding of certain processes in humans” (2014: 67). Ethnography is a qualitative methodology used to study the everyday life activities of a group of people through the collection of narrative interviews, observations in naturalistic settings, and review of cultural artifacts (Bernard, 2012). Focused participant observation, iterative data collection and analysis, and triangulation of different kinds of data generate a level of ethnographic detail such that a comparatively small number of subjects yields a comprehensive “experience-near” understanding of the research topic (Emerson et al., 2007, 2011; Geertz, 1974, 1983). Ethnographic methodology has been productively used in studies on autism, for example, by Fein (2011, 2015a, 2015b), Grinker and Cho (2013), Grinker et al. (2012), Hart (2014), and Silverman (2008, 2013). Our prior ethnographic research has examined the uses of healthcare records by parents of children with autism (Angell and Solomon, 2014) and families' experiences of Applied Behavior Analysis (Angell, Frank, and Solomon, 2016), communication during healthcare visits (Solomon et al., 2015, 2016), elopement and wandering (Solomon and Lawlor, 2013), school inclusion (Ochs et al., 2001), and dinner-time narrative discourse of children with autism and family members (Solomon, 2004).

The data for this article were drawn from a larger, 12-month ethnographic study on Latino families' experiences of their children's autism-related services (Angell, 2016).⁴ The study was designed to focus on issues pertaining to Latino children and parents; however, the analysis presented here does not relate specifically to the families' ethnicity and is intended to contribute to a more general discussion applicable to all individuals with autism. Ethnographic methodology allows researchers to explore the phenomenon of interest as it is experienced, understood, and narrated by the study participants (Heath and Street, 2008). Although the study initially aimed to focus on services such as therapies, interventions, and educational supports, the issue of children's safety and independence on school buses

⁴The study was the first author's dissertation research and was modeled after the second author's federally-funded study with African American families of children with autism titled *Autism in Urban Context: Linking Heterogeneity with Health and Service Disparities* (National Institutes of Health/National Institute for Mental Health, R01 MH089474, 2009–2012, O. Solomon, P.I.).

emerged as critically important for the families, motivating our focus on this topic. Specifically, in unrelated incidents, two children in the study were ‘lost’ (i.e. unaccounted for by the school district transportation department) while in transit from school to home. We analyze their parents' narratives about these traumatic experiences, recorded during interviews with the first author, as descriptive case studies. Qualitative case studies allow researchers to ask “how” or “why” questions pertaining to a “contemporary phenomenon within a real-life context” (Yin, 2009: 2). In social science, case studies have the ability to provide a level of closeness to lived-experience that is not possible in large-scale studies (Stake, 1995). The cases of two children in the study who were temporarily ‘lost’ while taking the school bus help to identify three related themes, *safety*, *independence*, and *participation*, that emerged from the other families' data collected for the study, as we discuss in the Findings section.

Study design and participants

In Phase 1 of the two-phase study (months 1-3), 12 families were recruited from a regional center⁵ in Los Angeles County. The cohort included 13 children with autism (10 boys, three girls; ages three years, four months to eight years, two months) and 21 caregivers (12 mothers, eight fathers, one grandmother). Audio-recorded narrative interviews took place twice with each family to understand their experiences related to their children's services. Families' socioeconomic status was not recorded, but they lived in cities with median household incomes between \$30,000 and \$80,000.

In Phase 2 (months 4-12), six families from the original cohort were selected based on heterogeneity sampling (e.g., whose stories represented a range of experiences; Patton, 2014). All six families chose to participate in Phase 2. Data collection included: (1) audio-recorded interviews; (2) video-recorded (where possible) observations in home, clinic, community, and school settings; and (3) children's health records (i.e., documents related to the child's services; Angell and Solomon, 2014). The Phase 2 cohort included seven children with autism (four boys, three girls); 11 caregivers (six mothers, five fathers); and two practitioners.⁶

Eligibility, recruitment, and consent

After University of Southern California Institutional Review Board approval (#HS-13-00589), the regional center sent recruitment letters to randomly selected families in their client database who met eligibility criteria: Self-identification as Latino or Hispanic; at least one bilingual⁷ (English/Spanish) parent; and child eight-years-old or younger with a documented autism diagnosis by a licensed professional and qualification for services at the regional center. Interested families contacted the first author by phone or email. Participants

⁵California Department of Developmental Services funds are distributed through 21 regional centers, nonprofit agencies that provide case management and funds for services for individuals with disabilities who live in the regional center's catchment area.

