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# Inclusive Sensory Ethnography: Studying New Media and Neurodiversity in Everyday Life

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## Abstract

Media and communication studies has recently begun to ethnographically explore the sensory dimensions of how individuals experience and perceive technology. This turn towards the sensorial has centered primarily on the five "external" senses (sight, sound, touch, smell, taste), and less so on "internal" vestibular and proprioceptive systems that concern bodily spatial positioning. I propose *inclusive sensory ethnography* to account for greater neurodiversity in how humans process sensory input, as well as a fuller range of multi-sensory encounters with new media. I ground this conceptualization in a qualitative study of young children on the autism spectrum with difficulties processing sensory information, and their social engagements with print, screen, and interactive media. Inclusive sensory ethnography reveals novel understandings of how the internal senses shape and are shaped by mediated relationships, practices, and intimacies. I discuss further implications for how disability and inclusive sensory ethnography can enrich the study of everyday technology use.

Keywords: ethnography, senses, technology, qualitative methods, autism, children and media

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Qualitative research on the experience of media—not solely its representational or textual aspects—has broadened in recent years to address the complex role of the senses in how humans perceive media content and communication technologies. Sensory ethnography, introduced by cultural anthropologist Sarah Pink (2015a, b), has emerged as one such methodological approach. It encompasses the study of how individuals use their senses in everyday mediated environments, the researcher's use of their own senses to understand other people's lives, and the relationship between these processes as well as their social, cultural, and ethical implications. Sensory approaches to ethnography have contributed new ways of understanding the affective dimensions of communication technology use (van Doorn, 2013) and the limits of audio-visual media in documenting multi-sensory experiences (Nakamura, 2013).

The "sensory" in sensory ethnography has been an on-going provocation for media studies scholars and across scholarly disciplines (Richardson & Hjorth, 2017). For some, senses such as touch are less singular modes of perception and more "ensembles" of affective, kinesthetic, and somatic ways of knowing (Paterson, 2007). Others have theorized mediated sense perception as synesthetic in nature, such as McLuhan's description of televisual images as "tactile promptings" (1994, p. 316). Besides the five "external" senses (sight, sound, touch, smell, taste), concerning that which is outside the body, insights from the clinical and scientific fields of occupational therapy, educational psychology, and neurobiology suggest that sensory processing also includes two "internal" sensory systems that tell us where the body is in space (Ayres & Robbins, 2005). These systems—vestibular and proprioceptive—pertain respectively to body movement and body awareness.

In this article, I propose *inclusive sensory ethnography* to better account for how the internal senses shape participation in and exclusion from daily uses of media and technology, as well as for natural variations in human ability to organize sensations coming from the body and the mediated environment. Omission of the vestibular and proprioceptive systems from the purview of digital ethnographers and ethnographers of the digital is a manifestation of less-inclusive sensory analyses. Inclusive sensory ethnography intervenes in ethnographic practice by addressing diversity in how both researchers and research participants process and interpret sensory information, the layered interconnections between the various senses, and the full range of potential multi-sensory encounters to be had with media and technology in daily life.

I ground conceptualization of inclusive sensory ethnography in an on-going multi-year qualitative study of children on the autism spectrum, and their engagement with print, screen, and interactive media.<sup>1</sup> Autistic individuals report processing sensory information in ways that can significantly diverge from the non-autistic population (Williams, 1998). This includes highly acute hearing, difficulty smelling extreme odors, having a high pain threshold, and trouble measuring proximity to other people (Donnellan, Hill, & Leary, 2010; Leekam et al., 2007; Grandin, 1996). Over or under reactivity to sensory input comprises part of the diagnostic criteria for Autism Spectrum Disorders in the American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (DSM-5) (2013), along with difficulties in social communication, social-emotional reciprocity, and repetitive and restricted behavioral patterns.

