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“And I look down and he is gone”: Narrating autism, elopement and wandering in Los Angeles

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Abstract

‘Wandering’ and ‘elopement’ have been identified as common in autism, affecting half of all diagnosed children ages four to ten, yet families rarely receive advice from practitioners even after the fact. Family perspectives have been missing from the literature as well as from public health and policy debates on how and when to respond to this problem. The problem of ‘wandering’ and ‘elopement’ reveals a complex intersection of larger issues encountered by families of children with autism. To consider these issues, this article examines ‘wandering’ and ‘elopement’ from the perspectives of African American mothers of children with autism, an underrepresented group in autism research. We consider how the mothers experience these behaviors and the response to these behaviors by professionals, such as service coordinators and law enforcement personnel working within various jurisdictions that become involved with the problem. We analyze the mothers’ narratives about ‘wandering’ and ‘elopement’ drawn from ethnographic interviews that were collected between October 1, 2009 and August 31, 2012. These interviews were part of a larger project on disparities in autism diagnosis and services that followed a cohort of 25 four to ten-year old children. Drawing on narrative, phenomenological and interpretive traditions, we trace the mothers’ developing understandings of ‘wandering’ and ‘elopement’ over time, and show how these understandings become elaborated and transformed. This article provides a nuanced, moment-to-moment and longitudinal picture of the mothers’ experiences of ‘wandering’ and ‘elopement’ that enriches the cross-sectional view of large-scale surveys about the problem and contributes unique insights at the family and community levels. Implications for professional awareness, clinical practice and service provision are also suggested.

Keywords

USA; African American; autism; elopement; family perspectives; mothers; narrative; wandering

Introduction

Daniel just turned five, so last summer he ran off at an amusement park, I found him in the parking lot by the car, like, “I’m ready to go”. And the second time, I was gone, he was at home with my husband, and he opened the door and left the house, and the police, we just found out that somebody picked him up and put him in their car because he was about to run out into the street.

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This story was told by Daniel's mother, Noreen¹, in a meeting of African American families participating in a research study on autism diagnosis and services in Los Angeles County, California. Simultaneously composed and emotional, Noreen conveyed in painstaking detail the terrifying experience that she and her husband endured when their then-four year old son, diagnosed with autism a year earlier, wandered off into busy city streets and disappeared from sight twice in a span of a few weeks. Noreen's experience is alarmingly common among families of children with autism. A national survey found that half of all children diagnosed with autism 'wander off' or 'elope' from their homes and schools, and police are involved in a third of these cases; these families rarely receive advice from practitioners even after the fact; and half of the families never receive any guidance from practitioners about this problem (Anderson et al., 2012; Law & Anderson, 2011). How can Noreen's story and similar stories of other families inform responsive, family-centered care for children with autism? How can we transform these moving accounts of personal distress into "experience-near" (Geertz, 1974: 28) data that contribute to practice- and policy-relevant debates on the provision of therapeutic interventions, support services and healthcare for children with autism?

Part of a larger project on disparities in autism diagnosis and services ('Autism in Urban Context: Linking Heterogeneity with Health and Service Disparities', National Institute for Mental Health, R01 MH089474, 2009–2012, O. Solomon, P.I.), our study draws on narrative, phenomenological and interpretive traditions to consider these questions (Kleinman, 1988, 1995; Lawlor, 2004, 2009, 2012; Lawlor & Mattingly, 1998, 2009, 2014; Mattingly, 1998, 2010; Mattingly & Lawlor, 2000; Ochs & Capps, 2001; Solomon, 2004, 2013). We examine narratives of 'wandering' and 'elopement' on two temporal, interconnected planes: one that considers the mothers' moment-to-moment experiences of the child's actions and the response that brings the child back to safety; the other, a longitudinal view of the mothers' developing framing of 'wandering' and 'elopement', and their negotiations with professionals working within various jurisdictions, from service coordinators to law enforcement personnel, about what a response to this problem should be. We use these terms in quotation marks to show their provisional nature.

We focus on mothers because they were the children's primary caregivers in all except one family in the study, and because they told most of the narratives in our data corpus about 'wandering' and 'elopement'. We follow a research tradition on motherhood as socially constructed, highly diverse and historically situated (Collins, 1994; Landsman, 1999, 2005; Lawlor, 2004; McDonnell, 1991). Moreover, we focus on African American mothers who are underrepresented in autism research and who face disparities in the age of their children's diagnosis, in the number of visits required to receive a diagnosis, and the likelihood of a misdiagnosis (Hilton et al., 2010; Lord & Bishop, 2010; Mandell et al., 2007, 2009). These disparities are associated with unfavorable developmental and health outcomes, and inadequate access to services (Liptak et al., 2008; Mandell et al., 2009; Thomas et al., 2007).