⁶We aimed to recruit professionals by invitation from the families in order to gain multiple perspectives on the children's services, but only two were successfully recruited. See Angell (2016) for details about recruitment challenges.

⁷The role of language is an important factor in understanding culture, as culture is in part embodied through language. We recruited bilingual, bicultural families because they are uniquely positioned to provide important insights about the intersection of culture and families' experiences of autism, as they straddle two cultural and linguistic worlds (Soto, 2007). As previously mentioned, however, cultural processes were not a focus of this analysis.

signed approved informed consent and confidentiality forms. Parents gave assent on behalf of the children with autism in the study, as none were able to give written consent.

Data analysis

The corpus consists of almost 80 hours of audio- and video-recorded data (40 interviews, 10 observations, and 60 fieldnotes) and 333 health records. Data were transcribed verbatim and pseudonyms used for all identifiable information. All data were stored on secure server at the Mrs. T. H. Chan Division of Occupational Science and Occupational Therapy at the University of Southern California.

Nine of the families in the study (nine mothers, five fathers, and 10 children) sent their children on the school bus at least one way (i.e., either to or from school); two families did not use school district transportation; and one family did not indicate whether they did or not.⁸

After the first interview, the first author created a visual timeline of each family's story. During the second interview, the timelines were used as a means of member checking, a qualitative research strategy that allows participants to verify, modify, or correct researchers' interpretations (Patton, 2014). Coding used a combined thematic and narrative analytic approach (Reissman, 1993) and NVivo10 software to identify and interpret how the parents assigned meaning to their experiences. After reading through the data set, the first author created a codebook, using a narrative approach of keeping stories intact.⁹ The codes were then refined through an iterative process of tacking back and forth between individual stories and the visual timelines to understand how parents' experiences with school transportation fit into broader family narratives. Discussion between the authors resulted in further refinement of the themes.

Findings

We describe case studies for two unrelated instances of children being 'lost' while on the school bus that happened in August 2014 during the first week of school, in different school districts, where each child was attending a new school for kindergarten.¹⁰ Both children had taken the bus the prior year to preschool with no incident.

Case 1: Jayden

Jayden, a minimally-verbal five-year-old with autism, had just started kindergarten. His parents, Sabine and Kyle, worked full time, and Sabine's mother was responsible for getting Jayden on and off the bus. On the third day of the new school year, Jayden and his grandmother missed the bus in the morning, so Sabine's sister drove Jayden to school. That afternoon, the bus did not arrive at its scheduled time, 2:28. Jayden's grandmother called

⁸Parents were asked in interviews about their experiences with their children's services, but they were not directly asked about school transportation, as this was an issue that emerged during data collection as significant to the parents.

⁹This approach differs from other qualitative analytic methods in which coding takes place in a line-by-line or section-by-section fashion (Reissman, 1993).

¹⁰The cases are presented as narrated to the first author by the parents in audio-recorded interviews. Unless otherwise indicated as taken from fieldnotes (i.e., some parts of Case 2), all quoted material, including statements made by other people, are quoted as narrated to the first author by the parents and thus constitute their memory of what those individuals said.

Sabine at work. Sabine called the school office and was told that the driver was probably just behind schedule. At 2:45, Sabine's mother called her again, saying, "*Mija*,¹¹ where's the bus? I'm getting worried." Sabine called the school district transportation department and overheard the bus driver's response to the dispatcher: "No Jayden on the bus." Sabine called Kyle, who immediately left work and drove to the school.