As with the rest of the population, autistic individuals are also users of information and communication technologies. Their preferred sensory media rituals unfortunately tend to be

<sup>&</sup>lt;sup>1</sup> I use the language of "autistic person," "person on the autism spectrum," and "autism" in this article. These terms are largely preferred by autism self-advocates over "person with autism" and "autism spectrum disorder." The notion of autism as a "spectrum" is itself imperfect, and may reinforce a hierarchy of abilities; see Thomas & Boellstorff, 2017.

understood in pathological and medical terms (Nolan & McBride, 2015). For example, parents and behavioral therapists might consider a child's repeated viewing of selected parts of a film to be a problematic fixation in need of correction, instead of a self-soothing stimulatory practice (or "stim"). Incorporating autistic individuals' experiences with new media may reveal normative assumptions about the sensing body that underpin sensory ethnographies of media and communication technology use, as well as theories of media effects such as uses and gratifications theory that emphasize the social and psychological needs that mass media fulfill without also accounting for sensory needs (Harrison et al., 2016).

Inclusive sensory ethnography works to uncover the interconnected nature of sensory experience and importance of the "internal" senses to media and technology use. This was encapsulated by my observation with Patrick,<sup>2</sup> a 4-year-old non-speaking autistic boy, and his mom, Jessie, as they sat on the living room couch, engaged in their near-daily viewing of the film *Despicable Me 2*. Jessie remarked how Patrick got "his sensory needs met" over the course of the film. "He had a lot. A lot. You have the oral. Between his feet, his hands. His vestibular," she said of his sensory seeking behaviors. How individuals separate out the sensory from the flow of everyday life, and the language that creates boundaries between marked and unmarked sensations (such as "sensory needs") shapes sensory experience for all.

I begin below to advance a rationale for inclusive sensory ethnography by highlighting relevant literature from disability studies, sensory studies, and media studies as means of understanding how mediated relationships, practices, intimacies, and spaces are forged around and through the senses. I then detail, based on my fieldwork, how the proprioceptive and vestibular systems, and well as their interrelation with other senses, shapes and is shaped by

<sup>&</sup>lt;sup>2</sup> All names have been changed as to preserve the anonymity of participants.

everyday media use. Inclusive sensory ethnography allows for more nuanced observations of the social, the sensory, and their co-configuration, particularly among an autistic population narrowly clinically defined by deficits in social skills and sensory processing. Lastly, I discuss broader implications for how inclusive sensory ethnography can enrich the social study of digital media, including exploring the creative ways individuals deal with sensoria that "misfit" their environments, the way cultural anxieties can enforce and reinforce sensory normativity, and the need to account for sensory processing differences in research practice itself.

## Situating Inclusive Sensory Ethnography

Three areas of research and critical thought on technology, society, and human difference are foundational to inclusive sensory ethnography. These include the medical, social, and cultural aspects of human sensory processing; the "sensory turn" in the ethnographic study of mediated environments; and the role of media and technology in whether and how people on the autism spectrum navigate and thrive in a sensory and social world largely designed for neurotypical individuals.

## **Neurodiverse Approaches to Sensory Processing**

Recognition of complex sensory differences, and their acceptance as part of one's identity and personality, is a core tenant of neurodiversity, or the idea that neurological differences in cognition are natural and valuable variations in culture and society (Broderick & Ne'eman, 2008). While not everyone with difficulty responding to and receiving sensory information has a diagnosis of autism or identifies as autistic, sensory processing difficulties are a common feature of autism. Ninety to ninety-five percent of school-age autistic children reportedly have issues processing sensory input (Leekam et al., 2007; Tomchek & Dunn, 2007).

Sensory integration theory (Ayres, 1979) posits that sensation affects human development, function, and behavior over the lifespan, but especially in childhood. Individuals may experience difficulties integrating and processing sensory information in two respects: having high or low thresholds for sensory stimuli, and responding actively or passively to sensory input (Dunn, 1997, 2001). Four types of sensory processing challenges thus emerge in environments that are not configured for an individual's differences: high threshold and passive response (low sensory registration), high threshold and active response (sensory seeking), low threshold and passive response (sensory sensitive), and low threshold and active response (sensory avoiding).