Public spending data from administrative entities that authorize and provide services for children with autism in California, the Department of Developmental Services (DDS) and the public school system, present a state-level picture of these disparities. In 2010, the year for which such data have been publicly reported, spending on white children's services at 14 of the 21 DDS' regional centers exceeded spending on services for African American children. Average spending for African American children was \$6,593 per child, while for white children it amounted to \$11,723 per child. There were also geographic differences in

¹All research participants' names are pseudonyms and all names of geographical localities and other identifiable terms have been changed.

the DDS spending ranging on average from \$1,991 per child in the inner city of Los Angeles to \$18,356 per child in Orange County. Similar disparities in spending on autism-related services were found in the school system. In the Los Angeles Unified school district during 2010–2011 academic year, 31% of white children with autism attending elementary school had behavioral aids, compared with 15.6 % of African American children. Published in a major local newspaper, The Los Angeles Times, these data produced a public uproar, a heated media debate, and a California legislative hearing on how the DDS allocates public funding for autism-related services (Los Angeles Times, 2012).

The theme that African American children and families are marginalized and treated unequally by institutions authorizing autism-related services was recurrent in our data. We present it briefly here to frame the discussion of ‘wandering’ and ‘elopement’. In various degrees of directness in referencing race, gender, economic disadvantage, autism and the larger notions of disability, the mothers in our study spoke about “our children” not receiving the interventions and services that they needed, and to “our parents” being looked down upon by officials making decisions about these services.

When the Los Angeles Times’ analysis of inequities in autism-related public spending (Los Angeles Times, 2011) was published, the mothers in our study told numerous stories of their own experiences of inequity in acquiring autism interventions and services for their children. They were appalled by the interpretation of the data that lauded white middle class parents as “warriors” and cast African American and Latino families as passive, uneducated and uninformed. Throughout these stories, the mothers spoke of their hard, relentless work of ‘fighting’ for services and interventions for their children. Inequities in autism-related services were seen by most of them as yet another manifestation of a larger historically rooted, persistent discrimination experienced by African Americans.

Consider how a mother in our study, Rene, who has two daughters with autism, describes her feelings about the inequities in services: *Being an African American, you feel really hopeless because the inequities are so deeply rooted. And you know, I'm not gonna kid myself, we can't change four, five hundred years of history. But that's why Black people are- African Americans are- have such a strong spirituality. Because there is so little justice, you know?*

Another mother, Karen, expressed a similar view: *It's almost a disconnection. That's what it feels like. The black community, it feels isolated and disconnected and that's what it feels like. And it's no one particular reason because it didn't just start.*

Related to this theme of historically-rooted discrimination was the mothers’ concern with the intersection of autism, gender and “being Black”. Because autism affects approximately four times more boys than girls, it also refracts the complex positioning of being an African American male with a disability. Here is how one of the mothers in our study, Layla, narrates this problem as she sees it in her son’s second grade classroom: *The teacher had three autistic kids in her class and they were all in the back and they were all separated from the other kids. And, you know, don't single him out like that, [Another mother: Right, mm hm] he is seven, he has the rest of his life being Black and being labeled autistic, you know, even if he is high functioning, he's got issues, so don't ostracize him in the second grade, you know.*

These mothers’ narratives of personal experience resonate with the Institute of Medicine’s findings (Smedley et al., 2002) that “differences in health care occur in the context of broader historic and contemporary social and economic inequality and persistent racial and ethnic discrimination in many sectors of American life” (cited from Nelson, 2002, p. 666). In these narratives, however, the portrayals of persistent injustice and societal disconnection

co-existed with a resistance to the marginalization (Jacobs et al., 2011; Lilley, 2013). The mothers' narratives were also characterized by painstaking attention to the particularities of their children's experience and of their children's autism. For several mothers in our study, the behaviors described in the research literature as 'wandering' and 'elopement' (Anderson et al., 2012; Law & Anderson, 2011) figured in important and unexpected ways in their developing understanding of their children. In the next section, we describe how the terms 'wandering' and 'elopement' *themselves* complicate an understanding of the children's behavior.

'Wandering' and 'elopement': Conceptual challenges

Challenges of understanding 'wandering' and 'elopement' in autism begin with the terms' commonplace usage. In everyday talk, "wandering" may denote romanticized images of nomadic travelers, while "elopement" usually signifies a hasty wedding. As Law and Anderson (2011) comment: "It's difficult to name the behavior because we know so little about it. Is it aimless, or are these individuals trying to reach a place or person? Is it motivated by fear, sensory-sensitivity, boredom, or curiosity? Is the person who wanders scared, joyful, or in a fog?" (p.2).

As we will show in this article, the ambiguity of the terms 'wandering' and 'elopement' is further reified by parents' and professionals' contradictory and often opposing views on actions and subjectivities of children with autism. Do these terms denote an intentionality, curiosity, resourcefulness, and appreciation of space and place? Or alternatively, an impulsive, irrational, physiologically-based escape from one's environment? The often elusive nature of the internal world of people with autism in general, and children with autism in particular, is a pressing and weighty problem for parents and caregivers. This challenge is often coupled with another hermeneutic struggle to differentiate whether these behaviors are related to autism or to being a child with a proclivity for exploration.

