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Beyond V40.31: Narrative phenomenology of wandering in autism and dementia

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Introduction

... Above all else, his favorite thing to do — more than browsing YouTube or playing music or eating candy — was to run. His daily life was regimented by necessity. His mother and brothers would walk him to and from the school bus. At school, his IEPⁱ consistently called for him to be closely supervised. And he chafed at confinement, seizing control any way he knew how and seeking out openings to forge out on his own: In 2011, his IEP singled out three behaviors: “grabbing at adults,” “going through other people’s personal belongings,” and “running in the hall.” He was described as running “all the time,” “throughout the day.” (...) He received medals at school for races when he was younger, and even when he was approaching high-school age, breaking off into a run was a constant temptation; his mother needed to escort him on the shortest of trips to his grandmother’s apartment four blocks away. Even his favorite game on the iPad was Temple Run, a first-person game with running and leaping and sharp turns that go on endlessly, winding through different landscapes. Running without stopping.

... The park is near the water, which some autistic kids are attracted to, so perhaps he ran toward the water. But the shoreline in that part of the park was blocked by a fence (...). So perhaps he kept running. Maybe down the block, to a hilly area, masked by shrubbery, along the mouth of Newtown Creek. There were places for Avonte to hide there, if, in fact, he was looking to hide — to stay out of school for as long as he could. And since no one came looking for him for at least an hour, maybe more, there was nothing to keep him from staying in those little hills,

Conflict of interest:

Olga Solomon declares that she has no conflict of interest.

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Compliance with Ethical Standards: All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

ⁱIndividualized Educational Program, an official U.S. school document outlining therapeutic services and their goals for a child with a disability.

wandering, running, exploring, until it got dark. Maybe he enjoyed being on his own. Or maybe he wasn't sure what to do. Maybe the more he ran, the less he could figure out how to get home.

... Fontaine, for her part, couldn't see her son bothering with the water, or with climbing a fence. "He likes the sprinklers, but not deep water," she says. His thing is running. Always has been. (...) She prefers thinking that Avonte was out on the streets, hours, days, weeks longer than the police say was possible. Maybe he **wandered** through Queens. Maybe he took the subway. Whatever he did, wherever he went, she sees him running. Running without stopping.

These excerpts are from a New York magazine article titled 'The Boy Who Ran: The Life and Death of Avonte Oquendo' which was based on interviews with Avonte's mother, Vanessa Fontaine (Kolker 2014). Avonte was a 14-year old African American boy with Autism Spectrum Disorder (ASD) who on October 4, 2013 got past a distracted security guard at The Riverview School, a high school in Queens, and ran out of the unlocked school door into the street. When the school security videos of Avonte running down the halls, out the door to the street, and turning the street corner in front of the school were released to the media and posted on YouTube, it was continuously replayed in the news and shared on the Internet. After months of intensive local and national news media coverage, relentless social media networking, "missing person" sign-postings, and searching by Avonte's family, the New York Police Department, and hundreds of volunteers, his remains were found by a passerby in the East River on January 16, 2014. A cause of his death was never determined.

In the excerpts above, Avonte's love for running is described by his mother as "his thing", a defining characteristic of his personhood that was rewarded with medals when he was younger. As his opportunities for running seem to have diminished as he got older, it became a constant temptation in a "life regimented by necessity". 'Running', however, is not equated with 'wandering' in Kolker's (2014) article: the words '**wandering**' and '**wandered**' appear with no clinically-relevant connotations that directly link them to autism, but rather are textually parallel to "*running*" and "*exploring*" (i.e. "*there was nothing to keep him from staying in those little hills, wandering, running, exploring, until it got dark*"). The details, most of which were provided by Avonte's mother, tell a story about a boy's love for running and being good at it: the specific examples leading to a picture of tendencies. Only with time, in the aftermath of Avonte's death, has this become a story about autism and wandering: a typification story that evaluates a behavior as clinically-relevant and aligns it with a diagnostic category (Maynard and Turowetz 2017). What did become linked to autism in Kolker's (2014) article is an attraction to water, a typification that Avonte's mother, who knew him best, rejected. Kolker (2014) describes in great detail ways in which she tried to enter into Avonte's subjectivity, imagine his intentions and his state of mind by mapping and tracing his possible movement through the area surrounding the school and the landscape beyond: wandering through Queens, taking the subway. Even the detectives, Kolker (2014) writes, were "trying to *channel* the interests and inclinations of a 14-year-old autistic boy" (n/p; italics added). By doing so, they were also engaged in urgent and rigorous intersubjective work to imagine Avonte's experience of moving through the physical space surrounding the school and beyond.

The experiences of Avonte's mother and other members of his family during and after the search are impossible to describe in an academic article, but their intersubjective work is strikingly recognizable to us from our ethnographic work on African American families' experiences of their children's ASD in South Los Angelesⁱⁱ. In our earlier work (Solomon and Lawlor 2013), we analyzed a narrative told by a mother in our study about a time when her 5-year old son walked away from her at a large amusement park:

"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. (...) 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." (p. 109).

A mother who participated in another studyⁱⁱⁱ described how, when her daughter ran away at a large international airport, she felt that she had to inhabit her child's very being and envision where she went. She then found her daughter at a moving baggage carousel (Lawlor and Solomon 2017).

The article excerpts (Kolker 2014) and our ethnographic examples above illustrate how, when a child with ASD 'wanders', the parents – mothers in the examples above – attempt to comprehend their child's subjectivity by imaginatively tracing his or her movement through space. From a theoretical perspective, a concern with how notions of personhood, subjectivity, intentionality, rational agency, and moral autonomy have been contingent upon biopolitical regimes governing movement of the human body through space has been shared by medical and psychological anthropologists, moral philosophers, critical race theorists, and more recently, critical autism theorists (Hilton 2017). It has been argued that the *space*, or what some have called the *landscape*, is not neutral but constitutes and is perceptually constituted by the person's experience of movement along its surfaces, pathways, or lines (Shepard 1967; Ingold 2007, 2015; Ingold and Vergunst 2008; Gibson 1979; Merleau-Ponty 1964). When the movement is deemed aberrant, and its pathways and lines are found 'wandering' rather than 'straight', the person may be construed as irrational, erratic, fugitive, disabled, a potential danger to self and others, and in need of surveillance, supervision, and restraint (Hilton 2017, Livingston 2009, Puar 2009.)

Combining critical race theory and critical autism studies to analyze the case of Avonte Oquendo, Hilton (2017) points out that 'while we must keep sight of the historical and epistemological distinctions separating the racist optics that have contributed to the denial of black sentience from the visual rhetorics that construe autism as an epistemological

ⁱⁱR01 MH089474, Autism in Urban Context: Linking Heterogeneity with Health and Service Disparities, 2009–2012, O. Solomon, P.I., M. Lawlor, Co-I; the other co-investigators were: Sharon Cermak, Marian Williams, Thomas Valente, Marie Poulson, and Larry Yin.

ⁱⁱⁱBoundary Crossings: Re-Situating Cultural Competence, MCHB # MCJ 060745; NCMRR, NICHD, NIH # R01 HD 38878; # 2 R01 HD 38878.

boundary, we must also consider how these separate visual logics function in tandem with one another” (p.227). The enforced ‘regimes of movement’, Hilton (2017) explains, determine “the means through which movement is produced as *freedom or as threat*” (Kotef 2015: 5, cf Hilton 2017, p. 229, italics added). Who decides among these two possibilities depends not only upon the hierarchies of power but also upon whose voices are the loudest and most resonant with dominant ‘stakeholders’ positions, and whose stories evoke the most primordial reactions in the general public as they become spread and amplified in the news and social media. Hilton (2017) argues that the presentation and interpretation of the school security footage was shaped by the history of representations of autism, rendering Avonte’s autism scientifically and culturally visible, and making it difficult to see him, a ‘nonverbal’ Black teenager with autism, as an autonomous subject with his own preferences, capabilities, and desires that are comprehensible, knowable, and predictable to others. Rather, Hilton (2017) argues, in the blurry school security video, Avonte’s experience is rendered as unknowable and opaque, his subjectivity “attenuated or wholly absent”, and obscured within an epistemological boundary separating him from the neurotypical autonomous human personhood (p. 227).

This view of Avonte stands in stark contrast with how his mother describes him in an interview for the New York magazine (Kolker 2014). We focus on the tension between these two epistemological positions. First, the experiential, embodied, intersubjectively accomplished forms of knowledge of people with ASD and AD who ‘wander’, and of their family members: both first- and second-person perspectives and experiences. Second, the biomedical and the genetic forms of knowledge that negate the “sociocultural, historical, and situated perceptions of the subjectivity, personhood, sociality, and ways of being for people who acquire or are “acquired” by the autism diagnosis” (Lawlor and Solomon 2017, p.232) or by the diagnosis of Alzheimer’s disease (see also Grinker 2010, 2015; McDermott 1993).

At the heart of our inquiry, as Elizabeth Fein (2015) noted in her discussant’s comments on a conference version of this article, is “the elusiveness of autistic subjectivity in a non-autistic majority world, and the complexities of representing and responding to modes of being that move with great speed across socially sanctioned boundaries” (n/p). The observation about “the complexities of representing and responding to modes of being” and “the movement across socially sanctioned boundaries” (Fein 2015) could also be extended to people with AD. Our goal in this article is to challenge the notions of ‘wandering’ as meaningless or lacking intention usually held in biomedical approaches to ASD and AD, which *a priori* cast people with these conditions as erratic and *always already* a danger to self and others. When a person’s movement through space is deemed aberrant, he or she may be construed as irrational, a danger to self because of a lack of self-awareness, and a danger to others because of a lack of empathy. These attributions put the person at risk of being excluded from the considerations and, more importantly, the obligations of the ‘moral community’ to ensure that he or she has a ‘good human life’ (Barnbaum 2008; Silvers and Francis 2009). Who counts as a ‘person’, what is meant by a ‘moral community’, how it happens to be in position to grant or deny someone a ‘good human life’, and even what constitutes a ‘good human life’ and according to whom, are all problems that are at once personal, philosophical, and political (Kittay 2009; Mattingly 2010, 2014), and are directly relevant to how ‘wandering’ is conceptualized and practically addressed in public health policy.

In our analysis of ‘wandering’ in ASD and AD, we draw upon the growing scholarship that contests highly generalized and often incorrect assumptions about experiences and capabilities of people with cognitive and developmental disabilities made by some theoreticians of moral philosophy, liberal theory, and bioethics. While making categorical, mostly negating, and highly consequential conclusions about lived experiences of people with cognitive and developmental disabilities, these theoreticians overlook the epistemic challenges that making such conclusions presents to their disciplines’ theoretical and ethical foundations (for review, see Barnbaum 2008; Bickenbach, Felder and Schmitz 2014; Kittay 2001, 2005, 2009). It has been argued from both within and outside these disciplines that these theoreticians’ contestations of ‘personhood’, ‘moral status’, and worthiness of a ‘good human life’ of people with cognitive and developmental disabilities have been made based upon a radical typification in the absence of an affinitive relationship with any such individual, and engendered by a lack of substantiated (i.e. beyond the hypothetical imaginary) familiarity with their experiences, proclivities, and capabilities (Bérubé 2009; Carlson 2010; Kittay and Carlson 2009). Even when there is an affinitive relationship, there is a possibility of misinterpretation and misrepresentation of meaning of a person with cognitive or developmental disability, which may have dire consequences (Chew 2014). Our analysis resonates with Deborah Barnbaum’s (2008) claim that “understanding the ethics of autism is invaluable in knowing how to best answer moral questions that emerge among the autistic and non-autistic communities” (Barnbaum 2008: 66). Finally, we draw upon Cheryl Mattingly’s (2010, 2014) work on “anthropology of morality grounded in a first person virtue ethics that takes disempowered people’s moral projects and their belief about the good seriously” (Mattingly 2014, p. xvi).

‘Wandering’ in both ASD and AD in the U.S. has been examined and addressed mostly from a *management and prevention* perspective. It prioritizes safety while primarily overlooking personal experiences of those who ‘wander’ and their families, thus limiting the range of potentially effective other strategies to address this issue. Drawing upon the scholarship outlined above allows us to ask whether singularly pursuing the management and prevention strategy (i.e. using monitoring, surveillance, and tracking technologies to keep persons with ASD and AD safe) is a *sufficient* response to ‘wandering’ that assures a ‘good human life’, a life with opportunities for “having a world” (Merleau-Ponty 1962) and for “world-making” (Fein 2015).

To this end, we draw upon narrative and existential phenomenology to examine ethnographic accounts and published narratives about ‘wandering’ in ASD and AD written by people diagnosed with these conditions. Approaching ‘wandering’ from an “experience-near” (Geertz 1974:28) perspective, we aim to develop a seemingly paradoxical but empirically-supported argument that ‘wandering’ is an expression of what French phenomenologist Merleau-Ponty (1962) called “having a world” (p. 146). We combine ethnographic and medical humanities approaches to examine multiple perspectives on ‘wandering’ – of those who ‘wander’, their family members, the practitioners who serve them – across narrative discourse genres, institutional contexts, and media of representation: ethnographic interviews, memoirs, fiction, news articles, blogs and other social media. We draw upon feature films and documentaries, legislative documents, and ‘wandering’ prevention toolkits. Such a multi-modal analysis reveals how ‘wandering’ is represented across multiple contexts

and modes of representation, and how certain kinds of narratives of ‘wandering’ become amplified or silenced.