All senses are implicated in sensory regulation, but the proprioceptive and vestibular are central because they convey how and where the body is moving (Ayres & Robbins, 2005). Proprioception refers to sensory information regarding the body's location in space created by the contraction, stretching, and compression of muscles, joints, and tendons. Signs of proprioceptive processing difficulties include frequent crashing and bumping into objects, and experiencing relief from deep pressure on the body, such as being under heavy blankets or enveloped in a "Squeeze Machine" (an invention of autistic researcher Temple Grandin). The body's vestibular receptors in the inner ear are responsible for maintaining a sense of gravity and balance, which tells the body if it is moving, how fast, and in what direction. Signs of vestibular sensory integration dysfunction include appearing to never become dizzy while spinning, and craving activities in which the feet leave the ground (i.e., swinging and jumping). Activities can stimulate both senses; bouncing on a trampoline, for instance, provides deep pressure through the feet and a feeling of flight.

Sensory regulation and dysregulation are not solely individual or biological in nature (per the medical model of disability), but culturally and socially shaped as well (Geurts, 2015; Goffman, 1963). Behaviors that many autistic people develop to cope with environmental sensory overload (such as hand flapping and avoiding eye contact) are often socially stigmatized (Donnellan, Hill, & Leary, 2010). Autistic children may be actively discouraged or punished for exhibiting these self-soothing behaviors (Bascom, 2012). The "inclusivity" of inclusive sensory ethnography thus reflects the position that humans have a wide range of sensory needs and make valid attempts to fulfill those needs in relation to their environments, in which media and technology are pervasive.

## Normative Bodies in Sensory Ethnography and Digital Media

Sensory ethnography sits within social scientific and humanistic approaches that have long attended to the phenomenological, social, and cultural construction of sensory experiences, and broadened ways of thinking about the senses beyond physiology and neurology (e.g., Gibson, 1977; Merleau-Ponty, 1962). Psychologists, designers, and historians illustrate how cultural norms, social roles, and aesthetic preferences for the senses form a basis for human interaction (Bull, Gilroy, Howes, & Kahn, 2006). Anthropology of the senses (Howes, 2003; Solomon, 2010) and sociology of the senses (Simmel, 1950) interrogate how social actors use sensory knowledge to structure culture and society, as well as reinforce and challenge a Western hierarchy of the senses that prioritizes sight.

Sensory ethnography joins conversations regarding the embodiment and emplacement of human sensory experience by "taking a series of conceptual and practical steps that allow the researcher to re-think both established and new participatory and collaborative ethnographic research techniques in terms of sensory perception, categories, meanings, and values" (Pink, 2015b, p. 7). Sensory ethnography does not privilege one ethnographic practice over another, but it is frequently associated with participant observation and interviews. As it intersects with digital ethnography, sensory ethnography focuses not only on embodied engagement with digital platforms and virtual spaces, but also how the interface between bodies and digital technologies configures sensory and affective experiences (Pink et al., 2016).

Sensory ethnographies of digital media and technology also challenge the representational and cultural agendas that have historically informed sensory studies (Pink, 2015a), notably the idea that senses are categories though which humans experience the world. Marshall McLuhan (1967, 1994), for instance, proposed medium-specific and standardized sensory effects on the body (i.e., "sensory ratios"). While mental and symbolic representations of the senses may shape our cognitive understandings of the sensory affordances of media technologies and content, sensory ethnography takes a more ecological approach to sensory perception; in particular, that the senses shape and are shaped by the ongoing and co-constituted nature of mediated environments, practices, and places (Richardson, 2010).

Technologically and socially determinist attributions of sensory effects to media persist however in the twenty-first century. In 2007, *WIRED* writer Clive Thompson (2007) argued that "Twitter and other constant-contact media create *social proprioception*." Thompson wrote of this "almost telepathic awareness" in explicitly embodied terms: "It's like proprioception, your body's ability to know where your limbs are. That subliminal sense of orientation is crucial for coordination: It keeps you from accidentally bumping into objects, and it makes possible amazing feats of balance and dexterity." The biological metaphor of "social proprioception," as but one sensory metaphor in media theory (Farman, 2014), is predicated though on a normative body that can effortlessly coordinate itself in networked spaces by responding to social cues and sensory input. Social proprioception renders invisible the ways in which one's proprioception is always already socially mediated. We gain a sense of the relative position of our body parts and the effort required for movement through resisting and complying with the built world (e.g., uncomfortable classroom chairs) and learning social and cultural techniques for controlling our bodily orientation to that environment (e.g., sitting still because we are told to do so by teachers).