Furthermore, the terms 'wandering' and 'elopement' both essentialize the children's behavior as clinically-relevant and obfuscate its impact on the parents and other caregivers, their personal experiences and knowledge of this problem, and the ways they struggle with it. Professionals responding to the problem may be hard-pressed to use the principles of family-centered care that regards families' perspectives as central to the framing of problems and intervention planning (Gance-Cleveland, 2006; Lawlor & Mattingly, 1998, 2009, 2014). In other words, when used in clinical discourse, the terms 'wandering' and 'elopement' may obscure from professionals the critical urgency and the life-threatening nature of the problem for the families. That the problems of 'wandering' and 'elopement' are critically urgent is indisputable. The behavior is linked to the highest standardized mortality for children with autism between ages 5 and 10 compared with any other age group (Shavelle et al., 2001) and prompted a new ICD9 code, V40.31 'Wandering in diseases classified elsewhere' (IACC, 2011).

Emic and etic approaches to understanding families' experiences of autism

The most recently reported prevalence of autism is one in 88 children, one in 54 boys and one in 252 girls (CDC, 2012). The biomedical model considers autism a spectrum disorder that impairs social communication and interaction across contexts, including social-emotional reciprocity, the use of eye contact and body language, and the ability to form and maintain age-appropriate relationships (APA, 2013). Another view is that autism is a culturally and historically contingent category that has been shaped by the medical establishment, parents, and affected individuals themselves (Bagatell, 2010; Grinker, 2007; Grinker & Cho, 2013; Grinker et al., 2011; Silverman, 2008, 2012; Sinclair, 1993). As Hacking (1995) explains, these often conflicting discourses "make up" different kinds of

people with autism because descriptive and diagnostic categories become assimilated into individuals' and families' practices and descriptions of themselves (see also Ortega, 2009). Some of these descriptions, Hacking (2009) argues, create thicker and richer images of subjectivities and inner lives of people with autism than do other descriptions. These different descriptions can "coexist and hybridize" (Eyal et al., 2010: 232) within the same family, and even within the same parent's understanding of a child with autism (see also Silverman, 2012).

Although interdisciplinary collaborations are common in autism research, studies gravitate toward either biomedical or social science poles (Solomon, 2010), divided along the emic / etic distinction (Geertz, 1974; Harris, 1964; Pike, 1967). As Harris (1976) explains, the emic / etic distinction is between "the entities and processes of social life that are real and important to the participants versus entities and processes which by virtue of their scientific status are capable of efficaciously explaining (and changing) social thoughts and activities regardless whether they are real or important from the participants' point of view" (p. 330). The etic perspective is used in the U.S. national survey studies that analyze large databases such as the National Survey of children's Health (Blumberg et al., 2012) where families' experiences are elicited through categorical or "yes/no" questions and terms designed to elicit information in specific areas of interest that include family functioning, child's health status and neighborhood characteristics as conceptualized by researchers (Kogan et al., 2008).

Autism presents an intriguing case study for the sociological debates about the credibility of storied accounts of illness or disability, and the validity of narrative-based methodologies to access the personal experience of those affected by it (Thomas, 2010). Beginning with the psychogenic theory of autism, and a more recent theory of autistic regression that confirmed parental accounts of social skill loss (Rogers, 2004), its history as a clinical category illustrates that research on families' experience of autism warrants keen analytic attention to their narratives, and their first-hand knowledge and expertise.

Our data show that families have much at stake and work hard to 'be known' by health care professionals and other service providers. Although the complexities of parent-professional collaboration can not be underestimated, only when professionals follow the philosophical principle of family-centered care to meet families "where they are at" (Lawless et al., 2008, p. 51) and to 'know enough' about families' perspectives, the parental expertise acquires the epistemic authorityⁱⁱ necessary for collaborative planning of how the children's complex needs, including problems of 'wandering' and 'elopement', should be addressed (Eyal, 2013; Eyal & Hart, 2010; Hodge & Runswick-Cole, 2008).

Methods

Data and the sample

As discussed earlier, this ethnographic project draws on narrative, phenomenological and interpretive traditions (Kleinman, 1988, 1995; Lawlor, 2004; 2009, 2012; Lawlor & Mattingly, 1998, 2001, 2009, 2014; Mattingly, 1998, 2010; Ochs & Capps, 2001; Solomon, 2004, 2008, 2013). Primary modes of data collection were narratively based interviews; social network interviews; participant observation in the home, clinical and community settings; fieldnotes; and document reviews. Ethical approval for the study was obtained from

ⁱⁱ'Epistemic authority' denotes an expressed attitude that one's knowledge and views are significant or authoritative with respect to the matter at hand, based upon one's social identity and 'epistemic rights' to information, including information derived from personal experience (Heritage & Raymond, 2005, p.15-16).

the University of Southern California Health Science Campus Institutional Review Board (protocol # HS-09-00386) and the clinical sites.

The clinical sites were four Department of Developmental Services' regional centers that establish eligibility and authorize services, a university hospital and a center for developmental disabilities in Los Angeles County. Recruitment was carried out through the anonymous mailings of letters describing the study to a randomly generated list of eligible children's addresses done by staff at study sites; placement of recruitment brochures in study sites' waiting rooms; website postings; and clinician referrals. To qualify for the study, the children had to be eight or younger at the time of enrollment, and ranged between the ages four and ten during data collection period. Enrolled children had a documented autism diagnosis by a licensed professional, and a projected need for interventions and services at one of the study sites.