What narrative and existential phenomenology teach us about ‘wandering’

As Barbara Meyerhoff (1986) writes in “Life, Not Death in Venice”: Its Second Life,

“One of the most persistent but elusive ways that people make sense of themselves is to show themselves to themselves, through multiple forms: by telling themselves stories; by dramatizing claims in rituals and other collective enactments; by rendering visible actual and desired truths about themselves and the significance of their existence in imaginative and performative productions” (p. 143).

“Showing themselves to themselves”, Meyerhoff (1986) writes, people not only make sense of themselves, but also make sense of themselves inhabiting their life worlds with others. We tell stories about ourselves to make ourselves understandable to others, to rearticulate our versions of ourselves as we are, as we should have been, and as we still may be. We make claims about ourselves to persuade others in the validity of our claims and interpretations (Meyerhoff 1986). When others tell stories about us, they show us how they understand us, our experiences and struggles (Ochs and Capps 2009). Narrative phenomenology of ‘wandering’ in ASD and AD, two conditions that often disrupt communication and intersubjectivity in both directions, for the person with the condition and for his or her interactants, can be analytically enhanced by existential phenomenology of the body and embodiment.

As was discussed in the introduction, understanding a person’s ‘wandering’ demands the rigorous intersubjective work of imagining the person’s experiences of moving through physical space and surrounding landscape. Merleau-Ponty (1962) has argued that “the body is our general medium for having a world” (p. 146), a vehicle by which people comprehend the phenomenal world (Lock 1997). Using existential phenomenology of the body together with narrative phenomenology helps us to bypass the dependence on language and tacit prioritization of cognition, or even narrative. It allows us to escape, as Spurling (2013) writes, “the mistake of rationalist philosophies to consider our lives as made of deliberate choices and decisions, whereas our life is directed on a pre-conscious level, so that conscious deliberation has the form of *post factum* rationalization” (p.16).

This narrative and existential phenomenological framework helps us to comprehend a kind of personhood where one may be unable to verbally narrate one’s experiences and yet is “intelligently embodied”, “is connected as subject with environment, bodily attached to a geographical location and encountering it in the fullest sense” (O’Loughlin 1995: 2). Disability studies and other disciplines interested in embodied ways of being in the world have made wide use of these concepts. This is because Merleau-Ponty’s phenomenology of the body helps to stop focusing on what is perceived as ‘missing’, i.e. normative speech or neurotypical cognition, and begin focusing on what is present, i.e. sensory and affective ways of being, acting and experiencing the world:

“Bodies have understandings of the world which are independent of any sort of cognitive map; these understandings are like a set of invisible but intelligent threads

which stream out between the body and that world with which the body is familiar. Cognition does not, somehow, screen the world at hand; that world is the body's directly. (...) Bodies have their worlds, and understand their worlds, without recourse to "symbolic" or "objectifying function." Consciousness – the "symbolic" or "objectifying" function – does not direct the body's movements; these are directed instead by the intelligent body's connections with the world at hand. It is the body, not an occupying consciousness, which understands its world." (O'Loughlin 1995, p. 2).

With this in mind, we now turn to the discussion of how 'wandering' in ASD and 'wandering' in AD became converged and categorized under one International Classification of Diseases – 9th Revision (ICD-9) code V40.31, 'Wandering in diseases classified elsewhere'.

'Wandering' in autism and dementia converge under the clinical gaze

Two previously separate research literatures – a more recent one on Autism Spectrum Disorder (ASD), and an older one on Alzheimer's disease (AD) and other types of dementia – have various descriptions of behaviors called 'wandering' and 'elopement', which are considered difficult to manage behavioral expressions of both ASD and AD. Although these terms may be used interchangeably, 'elopement' usually denotes an action of sudden and unexpected departure from a supervised environment without others' permission or knowledge. The clinical term 'wandering' denotes movement through space lacking exact destination, as when a person is disoriented or not self-aware.

The history of the joint categorization of 'wandering' in ASD and AD warrants attention as it helps us to better understand, as Hacking (1998) writes, "the central determinants of the contours of a medical entity" (p. 64). Before 2011, only 'wandering' in AD had an International Classification of Diseases (ICD) secondary code. After extensive efforts of autism parental advocacy groups supported by two U.S. government entities, Interagency Autism Coordinating Committee (IACC) and Centers for Disease Control and Prevention (CDC), in 2011 'wandering' in both ASD and AD were grouped under one International Classification of Diseases 9th Revision (ICD-9) code V40.31, 'Wandering in diseases classified elsewhere'. The code's extension from 'dementia, unspecified, with behavioral disturbance' and 'Alzheimer's disease' to 'autism or pervasive developmental disorder' and 'intellectual disabilities' was an outcome of advocacy efforts in the U.S. by parents whose children were diagnosed with ASD, a condition that became increasingly associated with 'wandering' in the public sphere. Led by the National Autism Association (NAA), a parent advocacy organization, these efforts were driven by an increasing number of fatalities due to drowning, hypothermia, and traffic accidents involving children with ASD who wandered from their homes, schools, and other supervised settings (McIlwain and Fournier 2012). In 2013, Avonte Oquendo's story became a part of this tragic trend.

As members of the Interagency Autism Coordinating Committee^{iv} (IACC) wrote in a public letter to Kathleen Sebelius, the U.S. Department of Health and Human Services Secretary at the time, the ICD code was needed "to collect data on ASD-related wandering, establish the

need for support and assistance for families affected, and help validate insurance coverage for personal locating devices and related expenses for families who are currently unable to afford them” (IACC 2011: p.2^v). But the code was also intended to help children with ASD and their families receive better services, or at least to officially justify the children’s need for consistent supervision and safety protocols, which could have been lifesaving in Avonte Oquendo’s case.

When the need for the code was first discussed at an IACC meeting in 2010, the NAA Executive Director, Lori McIlwain, whose 10 year-old son Connor is a ‘wanderer’, argued: “In my son’s case, that medical coding could really help in his IEP^{vi} process to provide very sound reasoning as to why he should never be left alone.” (IACC 2010: 71–72). During the same meeting, Wendy Fournier, President of the NAA and mother of a 10 year-old, Ali, whom she described as a ‘runner’, explained: “If we have this medical diagnosis code, we do have a much stronger position when we are dealing with the schools and we are asking them to put safety protocols into place for our kids. It will also help us as parents and caregivers to combat that misconception that it’s neglect or that this is simply bad behavior and our children are misbehaving. The fact of the matter is they can’t help it” (IACC 2010: 86). These excerpts illustrate that the management and prevention perspective on ‘wandering’ was a defining force behind merging ‘wandering’ in ASD and AD under the ICD code V40.31.

Since V40.31 was implemented^{vii}, however, it is unclear to what extent these expectations have been met. Studies on the usefulness of V40.31 to better understand and monitor ‘wandering’ have been, as far as we can tell, nonexistent. A rare mention of V40.31 was found in an on-line newsletter Autism Spectrum News, in an article by Harris and Robertiello (2015) titled ‘Autism and Safety: It’s Unpredictable’. As Harris and Robertiello (2015) suggest, the challenges of collecting data on ‘wandering’ stem from the kinds of data recorded during emergencies involving persons with ASD. A police report may not have a record whether the person involved has a diagnosis of ASD, making the accuracy of statistical data on safety of people with ASD unreliable. As a solution to this problem, these authors argue, “clinical use of the medical diagnostic code for wandering (V40.31) is one way to promote appropriate treatment planning and accuracy of tracking data” (Harris and Robertiello 2015: p.10).

While strategies to prevent ‘wandering’ have received significant attention from behavioral modification researchers (Lang et al. 2010; Perrin et al. 2008), research on the experiences of ‘wandering’ in ASD has been scarce (Anderson et al., 2012; Solomon and Lawlor 2013). The 2016 NAA statement to the IACC in support of wandering-preventive legislature lamented that 2015 was “the deadliest year on record for autism and wandering”; that families were still not being informed at the time of ASD diagnosis about its association with ‘wandering’; and that American Academy of Pediatrics’ ‘wandering’ prevention literature for families was underutilized (NAA 2016^{viii}, n/p). Because ‘wandering’ has been

^{iv}IACC is an advisory committee created by the U.S. Congress to coordinate federal activities of ASD research.

^vhttp://iacc.hhs.gov/publications/2011/letter_wandering_020911.shtml

^{vi}Individualized Educational Program, see endnote i.

^{vii}In 2015, V40.31 converted directly to an ICD-10 secondary code Z91.83, of the same name and scope.

conceptualized as an ever-present potential crisis, the crisis viewpoint has eclipsed any attempts to conceptualize ‘wandering’ as an outcome of sensory or experiential phenomena. Adult self-advocates with ASD, however, disagreed that ‘wandering’ has to be codified, prevented and managed, as discussed next.

Adult self-advocates’ views on V40.31: concerns with unintended circumstances

Adult self-advocates disagreed with parent advocacy groups that V40.31 was a positive development, as they have done on other issues such as genetic testing and a ‘cure’ for autism (Bagatell 2010; Chamak 2008; Ortega 2009; Sinclair 1993), although areas of agreement also exist, e.g. in a positive view of the neurodiversity movement (Kapp et al. 2013). Their response to V40.31 was consistent with the motto of the disability rights movement, “Nothing about us without us” (Ne’eman 2010).

A letter to the Centers for Disease Control and Prevention (CDC) signed by 40 adult self-advocacy groups of persons with disabilities and posted on the Autistic Self-Advocacy Network’s (ASAN) website, expressed concerns about “the significant potential unintended consequences” of V40.31 for people with disabilities and their families (ASAN 2011, www.autismadvocacy.org). The potential consequences of the code included blurring intentional and communicative actions with medically-relevant behavior that would qualify for coding, limiting self-determination rights of people with disabilities, and potentially increasing the use of pharmacological and physical restraints in clinical and educational settings (ASAN 2011; Graby 2011).

These concerns were not hypothetical: the opponents of V40.31 used their own experiences of “walking while autistic” (Graby 2011: 2) to explain why prevention of ‘wandering’ puts people with autism at potential *other* risks besides drowning, exposure, and traffic injuries. Several bloggers with ASD outlined the reasons for their opposition to V40.31. For example, Amanda (Amelia) Baggs in her blog ‘Ballastexistenz’ decries the term ‘wandering’ as a pathologizing characterization, using J.R.R.T. Tolkien’s quote “Not all those who wander are lost”:

“When non-autistic people walk out of their homes, they are “taking a walk” or “walking somewhere” or something like that. When autistic people walk out of our homes, we are... wandering! I don’t know what it is that gives people that impression. But I have been accused of wandering when: – Taking a walk. – Waiting outside rather than inside for staff to show up. – Trying to take a bus. – Running away from a fight that broke out at a day program. – Leaving the room to avoid reacting physically in anger. – Trying to escape institutions. – Going on long walks to explore the geography of an area. The assumption in all of these cases and many more is that we are just kind of moving around without any point to it. I suppose this should not be surprising, since most of what we do is described as

viii <http://nationalautismassociation.org/naas-statement-to-iacc-addresses-wandering-prevention-avontes-law/>

purposeless and pointless. Not all those who “wander” are lost. Or even wandering (Baggs 2005).

Another adult with ASD, Lisa Daxter (2011) in her blog “Reports from a Resident Alien”, writes about being severely mistreated by her stepfather as an eight-year old, which one day resulted in her walking away from home “wearing socks but no shoes” and not knowing the exact location of her intended destination, her grandmother’s house. In this excerpt, she not only describes her concerns about people with ASD but also shows a keen understanding of what a person with AD may experience when ‘wandering’:

“Leaving the place where you are “supposed to” be is not something that someone merely does “because she’s autistic” or “because he’s got Alzheimer’s” or “because she’s developmentally delayed”. It’s not a symptom of a disease; it’s a behavior that people display for a reason. It can be a decision to leave a dangerous or threatening environment, as I did when I left the driveway and started walking down the road. It can be a declaration that you want to do something for yourself, such as when a man with Alzheimer’s tries to find the corner store to buy himself the milkshake that the nursing home cafeteria can’t prepare. It can be a simple decision to be somewhere, anywhere, where people are not watching you, monitoring you, and treating you with condescension—a desire for privacy, for autonomy” (chaoticidealism.livejournal.com).