Sabine called the school again and spoke to the principal, who told her that they were certain they had put Jayden on the bus. Sabine told her, "The bus is telling me otherwise. I'm at work. Please understand that I'm freaking out right now. What's going on?" The office staff contacted Jayden's teacher, who confirmed that she not only put Jayden on the bus but also told the bus driver, "This is Jayden." Sabine drove to the school and burst into tears when she arrived, exclaiming, "Where is my son? What's going on? I need to know where my son is." Recounting the story later to the first author, Kyle, who had been standing in the office for some time, said, "I couldn't even speak because I was afraid I was just going to start bawling. Because I was so angry and scared for my son."

Finally, the transportation department, on the phone with the principal, reported that Jayden had been found, an hour after he was supposed to have arrived at home. The bus driver said that Jayden had been hiding on the bus, a "red flag" to Kyle and Sabine because they knew that Jayden did not "have a concept of hiding." Kyle wanted to go pick Jayden up, but the transportation department would not tell him where Jayden was. Instead, Jayden was sent on a van back to the school. In the meantime, Sabine took the phone from the principal and said to the transportation director, "You guys lost my son, what happened?" He responded, "I don't know. I'll review it and call you." Sabine remembered thinking, "Say something like, 'Don't worry, ma'am, we'll take care of this, and we're so sorry about this'...Just say something to make me feel better!" Before they left the school, Sabine turned to the principal and said, through tears, "I trust you guys with my son daily. I need to know that he's safe. And I'm not feeling that right now."

The family went home and examined Jayden's entire body "just to make sure he's okay....It was just an awful feeling." Sabine's mother and sister called; "everybody's crying and...my mom [was saying], 'How about if he would've stayed in that bus the entire weekend!'" They thought about what might have happened during the hour that Jayden was unaccounted for. Kyle said:

We don't know where the bus is, it's a sub[stitute] bus, meaning we have no idea who the bus driver is...Did they take the bus back to the lot? Was he left in the bus? Was it, you know, is this guy a complete freaky pervert? Like we don't know any of this. And by that point, we had decided that we wanted to request the tape.

Kyle and Sabine asked the director of transportation to see the video from the fixed camera at the front of the bus. They were told that they could not see it because disciplinary action was being taken against the driver, and showing them the tape would make it public record. Sabine told the director:

¹¹Spanish for "my daughter."

You have to understand, I am the mother of a child who is nonverbal, autistic... You can tell me this entire time that nothing happened to him in the bus, but we don't know that. How can I trust this man if he lied to us saying that [Jayden] wasn't even in the bus?

Sabine called an “emergency IEP.”¹² She and Kyle, who had until then made it a point to be amicable with the school district, ‘put their game face on.’ The principal had viewed the video and gave them a moment-by-moment description of what it showed: The teacher escorted Jayden to his seat and said to the driver, “This is Jayden, he doesn't speak.” A moment later, another teacher brought another child onto the bus. The driver asked that teacher several times if Jayden was on the bus, but she repeatedly said she did not know who Jayden was. Because Jayden did not answer when the driver called the names of the children on the roll sheet, the driver did not stop at Jayden's house and repeatedly told the dispatcher that Jayden was not on the bus. Later, the driver looked at Jayden's backpack, realized who Jayden was, and told the dispatcher that Jayden was on the bus.

The principal said that Jayden was never “hiding” and that it was “hard to watch” because “all [the driver] had to do was look at [Jayden's] backpack.” Kyle believed that the principal was being honest. Exhausted and discouraged, he and Sabine decided to stop pressing the issue of viewing the video. The district implemented a system where all special education children wore nametags by which they were ‘checked in’ and ‘checked out’ on the bus.

“We feel he's being ignored.”

The day after the incident, Sabine sent the first author the following email:

We just had an awful experience with the district yesterday and I'd love to share it with you. The school OR the transportation system lost Jayden. We didn't know where he was for about an hour. There is so much to tell you about this... Kyle and I are still in shock, but we are thankful that he is ok. This road has just begun for us in regards to fighting with the district.