Twenty-five children from twenty-three families living in Los Angeles participated in the study. Twenty-two mothers and fifteen fathers and stepfathers, and seventeen extended family members also participated. The parents self-identified as African American. The socio-economic status of the families was left open, however, our study sites primarily serve lower SES families. Additionally, sixty-five professionals including physicians, behavioral therapists, occupational therapists, speech pathologists, teachers, and service coordinators participated in the study. The major part of the data was collected between October 1, 2009 and August 31, 2012. The data used for this article consisted of 196 narratively structured interviews with parents and 23 Collective Narrative meetings with the families described below. Selected ethnographic observations and video and audio-recordings of the children and their parents during clinical encounters with professionals were also used in data analysis.

Data collection approach

The participant observation involved data collection in the home, clinic, school and community contexts. Efforts were made to be minimally intrusive, and scheduling and observations were based on parent discretion. Professionals serving the children were only approached to participate in the study with the parents' permission. Whenever possible, we observed and video-recorded the children and their parents during appointments with the enrolled professionals. For some families, home was a frequent place of observation. Other families preferred to be interviewed and observed outside their homes in community settings. Participant observation placed us in the midst of the families' social life where there were continuous opportunities to build participant-researcher relationships based on trust that was critical for the quality of our data.

The trust was further supported by the Collective Narrative group interview methodology, a unique component of the study (Jacobs et al., 2011; Lawlor, 2009; Lawlor & Mattingly, 2001, 2009, 2014; Mattingly, 2010; Mattingly et al., 2002). Collective Narrative meetings involved subsets of the cohort consisting of six to eight families who met with the researchers to tell stories about their child's condition, their experiences during health care encounters, and the events that took place in the families' lives. The Collective Narrative approach is processual, relational, and evolving over time. It is based upon families' recognition of the longevity of engagement with each other and with the researchers. It differs from other group interview approaches such as focus groups that are designed around information-gathering shaped by the etic perspectives of the researchers and are usually time limited with little opportunity for rapport, relationship and trust building (Brown, 1999).

Although Collective Narrative meetings were facilitated by two researchers (the authors), the parents were able to shape their representations of the experiences through the manner in

which they narrated their stories of family life with autism. There were several ethical challenges in carrying out the study and a detailed analysis would warrant more space than is presently available. Although our research team includes experts in several fields, we were not in a position to respond directly to clinical questions and, in fact, received relatively few inquiries of this nature from families. A number of parents wanted to draw on the expertise of the researchers particularly as it related to views on their children's futures, a theme that was prominent in our data. These challenges were discussed in data analysis meetings, reflected in fieldnotes, and approached with vigilance in supervisory relationships.

Our methodology was designed to elicit meaning-making, thus providing opportunities for the families to share experiences that were significant or troubling to them. Similar to Gray's (2002, 2008) findings, some of these experiences were related to the children's communicative challenges, their sexuality, and their difficulties with continence. Other experiences were related to 'wandering' and 'elopement'. The narratives analyzed in this article were told not because we asked specific questions about this problem but because our methodology elicited the mothers' emic perspectives and because they were compelled to share their perspectives with each other and with us.

Out of 25 participating children, 9 had a history of the 'wandering' and 'elopement' behavior as reflected in their mothers' narratives during the data collection period. The 'elopement' and 'wandering' sub-corpus was compiled through computer-generated data-searches that included, in addition to 'elopement' and 'wandering', the terms used by the mothers such as 'run', 'dart' and 'bolt'. These narratives varied in length and some were retellings of the same experiences with additional details and new information.

Narrative analysis approach

The sub-corpus was analyzed using thematic and narrative analyses, with attention to the interactional dimension when video of the narratives was available. Thematic and narrative analyses are complementary and uniquely suited to capture the emic perspectives of the study participants. Thematic analysis was used to find patterns in the data both within and across cases, making minimal a priori assumptions about what thematic categories should be used (Bernard, 2012). Narrative analysis was used to identify and interpret the ways in which the mothers assigned meanings to their experiences and situated them in their broader life stories (e.g. Bruner, 1991; Lawlor, 2004, 2009; Mattingly, 2010; Mattingly et al., 2002; Solomon, 2013). These two forms of analysis allowed for an iterative process that moved between the particularities of individual experience during each 'elopement' and 'wandering' incident and the themes and patterns within and across families, informing our understanding of both.

Narrating the moment-to-moment experiences of 'wandering' and 'elopement'

Having described our conceptual framing and methodological approach to understanding African American mothers' perspectives on 'wandering' and 'elopement', we now return to Noreen's story. In the analysis that follows we seek to capture Noreen's moment-to-moment experiences of Daniel's actions and the response that brought him back to safety.