Inclusive sensory ethnographies of technology provide a more complete account of the senses and variations in their experienced intensity, understanding such differences not as outside theory building and inquiry but as a starting point. Though sensory ethnography emphasizes the fluid, multi-sensory nature of human experience, few scholars have employed it to study the media and technology experiences of disabled individuals whose sensory systems and sensory ways of knowing are largely marginalized in society (e.g., Hammer, 2013).

## Sensory and Social Dimensions of Autism and Technology

Disability is central to the broader sensory, social, and political potentialities of media and technology. This is reflected in the burgeoning intellectual communities around disability media studies and the senses (Goggin, 2017) and the cultural politics of sensory impairment in feminist science and technology studies (Mills, 2011). Such work reveals, for instance, how midtwentieth century cognitive researchers drew on computing metaphors (e.g., processing, input, feedback) to position their field as a science. Cyberneticists, engineers, and psychologists designed experiments testing how haptics and tactility might simulate or replace "lost" senses (i.e., blindness, deafness) (Jain, 1999). While haptic media studies scholars have critiqued such universalizing visions of sensory substitution (Paterson, 2017), there has been less focus in media studies/STS on vestibular and proprioceptive sensory processing in mediated spaces. In media and communication studies, autism has historically served more as a powerful rhetorical trope than empirically researched (Pinchevski & Peters, 2016). It is frequently invoked as a metaphor for social isolation, loneliness, and anti-sociality in the digital age (e.g., Balsamo, 1996; critique by Pasek, 2015). Autistic individuals are stereotyped as robotic, machine-like, and having a natural affinity for computers (Danforth & Naraian, 2007), in part reflecting a troubled legacy of gender, race, and class biases towards middle-upper class white males in autism diagnoses (Silberman, 2015). The theory of "autistic sociality" (Ochs & Solomon, 2010) challenges the biological essentialism of such metaphors though. Individual and sociocultural dynamics shape a range of possibilities for social coordination, with autistic sociality as one set of possibilities. Autistic individuals may prefer forms of social communication that do not necessitate eye contact (Grinker, 2010). As a result, there is growing recognition that autistic youth and adults have rich social experiences with media and technology (Gillespie-Lynch et al., 2014; Ringland et al., 2016).

Media play a role in autistic children's sensory seeking behaviors at home, the integrated ways in which they experience pleasurable stimuli, and how they learn to interpret their own sensoria. This includes "trampoline jumping while listening to music on headphones and watching television, [and] bringing [their] face close to [the] video screen and tensing [their] whole body" (Kirby et al., 2017, p. 148). Autistic children also report using media to adapt an unpleasant sensory experience (Kirby, Dickie, & Baranek, 2015), such as building a virtual display of fireworks within the video game Minecraft in place of the physical world version (Ringland et al., 2017).

Inclusive sensory ethnography contributes to understandings of the relationship between the sensory and the sociotechnical, specifically the role of media and technology in how autistic individuals manage sensory processing challenges, as well as the sensory dimensions of media use among people on the spectrum. This article addresses a need to understand sensory processing differences beyond a medical model of disability, the lack of a neurodiverse approach to the senses in sensory ethnography, and the detachment of the lived social experiences of autistic individuals from the sensuous study of digital media.

## **Practicing Inclusive Sensory Ethnography**

My conceptualization of inclusive sensory ethnography is grounded in empirical research, specifically on-going qualitative fieldwork on media and technology use among children ages 3-13 with developmental disabilities. I began this work in Southern California in 2012-2014 and it continues in the New England region of the US (2016-). Initially focused exclusively on non-speaking and minimally-speaking children (most of whom are autistic) (Alper, 2017), the work has shifted towards those on the spectrum, both with and without significant speech impairments. For this article, I draw from my research with 29 autistic children ages 3-8 (upon initial encounter) and their families across both phases of the work. Parents reported the professional autism diagnosis of their child, which prior research has validated as an accurate measure (Daniels et al., 2012). Thirteen children from that sample are discussed here (Table 1). The Institutional Review Boards at the University of Southern California and Northeastern University approved the studies.