Two weeks later, Sabine and Kyle told the first author the story in person, but their eagerness to give voice to their experience had been replaced with a dejected tone. Sabine said:

I think this is pretty much going to be the last time we talk about it... I don't see us wanting to relive this. Again, because, (sighs)... we're just sick of it, it's like, “Alright, let's just move forward.”... (sighs) Just trying to recover from all of this... We've actually even considered, maybe we should move districts, maybe we should just- well, because we just don't *feel* it, you know? I asked about lunchtime, “How do you know that my son eats lunch?”... Obviously, they're trying to push him to take care of himself, so all they do is just look over him, and make sure, you know, that he's okay, but well, “Are you trying to make him try new things? Are you

¹²Parents of children in special education in the US can submit a written request for an IEP meeting at any time. In California, if parents request an IEP meeting for any issue that does not require that the child be assessed, the meeting must be held within 30 days of the request, not counting days between regular school sessions or holidays in excess of five school days (California Department of Education, 1980, Sec. 56343.5). Parents sometimes refer to this as an “emergency IEP” when it is called for an urgent issue.

opening [containers] for him? What's the process?" I just feel...that [the teacher] should actually just be *informing* us of all of this. And she doesn't.

Sabine also expressed fear that the school staff were not committed to Jayden's future participation in regular education. This was reiterated during the final interview with the parents the following April:

First Author And nothing else has happened with the bus?

Sabine ...No (voice lowers). They still put the sticker behind him...On his back.

First Author With his name?

Sabine Yeah...No the bus is okay. The school- (voice raises), we're just- we're having issues because we feel that he's being ignored.

The bus incident marked a turning point for the family as their trust in the school district began to erode. The parents' story of Jayden was one of hope and possibility, motivating them to tirelessly work to support him to develop skills for future integration and participation. To them, the school staff had previously been key partners in this important endeavor. Now, however, Sabine and Kyle felt that the school district had not only failed to share the family's vision for Jayden but may even be untrustworthy with his wellbeing.

Case 2: Mateo Jr

Like Jayden, Mateo Jr was starting kindergarten. The first week of school, he did not take the bus because his younger sister was hospitalized and his mother, Fabiana, was staying with her at the hospital. While their mother was away, Mateo Jr's grandmother took care of him and his younger sister Isabella, who is also diagnosed with autism. Because Fabiana had not received any information about when and where Mateo Jr would be picked up by the bus, the grandmother had to drive him to school. Fabiana repeatedly called the school district transportation department from the hospital to receive information about the bus schedule, but her messages went unreturned.

Several days later, home from the hospital with her youngest daughter, Fabiana dropped Mateo Jr off at school and saw his classmates getting off a school bus. Fabiana asked the bus driver if Mateo Jr was on her roll list. The driver said yes, so Fabiana said, "Okay, he'll start taking your bus today. His name is Mateo Jr and he's in Ms. Hennington's class." The driver said that Mateo Jr would be dropped off at an elementary school near their house¹³ at 1:30.

At 1:25, Fabiana arrived at that school. At 1:45, thinking she had misunderstood the bus driver, she called the transportation department. She heard the dispatcher contact a bus driver, then report back to Fabiana, "We can't find him." Fabiana thought, "Oh god, where's my son!"

¹³In the US public education system, children with disabilities are often sent to a school that houses a particular special education classroom (rather than attending their neighborhood school). Mateo Jr was sent to a different school for his new special education kindergarten class, so the bus dropped him off at his neighborhood school.

At almost 2:00, a bus arrived. Fabiana, still on the phone, approached the driver, a different woman from the one she had spoken to that morning. Fabiana asked if Mateo Jr was on the bus. The driver yelled to the back of the bus, "Mateo Jr?" There was no answer. The driver told Fabiana, "Nope, he's not on my bus." The driver then looked at her clipboard and said, "Yep, his name is right here. He's supposed to be on my list, but he wasn't there when I picked him up, so I just left." Fabiana, alarmed, thought, "What the hell are you telling me!" The driver left and Fabiana, still on the phone with the dispatcher, began driving to Mateo Jr's school. On the way, the dispatcher said, "We found him. The bus driver will be there in ten minutes. Go back to the school where you were."