Some dementia researchers hold similar views on the problems that prevention and management view on ‘wandering’ presents in dementia care. Writing about the U.K. context, Robinson et al. (2007) conducted a systematic review and focus groups to examine the perspectives of different stakeholders, including people with mild dementia. They found that especially among professional and family caregivers, the main source of tension surrounding management of ‘wandering’ is between the prevention of harm and facilitation of a person’s civil rights to privacy and autonomy. Family members caring for a person with dementia tended to prioritize independence and right to privacy over potential risks of harm. Alternatively, professional caregivers and nursing staff prioritized safety over independence and privacy because of institutional regulations, liability concerns, and literal interpretations of the “do no harm” Hippocratic oath. Issues of consent and dignity of the person with dementia were also paramount for professionals when electronic tracking devices were considered because of the concerns with continuous and unauthorized surveillance, and the stigma of ‘tagging’ associated with the use of such devices in the criminal justice system (Marr 1989). There was a difference of opinion on this issue, however, among nursing facilities staff who felt that the use of electronic tracking devices was neither degrading nor dehumanizing compared to the use of physical restraints (Coleman 1993). Some people with dementia thought that wearing such devices would be sensible and unproblematic while others worried that their families would be looking after them only through the mobile phone: “It’s the relationship you’ve got with the person who is keeping an eye on you” (Robinson et al. 2007, p.400).

In spite of the vocal, well-reasoned, and articulate objections of self-advocates with ASD to V40.31, outside of the self-advocacy communities there has been little uptake of their perspectives on how to manage the problems of ‘wandering’. Even though they have

strongly and convincingly voiced their opinions, they are treated by the majority decision-makers as if “they have no entry into this theoretical conversation, nor can their points of view contribute to formulating the resulting principles of justice” (Silvers and Francis 2009, p. 478). Those with dementia are also treated as people who “once were but no longer are competent” and who “are accorded no direct entry” into this discussion: they “can participate only figuratively through extrapolations from their formerly articulated preferences and views” (Silvers and Francis 2009: 478). Similarly marginal in public policy and clinical practice have been the views of professionals and researchers who have voiced their concerns regarding the need for more situated, ethical, and contextually responsive decision-making practices to address ‘wandering’ (Robinson et al. 2007). A growing body of literature reflects an increasing recognition of the outside world as a potential therapeutic context to manage, and even to safely support, ‘wandering’: the usefulness of nature and “healing landscapes (...) as legitimate areas of health science and practice” (Whitehouse et al. 2012, p. 57).

‘Wandering’ in ASD and AD converge in legislative discourse

Between October of 2013 and January 2014, the story of Avonte Oquendo was probably the most highly publicized, nationally covered case of ‘wandering’, bringing it into every living room in the U.S., and propelling it both into the national U.S. public sphere and into the U.S. legislative arena. The political debates in response to Avonte Oquendo’s case resulted in ‘Avonte’s Law Act of 2014’ (S.163) introduced by Charles Schumer, a Democratic Senator from the State of New York (U.S. Library of Congress 2015). As Hilton’s (2017) points out, it is noteworthy that ‘Avonte’s Law’ amended the Omnibus Crime Control and Safe Streets Act of 1968, which was linked to the fears of racial unrest in the late 1960s and provided state and local law enforcement agencies with “direct fiscal aid for weapons, technology and personnel” (Simon 2002: 40). ‘Avonte’s Law of 2014’ was aimed to “reduce the risk of injury and death relating to the wandering characteristics of some individuals with autism and other disabilities, and safeguard the well-being of individuals with disabilities during interactions with law enforcement” (U.S. Library of Congress 2015, n/p). Among several specific actions, it secured funding for Global Positioning System (GPS) devices to be worn by students with autism attending public schools. Another local measure was approved by the New York City Council to provide funding for public schools to install alarm systems in special education classrooms. Both policy responses were intended in part to subsidize technical means of surveillance and monitoring as an effort to prevent and contain ‘wandering’ of children and youth with ASD. These responses, Hilton (2017) argues, must be understood in relation to the longer history of surveillance linked to the emergence of ‘race’ and ‘disability’ as “categories of social difference” that centrally implicated the body and its movement “in ways it should not” (p. 223, 225). Expanding and enhancing surveillance through increasingly sophisticated technologies that monitor the position of the body in space via GPS tracking devices attached to the body itself has become a singular *de facto* approach to securing physical safety of both children with ASD and adults with AD.

In March 2016, ‘Avonte’s Law’ was re-introduced as ‘Kevin and Avonte’s Law’ (S.2614), adding the name of another boy, nine-year-old Kevin Curtis Wills, also diagnosed with ASD, who drowned in Iowa’s Raccoon River in 2008. This new bill promoted initiatives to reduce

the risk of injury and death related to ‘wandering’ of children with ASD^{ix} and other developmental disabilities, but this time adults with dementia were also included. Similarly to the previous bill, ‘Kevin and Avonte’s Law’ was linked to fears of racially implicative criminal behavior and violence as it amended the expired Violent Crime Control and Law Enforcement Act of 1994. It also reauthorized the ‘Missing Alzheimer’s Disease Patient Alert Program’ under a new and more inclusive name, the ‘Missing Americans Alert Program Act of 2016’ (U.S. Library of Congress 2016), thus linking AD and ASD in legislative and public discourse. The bill was passed unanimously in August 2016, however, at the time of this writing it has yet to be enacted. This socio-historical background sets the stage for our narrative phenomenological inquiry into ‘wandering’ that is known to be common in children with ASD – and people with ASD as a group – and in adults with AD and other types of dementia.

‘The art of the translator’: Do the non-speaking get “to speak back and up”?

The debate on how to respond to wandering reveals a significant lack of attention to the experiences and needs of those with ASD who are unable to voice their views due to severe communicative challenges (Silvers and Francis 2009). There are, however, serious concerns regarding the ethical dilemmas presented by their absence in the debate as it remains unknown what responses to ‘wandering’ they may find acceptable, helpful, and otherwise ‘good’ (Kittay 2009). Similar questions are currently being asked about managing wandering of people with AD and other types of dementia who have limited ability to verbally communicate because of the progression of their illness: how do family members and professionals comprehend their everyday experiences related to ‘wandering’? How does ‘wandering’ of people with dementia get to be represented, interpreted and responded to by others in the absence of their voiced experiences, desires and needs? (George 2010; Gilliard and Marshall 2011; R. Taylor 2007; Whitehouse 2016; Zeisel et al. 2016).

As Kristina Chew (2014), mother of a son with ASD and a linguist by training, writes in “Autism and the task of the translator”, “The quandary in representing Charlie is that he, the one being represented is, all too often, limited in his ability to speak back and up about himself. I write about my son knowing that I may be very wrong about what he experiences, and that it may be a very long time before he uses language to tell me; that it may never happen” (p.305). Drawing on Walter Benjamin’s (1969) concept of *translation* to reframe people with autism as makers of meaning who warrant respect, she writes: “Like reading poetry, listening to my boy involves tuning my ear to the sound of his language, his idiom. (...) I approach speaking for and with Charlie like a translator who does not know the language of the original text and works without a dictionary or grammar guide, keenly aware that mistranslation is likely, if not inevitable, as I transform what’s said from one language into the terms of another.” (p.308–309) Because of “an urgent desire, a rush, to understand the utterances of someone on the autism spectrum, to “make sense”,”- Chew warns, the result may be “a bad translation, a misrepresentation of meaning that somewhat, sort of

^{ix}People of all ages diagnosed with ASD and other developmental disabilities were included

captures what was meant, but makes potentially fatal errors that may even involve reversals of meaning” (p.312).

‘Having your voice heard’, as Eva Feder Kittay (2001) reminds us, is a precondition of full participation in liberal societies through which marginalized groups achieve equality and freedom, with an underlying “conception of the person as independent, rational, and capable of self-sufficiency”, and “a conception of society as an association of such independent equals” (p. 559). How your voice is heard and by whom, and what kind of voice it has to be in order to be heard at all, has been less clear. People with cognitive differences and communicative challenges are often difficult to understand by others, including family members, which makes it difficult to ‘hear’ them. Others’ voices speaking on their behalf then become powerfully decisive on the “freedom or threat” dilemma (Hilton 2017), with predictable leanings toward the latter. As Kittay (2001) writes about telling others about her daughter, Seshe, “In speaking not only about her, but for her, I have already begun by describing her in the negative—as one who cannot speak for herself. (...) The positive set of responses is truer to who she is. Her limitations describe the face she shows to those who don’t know her, but they also convey the ways she cannot make her own way in the world. Knowing her capabilities, one gets a glimpse into the richness of her life and the remarkable quality of her very being.” (p. 559–560). The distinction made by Kittay (2001) stressing the “richness” of her daughter’s life and the “remarkable quality of her being” articulates in a few words the difference between the management and prevention view on personhood of people with ASD and AD who ‘wander’, and of the existential and narrative phenomenological “having a world” perspective. Without underestimating or overlooking the dangers of ‘wandering’, the latter is anchored in a keen appreciation of each individual’s unique quality of being and in his or her experience of movement through space.

Biomedical and socio-cultural perspectives on ‘wandering’

Most current studies of ‘wandering’ in dementia hold one of two contrasting positions. The biomedical view considers wandering as one of dementia’s behavioral and psychological symptoms, together with insomnia, agitation, aggression, anxiety, psychosis, and depression (The Healing Project 2007). From this perspective, ‘wandering’ is a behavioral problem, to be managed and curtailed (Cipriani et al. 2014). As Song and Algase (2008) write, “Wandering in persons with dementia poses considerable management problems, mainly due to difficulty in balancing the individual’s right to freedom of movement against the caregiver’s moral and legal responsibility to ensure the individual’s safety” (p. 318). This quote could be equally applicable to wandering in ASD. The tension identified by Algase et al. (2007) between ‘freedom of movement’ and ‘safety’, echoes Hilton’s (2017) discussion of movement as ‘freedom or threat’.

The less prevalent view on wandering is socio-cultural: Wandering stems from power relationships of caregiving and dependency, and the socio-physical contexts in which people experience their dementia and their care (Lyman 2000). This view argues that, as Kontos (2004) writes, “selfhood persists even with severe dementia, because it is an embodied dimension of human existence” (p. 829). This is why personal narratives written by people with AD offer such an important opportunity to understand how, and through what

representational and interactional means, people understand and articulate their experiences of self, their dementia, and “having a world” (Merleau-Ponty 1962) against the relentless slippage of memory.

From the biomedical perspective, ‘wandering’ is “dementia-related locomotion behavior having a frequent, repetitive, temporally-disordered and spatially disoriented nature” (Algate et al. 2007: p.13). According to this view, wandering reflects growing deficits of neurocognitive skills, and especially, it is assumed, of visual-spatial orientation. The assumption that the decline of cognitive skills inevitably leads to the loss of selfhood is central to this view.

If ‘self comes to mind’, as neuroscientist Antonio Damasio (2010) writes, what happens to the ‘self’ when ‘the mind’ loses its mnemonic power? Consciousness, Damasio (2010) argues, is “the phenomenal ability that consists of having a mind equipped with an owner, a protagonist for one’s existence, a self inspecting the world inside and around, an agent seemingly ready for action” (p. 3). In Alzheimer’s disease, the loss of factual and autobiographical memory has been linked to the changes – visible on brain scan – in the entorhinal cortex and the anterior temporal lobe cortices, severing their link to the hippocampus, the brain structure critical to formation of new memories. “The bedrock of autobiographical memory, Damasio writes, was eroded and was eventually just wiped out. (...) Along with the selective disturbances of mind, integrity of consciousness begins to suffer. (...) At first, the problem is predictably confined to the autobiographical consciousness. Because memory about past personal events can not be properly retrieved, the link between current events and between past events becomes inefficient” (p. 245).

This clinical description has a personal and poignant meaning for those affected by AD and to the people who care for them. John Bayley, the husband of the British novelist Iris Murdoch who had Alzheimer’s disease, writes in a memoir “Elegy for Iris” about being shown her brain scans by a doctor:

Showing me a tracing from the most elaborate of the brain scan Iris underwent a year or so ago, the doctor indicated the area of the atrophy at the top. The doctors were pleased by the clearness of the indication. I thought then – the old foolish Romantic idea of the Amazon – that her brain world had lost its unknown mysteries, all the hidden life that had gone on in it. It had been there, physically and geographically there. And now it was proved to be empty (Bayley 1999: p.259).

Thomas DeBaggio (2002) in his memoir “Losing my mind: an intimate look at life with Alzheimers” describes an embodied awareness of a slow dissolution of memory, chipping away of reality, language, and relationships:

“I become lost in the vocabulary of silence. Thoughts squiggle and writhe into sentences that disappear before they can be acknowledged. (...) Although subtle in attack, Alzheimer’s is the closest thing to being eaten alive slowly”. (DeBaggio 2002: p. 41).

The last haunting sentence illustrates the experiential implications of what Whitehouse and George (2008) called “the monstrous Alzheimer’s story” (p. ix) : an all-powerful disease that

slowly consumes the whole being of its victim. The tremendous power of the Alzheimer's story is in that it has become a "fearsome cultural myth" (*ibid*) that shapes the experiences of people in highly detrimental ways.

