



## “And I look down and he is gone”: Narrating autism, elopement and wandering in Los Angeles<sup>☆</sup>



Olga Solomon\*, Mary C. Lawlor

University of Southern California, Los Angeles, CA 90089, USA

### ARTICLE INFO

#### Article history:

Available online 5 July 2013

#### Keywords:

USA  
African American  
Autism  
Elopement  
Family perspectives  
Mothers  
Narrative  
Wandering

### 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.

© 2013 The Authors. Published by Elsevier Ltd. All rights reserved.

### 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.*

This story was told by Daniel’s mother, Noreen,<sup>1</sup> in a meeting of African American families participating in a research study on autism diagnosis and services in Los Angeles County, California.

<sup>☆</sup> This is an open-access article distributed under the terms of the Creative Commons Attribution-NonCommercial-No Derivative Works License, which permits non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

\* Corresponding author.

E-mail addresses: [olga.solomon@usc.edu](mailto:olga.solomon@usc.edu) (O. Solomon), [lawlor@usc.edu](mailto:lawlor@usc.edu) (M.C. Lawlor).

<sup>1</sup> All research participants’ names are pseudonyms and all names of geographical localities and other identifiable terms have been changed.

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, Ittenbach, Levy & Pinto-Martin, 2007; Mandell et al., 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, Ellis, McLaurin, Daniels & Morrissy, 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 \$6593 per child, while for white children it amounted to \$11,723 per child. There were also geographic differences in the DDS spending ranging on average from \$1991 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, Stith & Nelson, 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, Lawlor & Mattingly, 2011; Lilley, 2013). The mothers' narratives were also characterized by painstaking attention to the particularities of their children's experiences 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).

Download English Version:

<https://daneshyari.com/en/article/7336853>

Download Persian Version:

<https://daneshyari.com/article/7336853>

[Daneshyari.com](https://daneshyari.com)