Twenty minutes later, around 2:40, a bus arrived. The same bus driver with whom Fabiana spoke that morning at school opened the door and said cheerily, "Hi!" Fabiana said, "Where's my son?" The driver, laughing, said, "Oh, he's right here. I didn't realize he was on my bus." The driver said she had been dropping off children when Mateo Jr said, "Are you going to take me home? Because you passed my house." The driver, still laughing, told Fabiana, "So I turn around and I said, 'Well, who are *you*!' And he says, 'I'm Mateo Junyoh Weyes.'" ('Mateo Junior Reyes,' but he was unable to pronounce the 'r' sounds). Fabiana said later, "She was laughing, and I thought, 'This isn't a joke. You may think it's funny, but it's not your kid.'" She thought about what could have happened: "What if he fell asleep? What if he was nonverbal? What if, what if, what if, what if, what if, what if, what if?"

Mateo Jr's father, Mateo Sr, worked as a special education teacher in a different district. Sympathetic to school personnel, he and Fabiana always made an effort to be collaborative during IEP meetings. After the bus incident, however, they were outraged. Mateo Sr emailed a number of high-ranking administrators to call an "emergency IEP." In the IEP meeting, the transportation director told them that nothing like this had happened under his watch and assured them that it would not happen again. Mateo Sr, unconvinced by this guarantee, said, "I need a one-to-one aide for my son on the bus."

The district autism specialist, Julieta, said there would be a bus aide for two weeks, but "ultimately, we want him to be independent." The parents stepped outside to talk privately. Mateo Sr said, "Let's just take it and revisit it in two weeks. We *do* want to make him independent. We want him to be able to do stuff without mommy and daddy." Fabiana felt torn: "Part of me says, 'Yes, I know,' and another part of me is like, 'You can't guarantee that it's not going to happen again.'" She reluctantly agreed to the temporary bus aide.

Shortly after, Fabiana spoke to a friend, the mother of a girl with autism in the same school district, and discovered that a similar situation had happened to them. The previous year, this woman's "nonverbal" daughter was put on a school bus, but the driver and bus aide did not know who she was. The aide texted another aide to get the phone number of the girl's teacher, then texted the teacher a picture of the girl and the message: "Who is this and where does she go?" The mother found out the next day from the teacher but was too afraid to complain to the district, fearing her daughter might be mistreated. Fabiana was shocked to learn this, since the transportation director had been confident that children were never unaccounted for.

A few weeks later, an IEP was held to review the bus aide situation. The first author attended this meeting with Fabiana and Mateo Sr, who had a clear, unified message: They wanted the aide to be kept on the bus for the remainder of the school year, about seven more months. Julieta, the autism specialist, said that Mateo Jr was doing well and did not need the aide. Fabiana and Mateo Sr emphasized that *they* needed the aide on the bus for *their* peace of mind. Julieta emphasized that the IEP is for the *child's* needs, and an aide is not justified if a child does not have behavior problems. Per the first author's fieldnotes, Julieta said:

At the beginning of the year, there was this situation that was confusing for you, and you didn't know where Mateo Jr was... We recognize the conflict that you experienced... But at this point, there's not an issue... We can't keep an aide on the bus without a need.

Fabiana responded, "But when my son is misplaced, then it *is* about me." They finally came to agree that, because there were other children on the bus who *did* have behavior challenges, there would be one aide on the bus to supervise all the children, to be revisited when those children no longer needed the aide. Although this was not really what Fabiana and Mateo Sr wanted, they agreed.

"Eventually my son will be independent."