How does this dominant 'master narrative' of dementia and Alzheimer's disease that has become so ingrained in the U.S. discourse affect people's lived experiences of dementia, and the experiences of their caregivers? As George (2010) writes,

We have come to view people with dementia as "victims" who are ravaged by a singular marauding disease. Alzheimer's disease is personified as a "mind-robber" that "attacks" or "strikes" the brains of individuals, leaving plaques and tangles in its wake (p.1).

Calling to resist this terrifying narrative and the notion that cognition is the single source of personhood, Janelle Taylor (2008) writes in her autoethnography of her mothers' Alzheimer's:

"Not all of the "stills" and the "firsts" necessarily tell a grim story of unrelenting decline, loss, humiliation, and disappearance. Despite all the changes she has been through, my mother "still" is in many ways the cheerful, affectionate person I have always known her to be. Mom still enjoys gentle joking and teasing, as she always has. She still enjoys being around people, still beams radiantly at small children when she sees them, still enjoys the give and take of conversation." (J. Taylor 2008: p.333).

The biomedical and the socio-cultural views on dementia stand in stark contrast to each other, narratively framing the subjectivities of those who wander as either physiologically-based and irrational, or as meaning-based and responsive to the processes of illness, relationships with other people, own personal experience, and "having a world" (Merleau-Ponty 1962). What is at stake in these framings is the personhood of people with dementia, their subjectivity, their continuity of self, their agency and their embodied experience. What is also at stake is the subjectivity, agency and embodied experience of the caregivers and other family members, and the awareness of the relational, interpersonal and intersubjective dimensions of 'wandering'.

During the debates on V40.31, its proponents argued that 'wandering' is unintentional, irrational, compulsive, and "can't be helped" (IACC 2010: 86). The autistic self-advocates, however, insisted that 'wandering' is intentional, communicative, and may be prompted by troublesome experiences or events (ASAN 2011). The difference in these views is reminiscent of the divergence among personal accounts and most cognitive and behavioral research on both autism (Anderson et al. 2012; Rice et al. 2016; Baggs 2005, 2010; Prince-Hughes 2005; Williams 1992) and dementia (e.g. Algase et al. 2007; Cipriani et al. 2014; DeBaggio 2002; Potocny 2010; J. Taylor 2008; R. Taylor 2007). These contrasting views illustrate that the term 'wandering' has different meanings for different groups of 'stakeholders' in both ASD and AD, and that it denotes a multifaceted phenomenon that is perceived as more problematic by some people and less, or not at all, by others.

The multiple meanings of ‘wandering’

In our previous work (Solomon and Lawlor 2013) we identified conceptual challenges of understanding ‘wandering’ in ASD, linking it to the ambiguity of the term that is contributed in part by its romanticized, nonclinical meaning. Some researchers who study ‘wandering’ in dementia agree. Problematizing “historical inattention to certain beneficial aspects” of wandering, Algate and colleagues (2007, p.686), for example, warn that the complexity of the phenomenon combined with the deceptive simplicity and commonality of the term is what makes defining it more precisely so elusive:

“Wandering as a term, construct or behavior can appear deceptively simple to the uninitiated as well as to those in clinical practice or research concerned with wandering individuals. (...) Authors who neglect to define wander or wandering invite readers to apply any of the multiple and varied definitions that have appeared in over 30 years of research and/or apply wandering in its vernacular sense with any or all associated connotations. Far from simple, wandering is a multifaceted pattern of human activity, a fascinating and elaborate behavior that is difficult to define” (p. 686).

Another problem of conceptualizing ‘wandering’, Algate et al. (2007) point out, is a “notable absence in the literature of wanderers’ perspectives, presumably due to a typically limited ability to articulate needs or motivation” (p. 689). This inattention to wanderers’ own stories of their ‘wandering’ constitutes a narrative silencing that privileges the observers’ perspectives, and consequently, their priorities.

What this means for everyday care of a person with dementia can be gleaned from a quote from Ballenger (2006), a practitioner-researcher in the field of nursing. He describes one of his patients, whose name is Jesse, an elderly man who is always made to wear a restraint vest with which he is tied to his bed or to a geriatric chair to prevent him from ‘wandering’. Throughout the day Jesse would try to leave because he believed that he was late for work. Ballenger (2006) observed him trying

“to get free of the inexplicable and maddening barriers that kept him from getting where he needed to go, and me trying to guide him where I needed him to go and divert his attention from the fact that the vest was going to have to stay on. If I was lucky, he would resign himself to eating his breakfast and maybe fall asleep in the geri chair that I strapped him into while I took care of some other patients assigned to me. Sometimes, though, he’d stay angrily focused on the restraint, on his need to get somewhere (...) He was usually obsessed about work. I’d ask him where he worked, whether he liked it, and so on (...). I’d set him up in his geri chair in the hall folding towels or linens, which he would usually find absorbing for at least long enough to let me attend to another of my patients. (p.xi).

From this example, we can see how ‘wandering’ emerges as a problem for Ballenger because of how he perceives Jesse’s intentionality and cognitive abilities: Jesse’s desire to get “where he needed to go”, his “need to get somewhere” become a typification story (Maynard and Turowetz 2017) of difficult to manage behavior as symptomatic of the dementia diagnosis. Institutional priorities of care in a nursing facility where Ballenger is

responsible simultaneously for multiple patients also play a significant role in this typification. Keeping Jesse from leaving the facility as well as making him stationary while keeping him calm so that Ballinger can attend to these other patients is what guides Ballinger's communication with this person. In a sense, Jesse's desires and needs are sidestepped by the institutional order of the nursing facility so that releasing him from the restraint vest and taking him outside for a walk is clearly not an option. Other dementia researchers differ on this issue, arguing that being outside and experiencing the natural world is a necessary part of caring for people with dementia (Gilliard and Marshall 2012; Whitehouse 2016; Whitehouse et al. 2012), which, in practical terms, constitutes "having a world" (Merleau-Ponty 1962).

'Wandering' through a diagnostic kaleidoscope of history

'Wandering' as an existential need to seek and experience the world, sometimes in an altered state, is an ever-present theme in the world's literature as exemplified in Homer's 'Odyssey', Ibsen's 'Peer Gynt', and even Lagerlof's children's book 'The Wonderful Adventures of Nils'. In a collection of short essays, poems and drawings called "Wandering", the German-Swiss novelist Herman Hesse (1957 / 1972) writes: "This is the house where I say goodbye. For a long time I will not see another house like this one. (...) But the longing to get on the other side of everything already settled, this make me, and everybody like me, a road sign to the future." (p.5).

The grouping of 'wandering' in ASD and AD under one ICD-9 code V40.31 becomes especially intriguing in a historical context because it is not the first time that the phenomenon of 'wandering' has brought together two distinct diagnoses under the gaze of a clinical community. The linkage of 'wandering' in ASD and AD under V40.31 mirrors the grouping of behaviors called 'fugue^x', 'dromomania', or 'ambulatory automatism', the medical terms used in the late 19th century France for "strange and unexpected trips, often in states of obscured consciousness" (Hacking 1998: 8). In the late 1800s, 'fugues' were common among working class men who were diagnosed either with hysteria or epilepsy. The notion of 'obscured consciousness' as a feature of 'fugue' brings into focus the additional problem of discontinuity of the self presumably experienced by the 'fugeurs', a problem relatable to the question of agency and intentionality of people with ASD and AD who 'wander'^{xi}.

Besides a historical precedent when 'wandering' links two disparate psychiatric diagnoses, hysteria and epilepsy, the ideologically laden language that was used at the time to describe these behaviors and conditions warrants close examination. The 'epidemic' of what Hacking (1998) calls 'compulsive mad voyagers' (p.7) who traveled in an altered state of not knowing who they were, and where they were going and why, spread from the epicenter in Bordeaux to Paris and then to the rest of France, to Italy, Germany and Russia. Eventually, the 'epidemic' of what was then called 'ambulatory automatism' or 'dromomania' gradually

^xThe French word 'fugue' and the English word 'fugitive' originate from the Latin verb *fugere* that means 'to flee.'

^{xi}See moral philosophers Derek Parfit (1984) and Jeff McMahan (2002) on the problem of continuity of consciousness in people with cognitive disabilities including AD, and a counter-argument by feminist philosopher, social theorist and a mother of a daughter with cognitive disability Eva Feder Kittay (2009).

died out, as one of the diagnoses associated with it, hysteria, disappeared from the psychiatric nomenclature of mental conditions, and as the militarization of Europe and the start of the first World War turned the ‘fuguers’ into ‘deserters’ and ‘degenerates’ rather than men who were prone to sudden and unconscious disappearances and ‘mad travel’ across the European borders (Hacking 1998).

In the U.S. context of the mid-1800s, the French ‘fugue’ or ‘dromomania’ were transformed into “‘drapetomania’, the madness of runaway slaves” (Hacking 1998: p.65), officially introduced by a well-known University of Louisiana physician, Samuel Cartwright (1851) as a new ‘disease’ that makes “*man like an automaton or senseless machine*” (n/p). Furthermore, while the ‘fugue epidemic’ raged in Europe, the gaze of medical professionals in the U.S. was becoming steadfastly fixed on only some categories of people but not on others. For example, an American biologist and a founder of eugenics, Charles Davenport, in a 158-pages long publication titled “The Feebly Inhibited, Nomadism, or the Wandering Impulse, with Special Reference to Heredity”, commented in passing that “the feeble-minded and demented may wander without going into a periodic state”, which “paralyzes the inhibition” and leads to “nomadic impulses” (Davenport 1915, p.7; cf Hacking 1998, p. 67). “The feeble-minded and demented”, two categories of persons grouped together in this 1915 text via their common tendency to ‘wander’, were clearly not the focus of Davenport’s interest because, as he confidently writes, the term ‘nomadism’ “has been applied to a racial or tribal tendency to wander (...) and has racial connotations” (Davenport 1915: 7; cf Hacking 1998: 66). These texts by Cartwright (1851) and Davenport (1915) serve as an illuminating historical background for Hilton’s (2017) critical race theory and critical autism studies analysis of ‘wandering’, blackness and autism, as well as for our analysis presented here.

‘Wandering’ across media of representation: Alzheimer’s disease

Writing as a way contesting and resisting the decline of memory appears very significant in understanding the experience of dementia and ‘wandering’. “I would encourage people with a disease that alters their thinking to *write*; – Richard Taylor, who holds a PhD in psychology, advises in the preface to his 257 page – long personal narrative that doubles as a resource manual for people with Alzheimer’s disease and their caregivers, – “not just a journal of what happened today or a dozen *to do* lists for tomorrow. Think about yourself, your caregivers, your relationships, your present, and your future, – and *write*. (...) Writing has become a confirmation to me, of me, and by me. Some people believe “they think, therefore they are”. I write, therefore I am” (R. Taylor 2007, p. xviii).

Writing “at the cusp of fundamental altering” imparted by Alzheimer’s disease, Richard Taylor’s concerns are existential and poignantly personal, and at the same time, are those with which philosophers throughout recorded human history have grappled. The Cartesian foundation of Western philosophy, ‘I think, therefore I am’, on which much of moral philosophy and liberal theory has been built (e.g. McMahon 2003, Parfit 1984), for Richard Taylor becomes “I write, therefore I am”, as well as “How will I come back to myself? Who will I be? How will I know I exist? How will I fit in?” (R. Taylor 2007: xviii, 24). Searching for answers to these questions as he writes, Taylor is in constant, often anguished, dialogue

with the biomedical views of the disease that is slowly changing who he is. He is also in dialogue with the people in his life: his wife, his adult children, his extended family, his friends. Thinking about the biomedical account of “personality changes” in Alzheimer’s disease that makes one “more confrontational, paranoid, confused”, he decries the lack of biomedical knowledge or ‘care’ about “the what, when, where, and why of what happens to personalities of individuals diagnosed with the disease”:

“I have changed. I am changing. I don’t like it any more than you do. (...) I seem to have almost no control over who I am becoming. Frankly, sometimes I feel like I have little or no control over who I am. I argue more and listen less. I jump to conclusions, and I am sometimes fearful to express my opinion. Does not sound like the Richard you and I knew, does it?” (p.133) “Oh, how they want me to be the husband, the dad, the friend I was.” (p. 137).

Among many powerful insights that this book offers to the reader is the importance of one’s *control* over ones’ self, of having ‘a self’ that is experienced as reliably ‘there’, in some kind of a predictable existential space that is one’s own, and yet that continues to be in a relationship with others. Much has been written in social science and humanities about the ‘continuity of the self’, often in the context of cultural change (Gallagher 2000; Niesser and Fuvish 1994), although philosophical accounts also exist (Atkins 2000). The experiences of wandering in the context of this deep searching for the continuity of the self become visible in a different light that the code *V40.31* ever allows to capture:

“I have wandered away and I didn’t care, and I don’t care, although it sure upset a lot of people. I didn’t get upset about it. I was not and still am not afraid. Others are upset and afraid for me”. (R. Taylor, 2007: p.57).