Daniel first wanders off at an amusement park. Noreen remembers this experience as if it is happening before her eyes: "*We were going into the arcade and he was right beside me. And I look down and he is gone*". Although panicked, Noreen responds to this sudden crisis by imagining her son's subjective state: "*I am trying to think, like he thinks, what would he be doing?*" She goes to the parking lot and stands there: "*Like, 'let me wait a minute'*" and then she looks by their car and sees Daniel's feet. Noreen marvels at Daniel's ability to locate their car in a large, busy parking lot, something that no four year old should be able to

accomplish. Her narrative reflects the complex processes of negotiation and struggling with the etic and emic framings of her son's autism. For Noreen, Daniel's subjectivity is comprehensible, a quality that makes him available to both knowing others and being known by them, especially, in this case, by his mother. Noreen's ability to intersubjectively 'read' her son and trace his possible steps in order to find him becomes a lifesaving skill. Consistent with the earlier discussion of contradictory views that a parent may simultaneously hold about a child with autism, Noreen also experiences Daniel's actions as unfathomable. Similar to published accounts of a child's safe return after a 'wandering' or 'elopement' incident (e.g. Touchstone, 1998), autism is both a disorder that makes the child 'run off' and a special ability that allows him to accomplish the impossible: a four year old finds his family's car in a vast parking lot.

During the same individual interview, Noreen tells about a second incident of Daniel's wandering that took place a month later, that is also recast moment-by-moment: *Then just on Saturday, I was taking my daughter to a birthday party and my husband called me and said: "I can't find Daniel." He said: "I just heard the door open and so I start looking around, and Daniel is not around. So I go outside and start looking for him, can't find him anywhere, looking all around here, asking people." So he called the police. The police said: "Yeah, he was walking down the street." He was walking along the street next to the shopping center and some people saw him walking down the street in the restaurant and retrieved him and called the police. 'Cause that was-, the amusement park thing was the beginning of August, like the first weekend, and this was just Saturday.*

Similarly to her considering Daniel's subjectivity during the first wandering episode, here Noreen also ponders about Daniel's motivations behind walking out of the house, whether "he may have been thinking that he was gonna look for us", an explanation that frames Daniel as a relational being, a child who is attached to his mother and sister. In Noreen's narrative, the response to Daniel's actions by complete strangers (i.e. "some people" who "saw him walking down the street"), and the police is instantaneous, evincing recognition of the seriousness of the problem.

Over the course of the study, Noreen returns to these experiences during Collective Narrative meetings and thus provides an explanatory framework against which the other mothers make sense of their own experiences that they never knew were connected to their children's autism. For example, Lita, whose son Maurice had given her little trouble in the past, was stunned to hear Noreen's stories and to realize that she had been experiencing similar problems without knowing that they were related to Maurice's autism. She recounted two episodes of Maurice's behavior that can be described as 'elopement'. The first episode happens at a children's restaurant called Chucky Cheese's. Minutes after his disappearance, Maurice is found by his grandmother in a play area inside the restaurant.

The second episode is about Maurice nearly jumping off a 20-foot high platform at an amusement park. Lita recounts, moment-by-moment, her experiences: *So we're at least 20 feet in the sky (...) so Maurice, he just busts out, and it literally paralyzed me 'cause I-I couldn't move, he stopped right at the edge, and he looked over, and he-he just, he did like this (has her two hands together like a diver, and does the motion of diving forward) and he stopped his body, he just (does the motion again) and I grabbed him so fast, and all I could remember is I was shaking, I could literally see my hands just shaking, and I had to stop, the day was over for us, we went home, 'cause I could not focus, and I had to stop before I even got to my car, couldn't drive like that.*

Although husbands, other family members and police are involved in the immediate management of the problem, the mothers appear to be entirely on their own to make sense of

these terrifying and dangerous behaviors. The Collective Narrative meetings provided a forum for the exchange of experiences that turned into valuable, potentially life saving information for those mothers who were just beginning to experience their children's 'wandering' and 'elopement'. Families in the study did not share, in connection with these stories, any insights or recommendations that were gained from practitioners.

How this is possible can be glimpsed from a video-recorded interaction of one of the mothers in the study with her son's physician. During the discussion of a medication, the mother mentions the issue of her son's 'running away', but no uptake or follow-up questions are forthcoming from the physician who is still focused on the dosage of the child's medication:

Physician: What did it (the medication) do for him exactly?

Mother: He didn't run away from the classroom as much. I didn't hear about as many behavioral issues. I think last time when we here, he was actually, he almost made it out of the school.

Physician: Well, I think, the tablet form, there's a generic. I'm not sure about the liquid.

Mother: Oh, the liquid has a generic. It's covered by my insurance.

Taken together, these data support the view provided by Law and Andersen (2011) that little information is forthcoming from the practitioners. The consequences of this silence, as the narratives above suggest, can be traumatic and potentially tragic for the children and their families.

Developing understanding of 'wandering' and 'elopement' overtime

We now return to Noreen's story to follow her developing understanding of Daniel's wandering as a problem linked to autism. We show how the first experiences of what we call 'pre-wandering' gradually develop into a crisis. The core narratives analyzed here form a sequence of chronologically related stories that reflect Noreen's growing understanding of Daniel's 'wandering' and its connection with autism. These narratives were told during individual interviews with the first author and during a Collective Narrative meeting where both authors were co-facilitators of the group's interview process.

Noreen first talks about Daniel's 'running off' during the first interview in the spring of 2010. At the time Daniel attended an adaptive physical education (PE) class at school and was learning to safely climb stairs and jump off play structures. Adaptive PE is seen by Noreen as an intervention to address Daniel's limited awareness of "*things that are dangerous to do*". In this 'pre-wandering' interview, Noreen is concerned that Daniel will run into the middle of the street if not held by the hand. Although alarmed that Daniel is not aware of danger, Noreen does not yet feel, as she does later, that this behavior may be linked to autism.