The first author interviewed Fabiana and Mateo Sr immediately following the IEP. Standing in the school parking lot, Fabiana brought up Julieta's comments about "independence:"

Yeah, I want him to be independent obviously, but... that's not just like a slight little mix up. That's them telling me, "I cannot find your son. I don't know where he is at." And for a mom... Okay, so let's say your son or your daughter's a little older, they're a typical kid, but my son is five, he just turned five. I was like freaking out... I don't feel like they've ever taken responsibility and said, "I am so sorry."... It's more of, "Well, it *happened*, but he wasn't really *lost*." That's exactly what they said the first time... "He wasn't really *lost*. He was *somewhere*."

Mateo Sr also reflected on the IEP: "It's not like I'm asking for a lot... They're just not budging... Being a special ed[ucation] teacher myself... I know what districts can and can't do. They're just trying to save money and that's, you know, in my opinion, that's just not right."

Julieta's use of passive language such as "this situation was confusing for you" appeared to contribute to the parents' feelings that the district never took responsibility. Fabiana said, "Eventually my son will be independent. That's what I foresee for him, obviously." To Fabiana and Mateo Sr, an aide was not a *hindrance* to their son's independence but rather a *support* to help him to develop future independence.

Safety, independence, and participation

The children's safety, independence, and participation emerged as interrelated themes in the data corpus, including the narratives of the 10 other parents in the study (besides Jaden's and Mateo Jr's parents) who used school transportation. These parents described the ways that taking the school bus provided their children with an opportunity to gain independence,

which parents linked to their children's future abilities and community participation. The parents also expressed concerns, however, regarding their children's safety. Elizabeth decided that her son Tanok would take the bus home “to give him that independence,” but she dropped him off at school because she wanted to be able to “see what was going on” in the classroom. Later, when he changed schools, the family decided not to use school transportation because his commute would be an hour each way. Elizabeth said, “Our son is epileptic. It's hot these days, heat can trigger seizures. Is someone going to be there with him? He's nonverbal...So I'm like, ‘No way.’”

Another mother, Julia, worried that her son Luke, who was very small for his age, would be harmed by older children on the bus, who she feared would “knock him down, hurt him, of course unintentionally, but...There's way older kids...[who] sit next to him, so that's scary.”

Miriam and Dan, the parents of Olivia, remembered their initial fear about her taking the bus. Miriam said, “I didn't even want her on a bus, because she's only three, you know, so I was like freaking out.” Dan said, “It's a stranger picking up our child.” Olivia's therapist convinced them to try the bus, saying it gave Olivia an opportunity to gain independence. Both Julia and Miriam followed the bus to school in their cars for the first few days to make sure their children arrived safely.

Miriam described what it was like when the bus was late, recounting a recent experience:

I called the district, I'm like, “Where's my daughter? She's three, and it's an hour late.”...They had a substitute bus driver [who] had to go two routes. And I'm like, “Well, you guys should let us know.”...I'm not even home. So the babysitter's like, “So, Olivia's not here.”...I was like freaking out.

Discussion

The two case studies presented provide an in-depth look at how the parents experienced the school district transportation department's failure to deliver their children home from school safely and on time. Like the other parents in the study who used school transportation, Jayden's and Mateo Jr's parents viewed the school bus as an opportunity for their children to gain independence, which they linked to their hopes for their children's future participation as full members of society. For Jayden's parents, the loss of trust that the school district could keep their son safe led to doubts that school personnel were supporting him to participate in regular education classes and school activities. Mateo Jr's parents believed that their son would develop future independence *because of* support a bus aide provided. This differed significantly from the school district personnel's view that a bus aide would *hinder* the development of his independence, a logic that was observed throughout the study, most commonly in response to parents' inquiries about whether their children needed one-to-one assistance at school (see Angell, 2016).

Jegatheesan and colleagues (2010) found that South Asian Muslim immigrant parents living in the US, concerned that their children with autism might be mistreated, sometimes rode the bus with their children or drove them to school. These parents, however, also “firmly believed that participation in ordinary social life was the means by which children developed

and overcame limitations” (2010: 103). Similarly, the Latino parents in this study were *both* concerned for the safety of their children on school buses *and* believed that the children should be given opportunities to develop independence through participation. When professionals focus exclusively on children's independence, especially in the context of denying supports for the child, the argument implies that the two perspectives are mutually exclusive.