The intertextuality of different genres and media of representations of dementia creates a cultural snowball effect, with texts amplifying each other and engendering or contesting tacit power relationships (Briggs and Bauman 1992). For example, published autobiographical accounts generate on-line public dialogues in the comments sections. On the [amazon.com](https://www.amazon.com/Alzheimers-Inside-Out-1stfirst/dp/B006SVMVSY/ref=sr_1_2?ie=UTF8&qid=1471464666&sr=8-2&keywords=Richard+Taylor+Alzheimer's) site of Richard Taylor’s book, for example, a reader named Mauve who takes care of her 89 year-old mother writes:

“I had been invited into a world I needed desperately to FEEL, not just learn about, but FEEL” (*original emphasis*), and “I was convinced of the harm we who try so hard to help can do to the ones we love in our rushed quest for expediency^{xii}”.

This comment could have been a powerful counter-narrative to Ballinger’s (2006) account of his efforts to keep his patient, Jesse, securely tied by a restraint vest to a geriatric chair. Implicit in Mauve’s comment is the contestation of the management and prevention story focused only on safety at the expense of experience and the need to “have a world” (Merleau-Ponty 1962: 146).

Concerns about ‘wandering’ of people with ASD and AD have engendered not only large-scale socio-cultural, discursive responses in the form of books, blogs, and on-line clinical

^{xii}[amazon.com/Alzheimers-Inside-Out-1stfirst/dp/B006SVMVSY/ref=sr_1_2?ie=UTF8&qid=1471464666&sr=8-2&keywords=Richard+Taylor+Alzheimer's](https://www.amazon.com/Alzheimers-Inside-Out-1stfirst/dp/B006SVMVSY/ref=sr_1_2?ie=UTF8&qid=1471464666&sr=8-2&keywords=Richard+Taylor+Alzheimer's)

‘tool kits’ created by advocacy groups, but also films. In the last 15 years, there have been, to our knowledge, eight full-length films about Alzheimer’s Disease, including “Away from Her” (2007), “The Savages” (2007), “Iris: a Memoir of Iris Murdoch” (2001), based upon Murdoch’s husband John Bayley’s memoir “Elegy for Iris” (Bayley 2001); “Still Alice”, based upon Lisa Genova’s well-researched novel (Genova 2015), “”, and one short film, “The Fragile Storm” (2016). In the current digital age, the multi-modality of representations of dementia, and the accessibility of these representations across different platforms and on a very large scale, is significant: as books turn into films, blogs describe and advertise films, and documentaries portray blogs, personal experiences of dementia and the meanings derived from these experiences become amplified in the popular culture, with ‘wandering’ as one of dementia’s central problems.

‘Wandering’ across media of representation: Autism Spectrum Disorder

Similarly to dementia, the densely cross-referenced, continuously amplified multi-modal representations of ASD, and the spurring of dialogues among these representations, have also been taking place. There have been numerous feature films (e.g. ‘Rain Man’ (1988), ‘Temple Grandin’ (2010), ‘Mozart and the Whale’ (2005), ‘Mercury Rising’ (1998), ‘Snow Cake’ (2006), and ‘Life, Animated’ (2016) as well as an HBO documentary ‘George’ (2008), a BBC documentary “Tito’s Story” (2000), and other documentaries such as ‘Horseboy’ (2009), ‘Autism: the Musical’ (2007), and ‘Autism is a World’ (2004). These visual narratives have provided multiple cultural models of ASD and have guided the viewers in how to understand the experiences of people with this condition. There is also a body of literature authored by people diagnosed with ASD themselves, among them Temple Grandin (1995, 2006), Dawn Prince-Hughes (2004), Donna Williams (1992), and Tito Mukhopadhyaya (2011).

There are a few personal accounts of people with ASD who have written about their experiences of ‘wandering’. These accounts reveal that they see ‘wandering’ as both existentially compelling and also dangerous. In his book “The Reason I Jump: The Inner Voice of a Thirteen-Year-Old Boy with Autism”, Naoki Higashida (2007) writes about the reasons he wandered off from home:

“I can think of several reasons why I did it. It wasn’t because I wanted to go out for a specific purpose, like wanting fresh air. It was because – this is hard to put into words – my body moved because it was lured outside by something else. (...) It came down to this: if I didn’t go outside, I would cease to exist. Why? I can’t say, but I *had* to keep walking, on and on and on. Roads speak to us people with autism and invite us onward. (...) I stopped wandering off from home on the day I very nearly got mowed down by a car, because the fear of it made a deep impact on my memory. So when something drastic enough happens, I think we can rein in this habit of wandering off. Meanwhile, please keep an eye out for us...”

Another glimpse of a personal experience of wandering can be found in Donna Williams’ (1992) autobiography “Nobody Nowhere” where she describes her experiences when she was 12 years old:

“Often I found myself wandering out of the school. (...) I was never going anywhere in particular, just going. I’d climb the stairs at the high-rise flats, play in the elevator or try to find how to get on the roof with every intention to jump off and ‘fly’. (...) My teachers in the meantime were often out looking for me – sometimes even driving around the streets to catch me and bring me back.” (p. 62).

This excerpt shows Donna’s desire to experience the world on her own terms that include some very dangerous ideas about ‘flying’, as well as her awareness that the adults were frantically searching for her.

Parents’ memoirs about their experiences of their children’s autism have been proliferating for the last 20 years, the first dating back to Josh Greenfield’s trilogy about his son Noah (Greenfield 1972, 1986, 1989), and Clara Claiborne Park’s memoirs about raising her daughter Jessica (1982, 2002). Books have been turned into films, blogs of people with autism are cited in scientific articles, and there are multiple on-line instructional sources of information on how to prepare, and prevent, ‘wandering’ of children with ASD^{xiii}.

‘Wandering’ in the blogosphere

The National Institute on Aging at the U.S. National Institutes of Health collaborated with a cable TV company HBO on the “Alzheimer’s Project”, a public health series of four documentaries available via television, web, DVD, and print. Each documentary represents a ‘stakeholder’ perspective: of those directly affected, of their caregivers, of young children whose close relatives are affected, and of researchers. The documentary about personal experience of Alzheimer’s disease, called “The Memory Loss Tapes” follows seven people, each at a different stage of dementia.

One of the seven is Joseph Potocny, who is a ‘self-advocate’ not dissimilar to those who belong to the Autistic Self-Advocacy Network (ASAN). His blog “Living with Alzheimer’s”, and his subsequent book “Living with Alzheimer’s (*sic*): a Conversation if You Will” (Potocny 2010) have created an on-line community of over 44,000 visitors who share their own experiences and resources with each other. The blog became a virtual meeting place for people living with dementia, and a way to have a community unconstrained by geography and the need to leave one’s home to be with others. It also became an on-line place where family members and caregivers could talk and problem-solve with each other. Over time, it also became a poignant virtual memorial for the blog readers who had died.

The narrative nature of the blog fosters Joe’s connection with himself and others, and motivates him to write down his thoughts. Blog entries describing his experiences become shared and responded to by others. For example, Joe shares a haunting account of his fear of wandering and getting lost:

“I get lost in my own yard. I forget what I am doing, how to get back into the house, and stand there wondering whether whatever I wonder and thus far I have

^{xiii}e.g. an Autism Speaks web page ‘Preventing Wandering: Resources for Parents and First Responders’.

found my way back. I have grown afraid to leave my own house because I am not sure that even going to the mailbox I will stop and remember to come back. What scares me is, when will that line come when I step over and I don't come back?" (n/p)

One of the blog entries is about how important it is for Joe to leave a mark in the lives of other people with AD and their caregivers, to help them understand it better, and to make them better equipped to live with it. If 'social death', as Arthur Kleinman (2009) reminds us, is a removal of people from their human, social networks, then Joe Potocny's blog and the community it created can be seen as an engendering and an affirmation of 'social life'.

Similarly to Joe Potocny's "Living with Alzheimer's" blog that has become a meeting place where geospatial challenges and cognitive constraints of dementia are diminished, blogosphere and the Internet have been transforming the worlds of people with ASD. As Bagatell (2007) writes, the emergence of the Internet and the wide spread use of computers facilitated the self-advocacy movement and the formation of on-line communities of people with ASD. Bagatell (2007) quotes Judy Singer (1999) who writes: 'the internet has begun to do what was thought impossible—to bind autistics together into groups, and it is this which will finally enable them to claim a voice in society' (p. 67; cf Bagatell 2007, p.420). In Eve Kittay's terms, the Internet made it possible for people with ASD to have "their voice heard" not only as individuals but also as a constituency with self-advocacy rights. For example, as discussed above, when members of the Autistic Self-Advocacy Network's (ASAN) opposed the ICD-9 code V40.31, their arguments were voiced in a public letter to the CDC posted on the ASAN's website.

Drawing upon a study on the use of the Internet by people with ASD, Joyce Davidson and Michael Orsini (2013) explore what happens when "the selves and spaces with which one interacts in mutually constitutive ways are increasingly or even almost exclusively electronically mediated" (p. 287). They ask "what Internet use means for the geographies of some autistic persons' lives, (...) how it affects, for example, their daily mobility, their sense of social, spatial, and emotional connection, and what this in turn means for their sense of self" (p. 286–287). Does the Internet and the blogosphere enhance and expand sociospatial and relational horizons of people with ASD, or does it contract and close them down, making "the world feel somehow smaller or otherwise simply less" (p. 287) ? One of the participants in their study responds to this question: "I feel that my world has expanded because of the Internet, and I have grown to meet it" (Davidson and Orsini 2013, p. 285).

One of the most important, albeit still experimental, outcomes of their study is the suggestion that the Internet connectivity has an enormous potential to enhance the experiences of mobility for people with ASD. In a sense, the use of mobile technologies for locating self in space and finding a path to a desired destination that Davidson and Orsini (2014) suggest is an antithesis to wearing a geospatial positioning device that someone placed on you to know where you are if you become lost:

"Clearly, being online no longer equates to being at home, "stuck," or otherwise static, and findings suggest that the prospect of being simultaneously online and mobile could have an effect of unprecedented significance on the horizons of

autistic lives. That is to say, increasingly available and affordable wireless technologies can provide an invaluable source of portable information and support. Such connectivity might in turn feed into a mobile sense of security that could mitigate certain sources of social exclusion. To cite an obvious, if hypothetical, example, Wi- Fi could lessen navigational challenges associated with sensory overload in public places; consulting online maps or timetables for public transport would, for many, be far preferable to the nontechnological alternative involving a face- to- face request for assistance” (p.297).

This suggests a technologically mediated strategy to empower persons with autism in “having a world” (Merleau-Ponty 1962) where they are equipped to *use* technological Wi-Fi geospatial positioning devices rather than being passively *tracked* by them. Possibly the best of all possible worlds is a technology that allows both to locate self in space and find your way to your destination, *as well as* to allow others such as family members, or law enforcement if necessary, to have access to your location. This is an experientially informed, practical expansion of the management and prevention perspective on ‘wandering’ that supports and enhances agency, personhood and participation of persons with ASD while situating them in a specific landscape and connecting them within a social web of family and other relationships. In the second half of the article, we now turn to our ethnographic research on how ‘wandering’ of children with ASD is experienced by their parents and professionals who work with them.

Ethnographic Study of Families Experiences of ASD: Methodology and Data

The ethnographic project titled ‘Autism in Urban Context: Linking Heterogeneity with Health and Service Disparities’^{xiv} draws on narrative, phenomenological and interpretive traditions in its conceptualization, data collection and analysis (Kleinman 1995; Lawlor 2004, 2009, 2012; Lawlor and Solomon 2017; Mattingly 1998, 2010, 2014; Ochs and Capps 2001; Solomon 2010, 2013). Twenty-five children from twenty-three families living in Los Angeles participated in the study. Four California Department of Developmental Services’ Regional Centers located in Los Angeles County, a university hospital and a center for developmental disabilities served as study sites. Ethical approval for the study was obtained from the University of Southern California Institutional Review Board.

Recruitment was carried out through 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 years of age or younger at the time of enrollment. The children’s ages over the course of the study ranged between four and nine years. The children had a documented ASD diagnosis by a licensed professional, and a projected need for interventions and services at one of the study sites.

^{xiv}R01 MH089474, 2009–2012, O. Solomon, P.I., M. Lawlor, Co-I; the other co-investigators were: Sharon Cermak, Marian Williams, Thomas Valente, Marie Poulson, and Larry Yin.

Thirty-seven parents participated in the study, including twenty-two mothers and fifteen fathers and step fathers. Thirteen of the participating families were two-parent households and ten were single-parent households led by nine mothers and one father. The parents self-identified as African American. Seventeen extended family members also participated in the study. The socio-economic status of the families was left open, however, our study sites primarily serve lower SES families. The total number of subjects in the family cohort was eighty-eight. Sixty-five practitioners including physicians, behavioral professionals, occupational therapists, speech pathologists, teachers, service coordinators and other professionals also participated in the study.