By the next interview, in early summer of 2010, Noreen had experienced two separate episodes of Daniel's 'elopement' and 'wandering'. The second episode, discussed in the previous section, becomes the cornerstone of Noreen's efforts to acquire an extended year educational program that would provide a structured environment during the summer months. While the response of the police to Daniel's second incident of 'elopement' and 'wandering' is narrated by Noreen as instantaneous, the response of the regional center that authorizes autism-related services proves to be long in coming. Noreen returns to these experiences of 'wandering' and 'elopement' to tell the researcher about her efforts to acquire the extended year program that in her view would prevent Daniel from 'running off' again.

Noreen's story portrays, turn-by-turn, her interactions with a regional center supervisor. In this re-telling, Noreen articulates in great detail how she conveyed to this professional her understanding of Daniel's autism and his needs for a structured environment. She does so by linking the two 'wandering' episodes into a pattern of behavior that is attributed to a gap in structure, a behavior that will continue unless this gap is bridged through an extended year program. The authorization of the extended year program is portrayed as a warranted and natural response to Daniel's 'wandering', similar to the police response when he walked out of the house. Noreen portrays her interactions with the regional center supervisor as a moral battleground, a contestation between two worldviews: one that is based upon Noreen's concern for her child's life and safety, the other upon an institutional categories of eligibility and 'service-worth' (Marvasti, 2002).

Noreen marks the supervisor's words by lowering her tone of voice: *"Oh well, how often has it happened?" I was like "Well, it's happened three times". "Well, that's not often enough." I was like "Well, how often, you know, does it need to happen?" I was like "This is something serious". Obviously, you know, he could have wandered into the street and got hit or been kidnapped, you know, it's not something that, you know, frequent, but it only takes one time for him to get killed.*

Noreen laments the lack of acknowledgement of the seriousness of the problem by the supervisor. Similar to what Anderson et al. (2012) and Law & Anderson (2011) found in their national survey, neither advice nor interventions were forthcoming as a response to Daniel's 'wandering'. In the end of the conversation, the supervisor exercises her institutional power and one last time denies Noreen's request. As a way of saying good-bye, the supervisor comments *"Well, it's not like Daniel has run away"*. Beyond the notion of not being heard, this narrative reveals an asymmetrical distribution of power and epistemic authority among parents and professionals in position to authorize or deny services and interventions (Eyal, 2013; Eyal & Hart, 2010; Hodge & Runswick-Cole, 2008; Lilley, 2011). This narrative shows that the seriousness of the problem of Daniel's 'wandering' is open to debate and interpretation, rather than taken for granted as was the case in the police response. Further, this exemplar illustrates a gap between family and practitioner perspectives that impedes the 'partnering up' central to family centered care approaches.

The day after this individual interview, eight families, including Noreen's, met for a Collective Narrative meeting. The story that Noreen tells to the group is the story that we quote in the beginning of the article, about two incidents of Daniel 'running off'. Noreen enacts for the group the telephone conversation with the regional center supervisor. Directed to the group of other mothers, this narrative contains more anger than was apparent in the narrative told during the preceding interview with the researcher. The interactional space of the Collective Narrative meeting, the environment built upon the commonality of the families' experience often allowed for a more expansive and more emotional telling of a story. Noreen begins her story with Daniel's two incidents of 'wandering off', proceeding to the careful preparation of her written and verbal arguments for his eligibility for the extended year program based upon the regional center's own eligibility criteria, to the phone conversation with the supervisor that ended in denial of her request. She narrates the supervisor's talk in a deliberately monotone half-whisper, which stands in contrast to her own passionate, high-volume voice. When Noreen intones the supervisor's *"no no no no no"* the other mothers join in and echo her words, showing an identification with her experience.

Moreover, this version of the story contains a more elaborate version of the supervisor's epistemic position on Noreen's request that involves at least four reasons for the denial: 1) Daniel has not wandered off often enough; 2) Noreen is trying to acquire free daycare; 3) there are fiscal limitations to the services that the regional center will authorize, and 4) there

are other children that the regional center personnel have to worry about. Noreen's narrative captures a complex process of narrative co-construction and framing in the processes of autism services acquisition that involve the intersubjective interpretation of the other by both the parents and the professionals (Lawlor, 2009, 2012; Lawlor & Mattingly, 1998, 2001, 2009, 2014).

The problem of evidence in 'elopement' and 'wandering'

Similar to Lita's story about Maurice's behavior discussed earlier, other mothers responded to Noreen's story with experiences of their children's 'wandering' and 'elopement'. One of these stories was told by Eugenia whose sons, Sam and Jacob, are diagnosed with autism. Eugenia's story is a response to Noreen's not only because her story is about the time Sam was found far from home, miraculously unharmed. It is also about a response of the neighbors and the police to Sam's disappearance, and about achieving a shared understanding of the problem with a professional. In Eugenia's story, while she and her two older children are looking for Sam in their building, a neighbor sees him in the discount store four city blocks away and calls another neighbor who, in turn, calls Eugenia. When Eugenia appears at the scene, there are several police cars. Eugenia has to explain to the policemen why her 6-year old son is alone at a discount store.