The cultural primacy of independence in the US has been linked to the major economic shift in the global economy in the 1980s labeled neoliberalism, characterized by privatization, deregulation, and the defunding of social services (Harvey, 2005). Peacock and colleagues (2014) argue that in ‘more neoliberal’ countries, there is a pervasive, internalized discourse of “no legitimate dependency,” wherein the need for help is viewed as a sign of personal weakness. While the parents and professionals in this study shared the desire for children with autism to become more independent, the parents used it as proof that the child needed assistance, while the professionals used it to argue against the provision of assistance. Disability studies literature has highlighted the way that concepts such as *independence*, *self-sufficiency*, *choice*, and *inclusion*, which are central to the disability rights movement, have been appropriated by a neoliberal discourse but imbued with very different meanings and implications (Sherry, 2014). This is reflected in our findings in the different implications resulting from parents' and professionals' use of the concept of ‘independence’ – the former as proof of the need for support, the latter as a means of reducing spending.

In line with transnational privatization trends, 4,000 private bus companies are contracted by US public school systems to transport 25 million students to and from school (Price et al., 2012). The National School Transportation Association (NSTA, 2013) claims that outsourcing is a safer, more efficient model because “private school bus companies are experts at providing transportation” (2013: 35). The news reports in Supplemental Table 1, however, raise questions about 1) whether the outsourcing model leads to a lack of clarity about who is responsible for preventing further incidents, and 2) how well private company drivers are trained in transporting children on the autism spectrum.

In many of the news reports, school districts fired the private bus companies that they had previously contracted after the reported incident, but it is unknown what measures were taken to ensure that the next bus company personnel were better equipped to transport children with autism. For example, in Paterson, NJ, an eight-year-old boy with autism was dropped off by a school bus driver without a designated adult there to meet him (Supplemental Table 1, source 31). This, however, was the third bus-related incident in three years involving special education students in the Paterson School District (Malinconico, 2015). It appears that after each incident, the district fired the bus company and hired a new one, only to have an incident with the new company. What is perhaps most surprising is that the *first* of these incidents was the *death* of a 14-year-old girl with unidentified special needs who jumped out of the back of an understaffed, moving minibus, which the school board president said should have been a “wake-up call” for the district (Malinconico, 2014: 2). A school board member said, “I don't know how well they're doing picking these companies” (Malinconico, 2014: 6).

In another tragic incident in California, a 19-year-old young man on the autism spectrum died after being left on a school bus all day in near triple-digit heat (Supplemental Table 1, source 29). His parents reported that the regular bus driver always gave the young man a specific verbal cue to get off the bus (“Let’s go, [name]!”) (Chang and Avila, 2015: 12). They believe that their son stayed on the bus that day because there was a substitute driver who did not give the young man this cue, nor checked the bus for remaining passengers. The school district and bus company both denied fault, the district claiming that protocols like checking the bus are the company’s responsibility, until a lawsuit brought by the parents led to the discovery of documentation that acknowledged the driver’s responsibility. In response, the bus company admitted partial liability but claimed that the district had failed to “receive” the young man when the bus arrived at school and thus was partially liable.

These news stories raise questions about whether the outsourcing model, by making unclear who is accountable to prevent further similar situations, contributes at multiple levels to the disjuncture and fragmentation visible in the temporary ‘losses’ of Jayden and Mateo Jr. Educators Mathis and Jimerson (2008) argue that while privatization is appealing to administrators, “Private contracts may create new issues for school leaders, who remain legally responsible for a vital public function but who have lost effective control of the domain” (2008: 5). To the parents in the study, this “vital public function” was of great importance, as it implicated school personnel – and, by association, private bus company drivers – in the families’ aspirations for their children. It extended beyond merely transporting children safely between home and school, to parents’ hopes for their children’s futures, linking the activities of children at home, school, and the spaces in-between, to their future capacities as adults to actively participate in their social worlds and the society at large.