The major part of the data corpus was collected between October 1, 2009 and August 31, 2012, with several follow-up meetings through May 2014. The participant-observation component involved collecting observational and interview data in the home, clinic, school, and community contexts. For some families in the study, home was a frequent place of observation while other families preferred to be interviewed and observed in community settings such as parks, restaurants, children's museums and other locations. Participant observation placed us in the midst of the families' social life where there were continuous and on-going opportunities to build participant-researcher relationships built on trust. The total data corpus collected for the study consists of 196 narrative-based interviews with parents, 26 Collective Narrative meetings with families, 3 Collective Narrative meetings with practitioners, 24 social networks interviews with parents, 4 interviews with extended family members, 7 interviews with the children in the study, 43 interviews with practitioners, 51 observations in health care and clinical settings, 25 home observations, 28 community observations, 15 school observations, 7 observations at Individualized Educational Program meetings, and 67 medical and school records reviews. Digital audio- or video-data were uploaded to a password-protected secure data server and transcribed using Inscribe software that links audio- and video-data to time-coded text. The findings presented below are organized around several themes that emerged from the narrative, thematic and categorical analysis.

'Wandering' of children with ASD as evidence of capacity

The ambiguity of the term 'wandering' not only hinders its conceptualizations, but also gives rise to different points of view on subjectivities of persons with ASD. Does 'wandering' denote an intentionality, curiosity, and appreciation of space and place? Or alternatively, an impulsive, irrational, and possibly physiologically-based flight or escape from one's environment as the biomedical literature suggests? Is it possible that 'wandering' in ASD reveals a unique but profound and untapped capacity in spatial localization, and an exploratory impulse that evinces the desire to "have the world" (Merleau-Ponty 1962)?

The nuances of what the term 'wandering' means for family members have not been sufficiently examined. Deciphering the internal world of people with ASD is an on-going and arduous task for many family members. The search for understanding and the processes of attribution of intentions to behaviors are deeply compelling and consuming. The search sometimes involves improvisation, translations of ambiguous signs and meanings, and morally-laden and highly consequential experimentations (Mattingly 2014). There is also a

keen awareness of one's own limitations. As Kristina Chew (2014) writes, 'translating' her son Charlie involves

"Bearing witness to our own insufficiency, to the inscrutability of the otherness we are trying to speak for and represent, across unfathomable distance – this recognition of the necessity and futility of our attempts to know can leave us speechless" (p.313).

Family members are faced with a hermeneutic struggle to differentiate which aspects of 'wandering' are due to ASD and which are reflective of developmentally appropriate, albeit problematic, childhood behavior. What constitutes a 'problem behavior' is also open to different participants' interpretations. The emic / etic dichotomy (Geertz 1974; Pike 1967) divides in problematic ways the professional knowledge of biomedicine and the parental experiential knowledge of their children with ASD (Silverman 2008, 2012). The experiential knowledge engenders an openness to complexity and interdependence, and a worldview that extends beyond narrowly defined criteria of normality (Fisher 2007).

Our data suggest that parents struggle with this distinction, especially when their children provide reasons for their 'wandering', e.g. packing up a suitcase and wanting to move to the great grandmother's house, or wanting to go back to the house from which the family just moved. In the following example, Liora, a mother in our study, shared in an interview her concerns about her son, Leo, who was about 6 years old at the time. Liora describes a seemingly simple, but morally complex strategy that the family developed to better understand Leo's capability to wander away from home:

"Every time we discipline him he lashes out on his grandma and he go 'I'm not going home with her, I'm running away'. That's the thing we don't like to hear because we don't know- when we're not around, Leo, what is he thinking? Is he thinking 'this a good time for me to run away, nobody watching me'?"

In a later interview, Liora described how Leo finally acted on his words and how she and Leo's grandmother responded:

"Well, he did it. We played it for him, you know, to see how far he would go. Leo went and packed his Fruit Loops, his carry on overnight bag. I went and I parked down the street to see how far he was going to go. His grandma was behind him between the park and- this boy was getting ready to go to the main intersection. I mean – [Grandmother: With a suitcase] with suitcase and- [Grandmother: Underwear, socks and- and three outfits]."

As Mattingly (2014) writes,

"Parents are called upon to try to ascertain what is best for their children and for other tasks and problems that they must simultaneously address. This is, in other words, a complex reasoning task that engenders ongoing moral deliberations, evaluations, and experiments in how to live" (p.4).

Parents are not the only group reckoning with 'wandering' in complex and unexpected ways. In the story about 'wandering' below, the teacher, Kylie, constructs Monica, her student with ASD, as a resourceful, intelligent child who is intersubjectively attuned with her:

“I’ll share a story with you. One day I was at work and we were doing the theater project after school. And, you know, for work I have to dress somewhat nice. You know, you have to wear business casual-type clothes. And I was wearing a pair of leopard flats. And I can’t run in these flats, and she knows it. So she takes off one day. Had to leave the situation. She’s off and running, and I can’t run in these shoes. So I had to literally take off the shoes and run after her down the hall. So I run after her down the hall. And then yesterday she looked down at my shoes, and I was wearing sneakers instead of, instead of, you know, my flats for work. And she looks down at my shoes yesterday and she was like, “Where are your other shoes?” (Laughs.) So ... Yeah. She’s a very funny girl. She has a great sense of humor. You know, when she gets mad at me she’ll tell me I’m just in it for the money. And anybody that knows anything about non-profits-, you’re not in it for the money. But she gets mad at me and she’ll say things like that. But I know she doesn’t mean it.”

Kylie’s narrative is rich with interpretation of Monica’s understanding of the situation: Monica knows that her teacher cannot run in her nice business-casual flats. The response of the teacher is indicative of her commitment to this child’s safety: she runs after Monica barefoot because then she can run faster and catch up with her before Monica leaves the building. There is no irritation or anger in Kylie’s story, only marveling at Monica’s capacity to notice that she is wearing a different pair of shoes than the day before, shoes designed for running. Kylie also gently humors Monica’s outspoken opinions that she is “in it for the money” although Kylie believes that Monica does not mean this accusation. In this short excerpt, we can see this teacher’s nuanced understanding of her student and the student’s intention to “take off” in order to “leave the situation”, quite a different view from a behavior that ““can’t be helped” (IACC 2010: p.86).

‘Wandering’ of children with ASD as evidence of attachment

Another family in our study, Jean, Gary and their three sons, lived near a busy intersection. It was constantly on their mind that Jacob, in their own words, was a ‘runner’. Gary remembered in an interview:

“And last time I had left the house and I had walked down the corner, crossed the street, I can’t remember where I was going but I was getting ready to continue walking down the block and I turned around and looked across the street, and here comes Jacob running down the block. I was just like ‘oh no’, ‘cause I was trying to figure out a way I could get across the street before he got into the street and she (Jean) was right behind him. You know, ‘cause I think he was trying to follow me ‘cause he knew I had just left. Yeah, that was scary. That was real scary”.

Although terrified by his son’s actions, Gary makes a relational interpretation: *‘I think he was trying to follow me ‘cause he knew I had just left’*. Another family, Michelle and Jonathan, had a similar interpretation when their son, Simon, 4 years old at the time, walked out of their house after his mother and older sister Chiara left to go to a birthday party. The family lived in a neighborhood surrounded by busy streets lined with shops and restaurants. Realizing that Simon was missing, his father called the police who just received a phone call

from a man who minutes earlier stopped a young boy from entering a busy intersection. In one of several retellings of this story, Michelle said:

“When he walked out the house, he may have been-, because Jonathan said he was upset when Chiara and I left, you know. But he had calmed-, seemingly calmed down because he was playing with the toys so he, you know, seemed like everything was fine, so I think Jonathan said he was downstairs in the garage when he heard the door and went and looked for him so he may have been thinking that he was gonna look for us, yeah”.

The narrative portrayals of Jacob and Simon as relational and intentional social actors who left the house to look for their parents offer a story quite distinct from the management and prevention view of ‘wandering’ as a compulsive behavior that “can’t be helped”. Michelle and Gary’s stories also do not directly voice a concern with a possibility that their children’s ‘wandering’ could be seen as a sign of parental neglect, which was powerfully highlighted by the NAA President Wendy Fournier in her argument for the necessity of the code (IACC 2010).

Other data in our corpus show, however, that children’s ‘wandering’ presents parents with a difficult task of performing a ‘good parent’ identity (Goffman 1959) in the face of open or implicit blame from human services professionals, law enforcement, and child protection agencies who operate under the management and prevention view. Our ethnographic data corpus documents families’ management of ‘wandering’ as a transactional and relational process where success is hindered by insufficient supports and services, which is often interpreted as evidence that their children are not ‘service-worthy’ (Marvasti 2002; Solomon and Lawlor 2013). There are very few existing services or supports to help with ‘wandering’, and both Jacob’s and Simon’s parents tried to but were unable to secure them. The increasingly neoliberal climate in the U.S. health and social services system promotes expectations of self-reliance and financial independence, and significantly reduces the purview of federally- and state-funded interventions and services for ASD. It is tacitly assumed that the parents carry the primary responsibility for management and prevention of their child’s ‘wandering’.

Conclusion

In Avonte Oquendo’s case, a wrongful death suit was filed by Avonte’s mother against the Riverview School’s officials and the New York Police Department school safety division for failing to monitor the school’s exit doors and for not properly supervising Avonte who was known to be a ‘runner’. The lawsuit outlined in painstaking detail the sequence of events that led to Avonte’s death, including the fact that his teachers never read his IEP, and that the codes to the school security video were not available for two hours from the moment the school officials acknowledged that Avonte was missing, delaying the knowledge that he did in fact make his way out of the school’s building. The city of New York had agreed to pay \$2.7 million to settle the suit. In a statement, Vanessa Fontaine said: ““No amount of money can ever heal the pain or somehow lessen the loss. I only hope the Department of Education and the city of New York take the sorely needed steps to properly care for all their students, especially the ones with special needs.” (Marzulli 2016).

While Vanessa Fontaine's statement was not specifically directed at scholars of moral philosophy, liberal theory, and bioethics, its relevance is easily discernable: the person with ASD or AD is a collective responsibility, not just a responsibility of a parent or a caregiver, independently of whether the person can participate "in the prescribed process for forming personalized ideas of the good" (Sillers and Francis 2009, p. 475). The resources that are necessary to fulfill a parent's and family's obligation to the child's development, growth and safety are "at least partially supplied by the larger society" (Kittay 2009, p. 623). "No child, – Kittay (2009) writes, – is simply the parent's own private matter" (p. 623). Moreover, as Deborah Barnbaum (2006) writes, "both autistic and non-autistic persons must be perceived as full members of the moral community because exclusion of one will impair the moral status of the other. (...) Persons without autism are harmed by treating a person with autism in a particular way" that does not accord the person with autism moral status (p. 103).

But what resources should be used and how? This question goes back to our concern with whether the management and prevention perspective on 'wandering' anchored in surveillance and technological means of tracking a human body in space is *sufficient* to provide a 'good human life' and opportunities to "have a world". Knowing what *is* sufficient requires the same high stakes, high pressure intersubjective work that the mothers whom we quoted in the beginning of our article did to inhabit their children's bodies and minds. Kittay (2009) writes about the critical importance of 'seeing' into the experiences of people with a disability as a "close personal attentiveness": "a form of subjectivity, an act of imagination, a way of looking that is necessarily in part determined by some private perspective". The result is that "the close attentive eye needed to care for the dependent individual gives rise to perceptual capabilities that are not shared by those who have at best a glancing acquaintance" (p.623). Only this kind of seeing can decipher not only where the person may be in a situated landscape, but also what kind of freedom of movement the person needs to "have a world" (Merleau-Ponty 1962).

Our analysis resonates with Hilton's (2017) call to act upon "the urgency of developing alternative ways of responding to the forms of errant movement evoked by terms such as "wandering" and "elopement," ways that are organized instead around the possibility of embracing (rather than policing or pathologizing) the distinctive sensory dimensions of autistic embodiment " (p. 231). Could the ICD-9 code V40.31 become a starting point to expand the prevention and management viewpoint on 'wandering' in a way that would be responsive to "world-having", and by extension, world-making projects? Could it be possible to coordinate multiple responses to wandering, those directed at safety and those directed at "having a world"? Could there be "an assemblage of cultural resources—structures, stories, relational commitments" (Fein 2015, p. 305) to render the challenges associated with 'wandering' of people with ASD and AD less restrictive of movement through spaces and landscapes, and more supportive of participation in the practical lived worlds of families, communities and the broader society? Could public health efforts to prevent and manage 'wandering' recognize "the reality that even the best care sometimes excludes contact with nature which", – as Gilliard and Marshall (2012) write-, "is an innate need for us all" (p.14) ? We hope that this article generates new insights for clinical practice, policy and public health efforts to address the problem of 'wandering' not through creating

more constraints and restrictions on movement for persons with ASD and AD, but through understanding and responding to their human, existential need of “having a world”.