In contrast to Noreen's construction of Daniel's subjectivity, Eugenia portrays Sam as so cognitively impaired that he does not even recognize her as his mother: *Of course by the time we get there there's four police cars and six cops. So I'm explaining, "He has autism, he's not verbal, probably doesn't really know who I am, but I AM his mother, I know we don't really look alike but I AM his mom, please give me my child"*. The likelihood of a police report and the possible involvement of child protection services is averted because Sam runs off in front of the policemen and Eugenia. This prompts one of the officers to say to Eugenia, as they both breathlessly run after the boy, *"Oh, I know what you mean"*. The accomplishment of a shared understanding of this problem by Eugenia and the policeman is what Noreen is striving for and cannot achieve with the regional center supervisor.

Eugenia's story ends with her service coordinator (i.e. a regional center official in a lower position than the supervisor portrayed in Noreen's story) offering and authorizing In Home Supportive Services (IHSS) to provide Eugenia with help managing Sam's complex needs. Eugenia's experience differs in this regard from Noreen's. Eugenia portrays her service coordinator's offer of help in response to Sam's 'wandering' and 'elopement' as follows: *She said "You know what, you're not parenting, this is not normal parenting, you need some help." I said "okay"*.

It is significant in Eugenia's story that the service coordinator offered the services without Eugenia ever asking for them, as a response to Sam's behavior and not to Eugenia's request. Noreen's and Eugenia's narratives illuminate ways in which 'wandering' and 'elopement' present a serious challenge for African American families in the human services domain. In the institutional worlds of service provision there is a dilemma of what constitutes evidence for children's 'wandering' and 'elopement', and how much epistemic authority a parent has to exert in order to be helped with this problem. Because children with autism do not often manifest these behaviors in the presence of practitioners and others as in Eugenia's story, these professionals have to either rely on parental accounts to authorize interventions and services, or challenge these accounts. Participants' collaborative stance, often across racial, ethnic and cultural differences, and the professionals' 'good enough' understanding of the child's home and family life (Lawlor, 2004; Lawlor & Cada, 1993; Lawlor & Mattingly, 1998, 2009, 2014; Mattingly & Lawlor, 2000) are decisive factors in how the service system will respond to the problem of 'elopement' and 'wandering'.

“Too little too late”: long-term lack of services and its consequences

The last example presented in this article demonstrates the larger problem of disparities in services and the place ‘elopement’ and ‘wandering’ occupy in them. Consider the experiences of Geena whose daughter, Gayle, was eight years old at the time of enrollment in our study. An articulate and precocious child, Gayle has had a difficult diagnostic history. At the age of three, Gayle was diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (APA, 2000) that disqualified her from regional center services. She did, however, qualify for services through the school system that has different eligibility criteria. Gayle’s first ‘elopement’ was at age three when she first bolted in front of a mail truck.

Although Geena’s story of her pursuit of services and interventions for Gayle is too complex to discuss in detail in this article, a part of this story is directly related to our discussion. At age eight, Gayle was diagnosed with Autistic Disorder by a regional center psychologist, which qualified her for autism-related services through the regional center. But, as her mother repeatedly said in an individual interview about Gayle’s latest ‘elopement’, this was “*too little too late*”.

Getting off the school bus in front of the family’s house, Gayle breaks away from her mother and runs fast down the busy street. Similarly to Noreen’s, Lita’s and Eugenia’s recounting of their children’s actions, Geena remembers this experience moment by moment: *She breaks away from me and runs towards the park. She runs down the street, across the street and I pretty much know where she’s going because she’s ran there before, she decided she wanted to go, instead of going straight down the street, she wanted to cross. But she doesn’t look for any cars, she runs straight out in the middle of the street and almost gets hit by a car.*

After Geena’s brother-in-law helps to bring Gayle home, Geena calls the regional center service coordinator to tell him about the incident. In the interview, Geena tells how the service coordinator called the next day to say that Gayle will be provided with a one-on-one behavioral aide at school, a service that Geena has been trying to acquire for a long time. He called again to let Geena know that an authorization has been made for a residential placement for Gayle in Sunny Side, a town in Los Angeles County, that Geena has been requesting.

Geena remembers this conversation and her feelings about the services that have been finally authorized for Gayle: *Now she almost dies and gets hurt and then they want to help me? This is how the system works! So now I have the services that I wanted, that we knew-but it’s too little too late for Gayle.*

This example raises the question of whether this family’s crisis could have been averted by the provision of timely services for this child and her family. Already existing disparities in services for African American children with autism and their families seem to create an even more urgent public health, human services and public policy problem when ‘elopement’ and ‘wandering’ are part of the picture.

Discussion

For the mothers in our study, the stories of ‘wandering’ and ‘elopement’ become vehicles for pondering what kinds of social contexts they are inhabiting, and within what kinds of subject positions they are placed (Mattingly et al., 2002). The mothers narrate ‘wandering’ and ‘elopement’ of their children with autism as highly traumatic events that warrant an immediate emergency response to bring their child to safety, as well as a response from

service professionals, such as an empathic stance and an authorization of services to mitigate the behavior. These narratives have to be collaboratively co-constructed by both the mothers and the professionals, and this co-construction requires significant interactional, intersubjective and relational work (Lawlor, 2009, 2012; Lawlor & Mattingly, 1998, 2001).