The case studies provide an ethnographic account of moments of disjuncture, where parents, believing that the system to which they entrust their children will foster the children’s development and participation, discovered with terror that the fractured system may not even be trusted to keep track of their children. Although the loss was brief, the subsequent finding of the children failed to ameliorate the parents’ sense of loss and fear for their child’s safety, as the institutional response was deeply inadequate to respond to the parents’ concerns. Having experienced a profound breach of trust that was difficult to overcome, the parents themselves became disengaged with the systems, their participation fundamentally altered as they became more vigilant and less trusting, not only about their child’s school transportation safety, but about their entire educational experience.

The school transportation system becomes even more fractured when a private company, with its own interests separate from the school district, enters the scene. Our analysis reveals the precarious infrastructure and uncertain practices of school transportation companies responsible for monitoring children with autism while in transit between school and home. It also reveals a certain kind of a monitoring *gaze* that is crucial for the children’s safe return: A gaze that sees the children on the bus as individuals, known by their names, by their strengths and vulnerabilities, and by the identities of their parents and other family members who are waiting for them at the bus stop. This monitoring fails when the children are handed by school personnel over to the care of “strangers” working for the transportation company,

whose gaze is unable to locate the children as individuals belonging to a specific family and place. The risks of taking school transportation are engendered when the desired developmental ‘independence’ of children with autism encounters the economic and institutional ‘independence’ of privatized school transportation companies, making it possible for the companies’ personnel to evade the bonds of familiarity and awareness that assure the children’s safe return home from school.

Limitations

This study was limited to the experiences of bilingual Latino parents of children with autism living in Los Angeles County; therefore, we are unable to make claims about how these findings compare to the experiences of children and families of other racial or ethnic groups. Efforts to reduce bias and enhance credibility included prolonged data collection, triangulation of data collection methods, and member checking. As with all qualitative research, our findings are not intended to generalize to a large population. Rather, the strength of this qualitative approach is in providing an in-depth understanding of lived-experience, and in identifying a problem that warrants further attention from research and clinical communities. Future studies are needed that examine the transportation experiences, including safety risks, of children with autism from all racial and ethnic groups.

Conclusion

The qualitative findings presented in this paper, along with the reported incidents in which children with autism were harmed or put at risk while taking school transportation, indicate an urgent need to address the “transport situation” (Falkmer et al., 2001) for individuals on the autism spectrum. As we have argued, this necessarily involves starting from the experiences and perspectives of individuals with autism and their families (Nicolaidis et al., 2011; Pellicano and Stears, 2011), to collaboratively discover new forms of environmental modifications that will enable individuals with autism to safely travel throughout their communities. As argued by the parents in the study, safety and independence are not mutually exclusive; rather, both must be supported.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Risk categories extracted from US news media reports of incidents involving students with autism on school buses.

Risk Category	Number of Incidents¹⁴ (%)
Negligence by staff	
• Failure to ensure student safely exited bus	10
• Failure to adequately supervise student	4
• Let student off bus without designated adult present	4
• Failure to respond to bus alarm/disabled alarm	2
• Put student on wrong bus	1
• Failure to follow assigned route	1
• Let student off at wrong stop	1
Total	23 (65.7%)
Abuse by staff	
• Physical	11
• Verbal	2
• Sexual	1
• Emotional	1
Total	15 (42.9%)
Administrative failure	
• Failure to notify parent/guardian of student absence	3
• Failure to respond to previously raised concern	2
• Scheduling problem	2
• Inadequate number of personnel/staff	1
• Failure to locate bus transporting student	1
• Failure to seek immediate medical attention for student	1
Total	10 (28.6%)
Abuse by other student(s)	
• Physical	3
• Emotional (e.g. bullying)	2
• Verbal	1
• Sexual	1
Total	7 (20.0%)
Staff/administrator mismanagement of student behavior	
• Responded with abuse or threat of abuse	5
• Responded with law enforcement	2
Total	7 (20.0%)

¹⁴ Refer to incidents reviewed in Supplemental Table 1.