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References

- Algase, Donna L., Helen Moore, D., Vandeweerd, C., Gavin-Dreschnack, DJ. Mapping the maze of terms and definitions in dementia-related wandering. *Aging & Mental Health*. 2007; 11:686–698. DOI: 10.1080/13607860701366434 [PubMed: 18074256]
- Anderson, Connie, Kiely Law, J., Daniels, Amy, Rice, Catherine, Mandell, David S., Hagopian, Louis, Law, Paul A. Occurrence and family impact of elopement in children with autism spectrum disorders. *Pediatrics*. 2012; 130(5):870–877. [PubMed: 23045563]
- American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th. Washington, D.C.: American Psychiatric Association; 2013.
- Atkins, Kim. Personal Identity and the Importance of One’s Own Body: A Response to Derek Parfit. *International Journal of Philosophical Studies*. 2000; 8(3):329–349.
- Autism Speaks. Aggressive and Challenging Behaviors Tool Kit. 2012. <https://www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit>
- Autism Speaks. Bipartisan senators introduce bill to protect individuals who wander. 2016. <https://www.autismspeaks.org/advocacy/advocacy-news/bipartisan-senators-introduce-bill-protect-individuals-who-wander-0>
- Autistic Self Advocacy Network. Joint letter to CDC on proposed ICD-9-CM wandering code. 2011. <http://www.autisticadvocacy.org/modules/smartsection/item.php?itemid=135>
- Bagatell, Nancy. From cure to community: Transforming notions of autism. *Ethos*. 2010; 38:33–55.
- Baggs, Amelia. Wandering. 2005. <https://ballastexistenz.wordpress.com/2005/08/01/wandering/>
- Baggs, Amelia. Regarding Neli Latson. 2010. <http://ballastexistenz.wordpress.com/2010/06/23/regarding-neli-latson/>
- Ballenger, Jesse F. *Self, Senility, and Alzheimer’s Disease in Modern America: A history*. Baltimore: The John Hopkins University Press; 2006.
- Barnbaum, Deborah R. *The Ethics of Autism: Among Them but not of Them*. Bloomington: Indiana University Press; 2008.
- Bayley, John. *Elegy for Iris*. New York: Saint Martin Press; 1998.
- Bérubé, Michael. Equality, Freedom, And/Or Justice For All: A Response To Martha Nussbaum. *Metaphilosophy*. 2009; 40(3/4):352–365. Special Issue: Cognitive Disability And Its Challenge To Moral Philosophy.
- Briggs, Charles L., Bauman, Richard. Genre, intertextuality, and social power. *Journal of Linguistic Anthropology*. 1992; 2(2):131–172.
- Bruner, Jerome. Narrative, culture, and psychology. In: Antonietti, Alessandro Confalonieri, Emanuela, Marchetti, Antonella, editors. *Reflective Thinking in Educational Settings: A Cultural Framework*. New York: Cambridge University Press; 2014. p. 221–226.
- Call, Nathan A., Pabico, Ryan S., Findley, Addie J., Valentino, Amber L. Differential reinforcement with and without blocking as treatment for elopement. *Journal of Applied Behavior Analysis*. 2011; 44:903–907.
- Carlson, Licia. Who’s the Expert? Rethinking authority in the face of intellectual disability. *Journal of Intellectual Disability Research*. 2010; 54(s1):58–65. [PubMed: 20586885]

- Cartwright, Samuel. De Bow's Review. Southern and Western States. Volume XI, New Orleans. AMS Press, Inc.; New York: 1851. Diseases and peculiarities of the Negro Race. Reprinted by 1967. www.pbs.org/wgbh/aia/part4/4h3106t.html
- Chamak, Brigitte. Autism and social movements: French parents' associations and international autistic individuals' organizations. *Sociology of Health & Illness*. 2008; 30:76–96. [PubMed: 18254834]
- Chew, Kristina. Autism and the Art of the Translator. In: Davidson, Joyce, Orsini, Michael, editors. *Worlds of Autism : Across the Spectrum of Neurological Difference*. Minneapolis: University of Minnesota Press; 2013. p. 305-317.
- Charon, Rita. Narrative medicine: A model for empathy, reflection, profession, and trust. *JAMA*. 2001; 286:1897–1902. [PubMed: 11597295]
- Charon, Rita. *Narrative Medicine: Honoring the Stories of Illness*. New York: Oxford University Press; 2006.
- Cipriani, Gabriele, Lucetti, Claudio, Nuti, Angelo, Danti, Sabrina. Wandering and dementia. *Psychogeriatrics*. 2014; 14:135–142. [PubMed: 24661471]
- Coleman, Erica A. Physical restraint use in nursing home patients with dementia. *Journal of the American Medical Association*. 1993; 270(17):2114–2115. [PubMed: 8411581]
- Damasio, Antonio. *Self Comes to Mind: Constructing the Conscious Brain*. New York: Pantheon; 2010.
- Daxter, Lisa. Wandering. 2011. <http://chaoticidealism.livejournal.com/92327.html>
- Davidson, Joyce, Orsini, Michael. The Shifting Horizons of Autism Online. In: Davidson, Joyce, Orsini, Michael, editors. *Worlds of Autism : Across the Spectrum of Neurological Difference*. Minneapolis: University of Minnesota Press; 2013. p. 285-303.
- DeBaggio, Thomas. *Losing my Mind: An Intimate Look at Life with Alzheimer's*. New York: Simon and Schuster; 2002.
- Fein, Elizabeth. Autism: Challenging Expert Models. Discussant Remarks; Society for Psychological Anthropology Biennial Meeting; Boston. April 11, 2015; 2015.
- Fein, Elizabeth. Making Meaningful Worlds: Role-Playing Subcultures and the Autism Spectrum. *Culture, Medicine and Psychiatry*. 2015; 39(2):299–321.
- Fisher, James T. No search, no subject? Autism and the American conversion narrative. In: Osteen, Mark, editor. *Autism and Representation*. New York: Routledge; 2008. p. 51-64.
- Fox, Kathryn J. Self-change and resistance in prison. In: Holstein, James A., Gubrium, Jaber, editors. *Institutional Selves: Troubled Identities in a Postmodern World*. New York: Oxford University Press; 2001. p. 176-192.
- Gallagher S. Philosophical conceptions of the self: Implications for cognitive science. *Trends in Cognitive Sciences*. 2000; 4:14–21. [PubMed: 10637618]
- Garro, Linda, Mattingly, Cheryl. Narrative as construct and construction. In: Mattingly, Cheryl, Garro, Linda C., editors. *Narrative and the Cultural Construction of Illness and Healing*. Berkeley: University of California Press; 2000a. p. 1-49.
- Garro, Linda, Mattingly, Cheryl. Narrative turns. In: Mattingly, Cheryl, Garro, Linda C., editors. *Narrative and the Cultural Construction of Illness and Healing*. Berkeley: University of California Press; 2000b. p. 259-269.
- Gallagher, Shaun. Philosophical conceptions of the self: Implications for cognitive science. *Trends in Cognitive Sciences*. 2000; 4:14–21. [PubMed: 10637618]
- Genova, Lisa. *Still Alice*. New York: Simon & Schuster; 2015.
- George, Daniel R. Overcoming the social death of dementia through language. *The Lancet*. 2010; 376:586–587.
- Geertz, Clifford. "From the native's point of view": On the nature of anthropological understanding. 1974
- Gibson, James J. The Theory of Affordances. In: Shaw, R., Bransford, J., editors. *Perceiving, Acting, and Knowing: Toward an Ecological Psychology*. Hillsdale, NJ: Erlbaum; 1977. p. 67-82.
- Gilliard, Jane, Marshall, Mary. *Transforming the Quality of Life for People with Dementia Through Contact with the Natural World: Fresh Air on My Face*. London: Jessica Kingsley; 2011.

- Grandin, Temple, Johnson, Catherine. *Thinking in Pictures: My Life with Autism*. New York: Random House; 1995.
- Grandin, Temple, Johnson, Catherine. *Animals in Translation: Using Mysteries of Autism to Decode Animal Behavior*. New York: Houghton Mifflin Harcourt; 2006.
- Graby, Steve. *Wandering Minds: Autism, psychogeography, public space and the ICD*. Presented at the Critical Disability Studies conference “Theorising Normalcy and the Mundane 2011”; Manchester Metropolitan University. 14th September 2011; 2011.
- Greenfield, Josh. *A Child Called Noah: A Family Journey*. New York: Holt, Rinehart and Winston; 1972.
- Greenfield, Josh. *A Place for Noah*. New York: Harcourt; 1986.
- Greenfield, Josh. *A Client Called Noah*. New York: Harcourt; 1989.
- Grinker, Roy Richard. Commentary: On being autistic, and social. *Ethos*. 2010; 38(1):172–178.
- Grinker, Roy Richard. Notes on a puzzle piece. *Autism*. 2015; 19(6):643–645. [PubMed: 26378295]
- Hacking, Ian. *The Mad Travelers: Reflections on the Reality of Transient Mental Illness*. Cambridge: Harvard University Press; 1998.
- Harris, Jill F., Robertiello, Adrienne P. Autism and safety: It’s unpredictable. *Autism Spectrum News*. 2015; 7(4):10–12.
- The Healing Project. *Voices of Alzheimer’s: The Healing Companion: Stories for Courage, Comfort and Strength*. Brooklyn: LaChance Publishing; 2007.
- Hesse, Herman. *Wandering: Notes and Sketches*. Wright, James, translator. New York: Farrar, Straus & Giroux; 1957/1972.
- Hilton, Leon J. Avonte’s Law: Autism, Wandering, and the Racial Surveillance of Neurological Difference. *African American Review*. 2017; 50(2):221–235.
- Ingold, Tim. *Lines: A Brief History*. New York: Routledge; 2007.
- Ingold, Tim. *The Life of Lines*. New York: Routledge; 2015.
- Ingold, Tim, Vergunst, Jo Lee. *Ways of Walking: Ethnography and Practice on Foot*. New York: Routledge; 2008. Introduction; p. 1–20.
- Interagency for Autism Coordinating Committee. US Department of Health And Human Services Interagency Autism Coordinating Committee Full Committee Meeting Friday. 2010. October 22, 2010 <https://iacc.hhs.gov/meetings/iacc-meetings/2010/full-committee-meeting/october22/#transcript>
- Interagency for Autism Coordinating Committee. IACC Letter to Secretary Sebelius on Wandering. 2011. February 9, 2011. https://iacc.hhs.gov/publications/general/2011/letter_wandering_020911.pdf
- The John Hopkins White Papers. *Memory*. Baltimore: The John Hopkins Medicine; 1999.
- Kapp, Steven K., Gillespie-Lynch, Kristen, Sherman, Lauren E., Hutman, Ted. Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*. 2013; 49(1):59–72. [PubMed: 22545843]
- Kittay, Eva Feder. *When Caring Is Just and Justice Is Caring: Justice and Mental Retardation*. Public Culture. 2001; 13(3):557–579.
- Kittay, Eva Feder. At the Margins of Moral Personhood. *Ethics*. 2005; 116(1):100–131. [PubMed: 16578953]
- Kittay, Eva Feder. The Personal Is Philosophical Is Political: A Philosopher and Mother of a Cognitively Disabled Person Sends Notes From the Battlefield. *Metaphilosophy*. 2009; 40(3/4): 606–627. Special Issue: Cognitive Disability And Its Challenge To Moral Philosophy.
- Kittay, Eva Feder, Carlson, Licia. Introduction: Rethinking philosophical presumptions in light of cognitive disability. *Metaphilosophy*. 2009; 40(3/4):307–330. Special Issue: Cognitive Disability And Its Challenge To Moral Philosophy.
- Kleinman, Arthur. *Writing at the margin: Discourse between anthropology and medicine*. Berkeley: University of California Press; 1995.
- Kleinman, Arthur. Global mental health: A failure of humanity. *Lancet*. 2009; 374:603–604. [PubMed: 19708102]