What processes may hinder this narrative co-construction? Landsman (1999) explains how children with disabilities and their mothers may be undervalued in the consumer culture. In our study, ‘wandering’ and ‘elopement’ refracted the problem of being ‘undervalued’ in ways linked to larger issues experienced by the families. Based upon the mothers’ narratives, the children in the study who ‘wandered’ or ‘eloped’ were ‘valued’ enough so that their disappearance triggered an immediate response from the police, the neighbors and the community, but some children were not ‘valued’ enough to be offered services to prevent another attempt of ‘wandering’ and ‘elopement’. Which authoritative institutions have or have not claimed jurisdiction (Eyal, 2013) over ‘wandering’ and ‘elopement’ may provide some insight into the situation: the health care and the autism services systems have been reticent to claim the problem as their responsibility while the law enforcement has been fully engaged with it (Hall et al., 2007).

There are several insights to be gained from our data. First, the absence of professional advice, identified by Law and Anderson (2011) and Anderson et al. (2012) and supported by our data, creates an enormous hardship and stress for the families. The problem is complicated by the ambiguous nature of the terms ‘wandering’ and ‘elopement’, as discussed by Law and Anderson (2011), that points to contradictory views on actions and subjectivities of children with autism while essentializing their behavior as clinically-relevant and obfuscating its impact on the parents and other caregivers. This may have important consequences for clinical practice and service provision particularly when practitioners do not recognize the urgency of the problem. Recognizing ‘elopement’ and ‘wandering’ in parents’ discourse and intervening promptly with advice should become an area of training for practitioners.

Second, the dissonance between families’ and professionals’ perspectives on the problem reveals the failures of the family-centered care movement to fulfill the promise of effective, responsive partnerships. One of the classic mantras of the family-centered approach is meeting families “where they are at” (Lawless et al., 2008, p. 51). Despite the awkward grammar, this mantra points toward a kind of ‘partnering up’ intended to facilitate the processes of naming and framing problems, sharing and distributing expertise, and addressing needs in a manner that is both effective and supportive of family life. As Lawlor and Mattingly (2014) have argued, family-centered care is “an experience that happens when practitioners effectively and compassionately listen to the concerns, address the needs, and support the hopes of people and their families” (p.154). The African American mothers’ narrative portrayals of ‘elopement’ and ‘wandering’ described in this article are particularly clear exemplars of the kinds of problems that the family-centered care movement was intended to resolve.

Third, our data show that mothers whose children ‘wander’ or ‘elope’ face a difficult task of performing a ‘good mother’ identity (Goffman 1959) in the face of open or implicit blame from others. During healthcare encounters or interactions with service coordinators, mothers are at work to present themselves as ‘good mothers’ and engage the professionals in narrative, moral reasoning related to interventions and services to address their children’s needs. As Smedley et al. (2002) argue, both structural and interactional processes contribute to health care disparities and “unequal treatment” of racially and ethnically diverse families. While the mothers in our study told stories about their experiences of ‘deeply rooted inequities’ in autism-related services, often framing these inequities as another example of

discrimination experienced by African Americans, both these experiences and *their significance* to the families may be obscured from service providers by racial, ethnic and cultural differences, embedded prejudices and preconceptions about ‘poor parenting’. ‘Elopement’ and ‘wandering’, as a multifaceted problem that begins with description and naming, makes the gap in ‘knowing enough’ about the families (Lawlor & Mattingly, 1998, 2009) especially visible. Moreover, this gap in understanding families’ perspectives appears to perpetuate the inequities. Our data show that families’ independence and self-reliance in the management of their children’s autism are transactional and relational processes that are placed at risk by insufficient services and interventions.

Finally, what emerges in the data is how communities are affected by the problem. In many of the stories, it is the neighbors or complete strangers who see the child walking down the street or wandering in a store and suddenly find themselves having to ‘retrieve’ the child from a dangerous situation, given that the most common locations from which children with autism ‘wander’ or ‘elope’ are their homes (74%), stores (40%), and schools (29%) (Anderson et al., 2012). Moreover, close calls with traffic injury were reported in 65% of all elopement cases in the Anderson et al. (2012) survey, suggesting that motorists may find themselves in unpredictable and terrifying situations when encountering children with autism who ‘wander’ in traffic areas. “What is at stake” (Kleinman, 1988, p.55) in these narratives extends beyond the children’s ‘wandering’ and ‘elopement’ to the issues of social justice for the children, their families, and the larger community. The problem becomes a test for the moral conduct of the systems of care: a response that acknowledges the problem and provides immediate and practical means to its containment.

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Research highlights

We examine African American mothers' experience of their children's autism
We provide an ethnographic perspective of 'wandering' and 'elopement' in autism
A moment-to-moment and longitudinal views of mothers' experiences are offered
Emic / etic perspectives and disparities in services are linked to the problem
Implications for practice and service provision are discussed