- Kolker, Robert. The Boy Who Ran: The Life and Death of Avonte Oquendo. New York Magazine. 2014 Mar 30. 2014.
- Kontos, Pia C. Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Aging and Society*. 2004; 24(6):829–849.
- Kotef, Hagar. Movement and the Ordering of Freedom: On Liberal Governances of Mobility. Durham: Duke University Press; 2015. 2015
- Lai, Claudia KY., Arthur, David G. Wandering behaviour in people with dementia. *Journal of advanced nursing*. 2003; 44(2):173–182. [PubMed: 14521683]
- Lang, Russell, Davis, Tonya, O'Reilly, Mark, Machalicek, Wendy, Rispoli, Mandy, Sigafoos, Jeff, Lancioni, Giulio, Regeher, April. Functional analysis and treatment of elopement across two school settings. *Journal of Applied Behavior Analysis*. 2010; 43(1):113–118. [PubMed: 20808501]
- Livingston, Julie. Debility and the Moral Imagination in Botswana. Bloomington: Indiana University Press; 2009.
- Lawlor, Mary C. Mothering work: negotiating healthcare, illness and disability, and development. In: Esdaile, Susan A., Olson, Judith A., editors. *Mothering Occupations*. Philadelphia: F. A. Davis; 2004. p. 306-323.
- Lawlor, Mary C. Narrative, development, and engagement: intersections in therapeutic practices. In: Jensen, Uffe Juul, Mattingly, Cheryl, editors. *Narrative, Self, and Social Practices*. Aarhus: Forlaget Philosophia; 2009. p. 199-220.
- Lawlor, Mary C. The particularities of engagement: Intersubjectivity in occupational therapy practice. *Occupational Therapy Journal of Research: Occupation, Participation and Health*. 2012; 32(4): 151–159.
- Lawlor, Mary C., Mattingly, Cheryl. The complexities embedded in family-centered care. *American Journal of Occupational Therapy*. 1998; 52(4):259–267. [PubMed: 9544351]
- Lawlor, Mary C., Mattingly, Cheryl. Understanding family perspectives on illness and disability experiences. In: Crepeau, Elizabeth B.Cohn, Ellen S., Boyt Schell, Barbara A., editors. *Willard and Spackman's Occupational Therapy*. 11th. Philadelphia: Lippincott Williams & Wilkins; 2009. p. 33-44.
- Lawlor, Mary C., Mattingly, Cheryl. Family perspectives on occupation, health and disability. In: Boyt Schell, Barbara A.Gillen, Glen, Scaffa, Marjorie, editors. *Willard and Spackman's Occupational Therapy*. 12th. Philadelphia: Lippincott Williams & Wilkins; 2014. p. 149-162.
- Lawlor, Mary C., Olga, Solomon. A Phenomenological Approach to the Cultivation of Expertise: Emergent Understandings of Autism. *Ethos*. 2017; 45(2):232–249.
- Lock, Margaret. Decentering the Natural Body: Making Difference Matter. *Configurations*. 1997; 5(2): 267–292. [PubMed: 11619578]
- Lyman, Karen. Bringing the social back in: A critique of the biomedicalization of dementia. *Aging and Everyday Life*. 2000; 29:331–50.
- McDermott, Ray. The acquisition of a child by a learning disability. In: Chaiklin, Seth, Lave, Jean, editors. *Understanding Practice: Perspectives on activity and context*. Cambridge: Cambridge University Press; 1993. p. 269-305.
- Marr, James. Electronic tagging. *Nursing Standard*. 1989; 4(9):54.
- Marvasti, Amir. Constructing The Service-Worthy Homeless Through Narrative Editing. *Journal of Contemporary Ethnography*. 2002; 31:615–651.
- Marzulli, John. Family of Avonte Oquendo, drowned autistic student, to receive 2.7 M in wrongful death suit. *New York Daily News*. Jul 28.2016 2016.
- Mattingly, Cheryl. *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Cambridge: Cambridge University Press; 1998.
- Mattingly, Cheryl. *The Paradox of Hope: Journeys through a Clinical Borderland*. Berkeley: University of California Press; 2010.
- Mattingly, Cheryl. *Moral Laboratories: Family Peril and the Struggle for a Good Life*. Berkeley: University of California Press; 2014.
- Mattingly, Cheryl, Lawlor, Mary C. Learning from stories: Narrative interviewing in cross cultural research. *Scandinavian Journal of Occupational Therapy*. 2000; 7(1):4–14. [PubMed: 21399739]

- Matteson, Mary Ann, Linton, Adrienne. Wandering behaviors in institutionalized persons with dementia. *Journal of Gerontological Nursing*. 1996; 22(9):39–46.
- Maynard, Douglas, Turowetz, Jason. Doing Diagnosis: Autism, Interaction Order, and the Use of Narrative in Clinical Talk. *Social Psychology Quarterly*. 2017; 80(3):254–275.
- McIlwain, Lori, Fournier, Wendy. Lethal Outcomes In Autism Spectrum Disorders (ASD) Wandering / Elopement. National Autism Association. Jan 20.2012 2012.
- McMahan, Jeff. *The Ethics of Killing: Problems on the Margins of Life*. New York: Oxford University Press; 2002.
- Merleau-Ponty, Maurice. *Phenomenology of Perception* Colin Smith, trans. London: Routledge and Kegan Paul; 1962.
- Meyerhoff, Barbara. “Life, Not Death in Venice”: Its Second Life. In: Goldberg, Harvey E., editor. *Judaism Viewed from Within and from Without: Anthropological studies*. New York: State University of New York Press; 1987. p. 143-170.
- Mukhopadhyaya, Tito Rajarshi. *The Gold of the Sunbeams and Other Stories*. Arcade Publishing; 2011.
- National Autism Association. NAA’s Statement to IACC Addresses Wandering Prevention, Avonte’s Law. 2016. <http://nationalautismassociation.org/naas-statement-to-iacc-addresses-wandering-prevention-avontes-law/>
- Ne’eman, Ari. The Future (and the Past) of Autism Advocacy, or Why the ASA’s Magazine, *The Advocate*, Wouldn’t Publish this Piece. *Disabilities Studies Quarterly*. 2010; 30(10) Retrieved from <http://www.dsquds.org/>.
- Neisser, Ulric, Rbyn, Fivush. *The Remembering Self: Construction and Accuracy in the Self-Narrative*. New York: Cambridge University Press; 1994.
- Nussbaum, Martha. The Capabilities of People With Cognitive Disabilities. *Metaphilosophy*. 2009; 40(3/4):331–351. Special Issue: Cognitive Disability and its Challenge to Moral Philosophy.
- Ochs, Elinor, Capps, Lisa. *Living Narrative: Creating Lives in Everyday Storytelling*. Boston: Harvard University Press; 2001.
- O’Loughlin, Marjorie. Intelligent bodies and ecological subjectivities: Merleau-Ponty’s corrective to postmodernism’s ‘subjects’ of education. *White Paper. Philosophy of Education*. 1995. <http://education.illinois.edu/epol/PES-Yearbook/1995.html>
- Ortega, Francisco. The cerebral subject and the challenge of neurodiversity. *BioSocieties*. 2009; 4(4): 425–445.
- Parfit, Derek. *Reasons and Persons*. Oxford: Clarendon; 1984.
- Park, Clara Claiborne. *The Siege: A Family’s Journey into the World of an Autistic Child*. Boston: Little, Brown and Company; 1967.
- Park, Clara Claiborne. *Exiting Nirvana: A Daughter’s Life with Autism*. Boston: Little, Brown and Company; 2002.
- Pike, Kenneth L. *Language in Relation to a Unified Theory of the Structure of Human Behavior*. 2nd. The Hague: De Gruyter Mouton; 1967.
- Perrin, Christopher J., Perrin, Stefanie H., Hill, Elizabeth A., DiNovi, Kristin. Brief functional analysis and treatment of elopement in preschoolers with autism. *Behavioral Interventions*. 2008; 23(2): 87–95.
- Piazza, Cathleen C., Hanley, Gregory P., Bowman, Lynn G., Ruyter, John M., Lindauer, Steven E., Saiontz, Deborah M. Functional analysis and treatment of elopement. *Journal of Applied Behavior Analysis*. 1997; 30(4):653–672. [PubMed: 9433790]
- Potocny, Joseph. Living with Alzheimer’s. n/d<http://living-with-alzhiemers.blogspot.com>
- Potocny, Joseph. *Living with Alzheimer’s (sic) : a Conversation if You Will*. Xlibris Self-Publishing; 2010.
- Prince-Hughes, Dawn. *Songs of The Gorilla Nation: My Journey Through Autism*. New York: Harmony Books; 2004.
- Prince-Hughes, Dawn. *Expecting Teryk: An Exceptional Path to Parenthood*. Columbus: Ohio University Press; 2005.

- Puar, Jasbir. Prognosis Time: Towards a Geopolitics of Affect, Debility and Capacity. In: Muñoz, José Esteban, editor. *Between Psychoanalysis and Affect: A Public Feelings Project*. Vol. 19. 2009. p. 161-72. spec issue of *Women & Performance*
- Rice, Catherine E., Zablotsky, Benjamin, Avila, Rosa M., Colpe, Lisa J., Schieve, Laura A., Pringle, Beverly, Blumberg, Stephen J. Reported wandering behavior among children with autism spectrum disorder and/or intellectual disability. *The Journal of Pediatrics*. 2016; 174:232–239. [PubMed: 27157446]
- Robinson, Louise, Hutchings, Deborah, Corner, Lynne, Finch, Tracy, Hughes, Julian, Brittain, Katie, Bond, John. Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. *Health, Risk & Society*. 2007; 9(4):389–406.
- Shepard, Paul. *Man in the Landscape: A Historic View of the Esthetics of Nature*. Athens, GA: University of Georgia Press; 1967.
- Sinclair, Jim. Don't mourn for us. *The Autism Network International Newsletter: Our Voice*. 1993; 1(3) http://www.autreat.com/dont_mourn.html.
- Sinclair, Jim. Is Cure a Goal?. 1998. <http://web.syr.edu/~jsincla/cure.htm>
- Silverman, Chloe. Fieldwork on another planet: Social science perspectives on the autism spectrum. *BioSocieties*. 2008; 3(3):325–341.
- Silverman, Chloe. *Understanding Autism: Parents, Doctors and the History of a Disorder*. Princeton: Princeton University Press; 2012.
- Silvers, Anita, Francis, Leslei Pickering. Thinking about the good: Reconfiguring liberal metaphysics (or not) for people with cognitive disabilities. *Metaphilosophy*. 2009; 40(3/4):475–498. Special Issue: Cognitive Disability And Its Challenge To Moral Philosophy.
- Simon, Jonathan. Speaking Truth and Power. *Law & Society Review*. 2002; 36(1):37–44.
- Singer, Judy. 'Why can't you be normal for once in your life?' from a 'problem with no name' to the emergence of a new category of difference. In: Corker, M., French, S., editors. *Disability discourse*. Philadelphia: Open University Press; 1999. p. 57-67.
- Song, Jun-Ah, Algase, Donna. Premorbid characteristics and wandering behavior in persons with dementia. *Archives of Psychiatric Nursing*. 2008; 22(6):318–327. [PubMed: 19026920]
- Solomon, Olga. Sense and the senses: anthropology and the study of autism. *Annual Review of Anthropology*. 2010; 39:241–259.
- Solomon, Olga. Autism and affordances of achievement: narrative genres and parenting practices. In: Long, Nicolas, Moore, Henrietta, editors. *The social life of achievement*. Oxford: Berghahn Books; 2013. p. 120-138.
- Solomon, Olga, Lawlor, Mary C. "And I look down and he is gone": Narrating autism, elopement and wandering in Los Angeles. *Social Science & Medicine*. 2013; 94:106–114. [PubMed: 23890970]
- Spencer, J William. Self-presentation and organizational processing in a human service agency. In: Holstein, James A., Gubrium, Jaber, editors. *Institutional Selves: Troubled Identities in a Postmodern World*. New York: Oxford University Press; 2001. p. 158-169.
- Spurling, Laurie. *Phenomenology and the social world: The philosophy of Merleau-Ponty and its relation to the social sciences*. Abingdon: Routledge; 2013.
- Taylor, Janelle S. On recognition, caring, and dementia. *Medical Anthropology Quarterly*. 2008; 22(4): 313–335. [PubMed: 19189720]
- Taylor, Janelle S. Beyond words: Traces of meaning in an abandoned kitchen. *Anthropology Now*. 2011; 3(2):62–64.
- Taylor, Richard. *Alzheimer's from the Inside Out*. Baltimore: Health Professions Press; 2007.
- van Manen, Max. Modalities of body experience in illness and health. *Qualitative Health Research*. 1998; 8(1):7–24.
- van Manen, Max. *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. Walnut Creek, CA: Left Coast Press; 2015.
- Whitehouse, Peter. The music of trees: the intergenerative tie between primary care and public health. *London Journal of Primary Care*. 2016; 8(2):26–29. DOI: 10.1080/17571472.2016.1152100.
- Whitehouse, Peter, George, Danny, Wigg, Johanna, Joseph, Brett. *The Myth of Alzheimer's: What You Aren't Being Told about Today's Most Dreaded Diagnosis*. New York: St. Martin's Griffin; 2008.

- Whitehouse, Peter, George, Danny, Wigg, Johanna, Joseph, Brett. From demedicalisation to renaturalisation: Dementia and nature in harmony. In: Gilliard, Jane, Marshall, Mary, editors. Transforming the Quality of Life for People with Dementia through Contact with the Natural World: Fresh Air on My Face. London: Jessica Kingsley; 2012. p. 55-69.
- United States Library of Congress. S.163 – Avonte’s Law Act of 2015. 114th Congress. 2015. <https://www.congress.gov/bill/114th-congress/senate-bill/163>
- United States Library of Congress. S.2614 – Kevin and Avonte’s Law of 2016. Missing Americans Alert Program Act of 2016. 114th Congress. 2016. <https://www.congress.gov/bill/114th-congress/senate-bill/2614>
- Williams, Donna. Nobody Nowhere. London: Jessica Kingsley; 1992.
- Zeisel, John, Reisberg, Barry, Whitehouse, Peter, Woods, Robert, Verheul, Ad. Ecopsychosocial interventions in cognitive decline and dementia: A new terminology and a new paradigm. American Journal of Alzheimer’s Disease and Other Dementias. 2016; 31:1–6. DOI: 10.1177/1533317516650806