Methods have included a combination of interviewing parents (solo and in pairs) at home, conducting joint interviews with parents and children, and participant observation by visiting homes and observing a media or technology activity that the child enjoys "doing with" another family member. The notion of "doing with" was left purposefully open for families participating in the research to define emically (Becker, 1986), spanning limited interaction between the child and family member while co-present in the same room, to four co-present family members jointly playing Minecraft. In the interview setting, parents often scaffolded my conversation and helped me gain an understanding of their child's "sociocommunicative lifeworld" (Sirota, 2010, p. 94),<sup>3</sup> while participant observations allowed for naturalistically studying the daily activities of autistic children, particularly those who did not consistently use spoken language (Spitzer, 2003). The degree of my own participation ranged from active participation to quiet observing. All encounters were audio recorded and most documented with photographs.

The development of an inclusive sensory ethnographic approach was iterative-inductive (O'Reilly, 2012); only by observing autistic children's actual digital practices during the first phase of research and by interviewing their parents about family rituals and regular activities did the role of the senses draw my attention. For example, when I observed 6-year-old Talen at home turning the volume way up on his iPad and holding it up to his ear, I asked his mom Kameelah why she thought he liked to do that. She posited that it was because of "a sensory something" (Alper, 2017). Over the course of research in 2013-2014, parents also increasingly mentioned "sensory-friendly" films in local movie theaters (generally, showings in which the sound is lower and the lights are less dim) as recent additions to their family's media routines.

I incorporated this emergent theme of the sensory into field notes during observations and questions for parents in the second phase of research two years later. I avoided framing such questions in medical or pathological terms, instead choosing to ask if their child had any "sensory stuff." After entering all memos and transcripts into MAXQDA, I employed a purposeful and compatible combination of coding methods (Saldaña, 2013). Holistic coding of "sensory stuff" laid the groundwork for more detailed provisional coding of different sensory

<sup>&</sup>lt;sup>3</sup> For instance, when Olivia mentioned eating dinner as an activity she likes to do with her family, her mom, Bailey, turned the conversation towards cooking, encouraging Olivia to talk about her love of the TV show *Cake Wars*.

systems (e.g. proprioception, tactile) and descriptive coding of sensory-related objects (e.g. trampolines) allowed for connections between these materials and their uses across participants (Dey, 1993).

Though I worked mainly as a sole ethnographer, I used several strategies for checking the progress of my analysis while in the field and afterwards (Ezzy, 2002). This included conversations with autistic and non-autistic parents and caregivers about emergent themes; debriefs with research assistants following joint fieldwork visits and discussion of their analytic memos; an initial round of coding as I corrected transcribed interview transcripts; maintaining a reflective journal on emergent themes during fieldwork; writing analytic memos for each observation and interview; and jotting down insights that occurred between field visits. Autistic and non-autistic academic experts in media and human development also provided feedback based both on scholarship and their lived experiences.

## Making Sense of New Media through Inclusive Sensory Ethnography

Below, I detail how the proprioceptive and vestibular senses shape domestic spaces, intimate relationships, and family practices during media use, as well how those senses shape and are shaped by other sensory ways of knowing.

## **Proprioceptive**

Shared media experiences while sitting on the sofa provided various opportunities for close physical intimacy and proprioceptive input for several children. Molly's mom, Abbey, said that while watching TV with Abbey's dad, "they'll cuddle and he'll squeeze her and she loves that." Besides an immobile television set, mobile devices also enable sitting side-by-side on the couch over the shared small screen. Molly noted that Abbey will "need to be thigh-to-thigh with me…She'll definitely be on the phone and sit right next to me." I observed Abbey engaging in

this behavior, sitting down right next to Molly, who rubbed Abbey's leg, arm, and back. "She likes to be rubbed or squeezed," said Molly, "Otherwise, she has to be right touching me." Chike also preferred this sensation. His mom, Esosa, explained, "If everybody is down here [watching television] (points towards living room), [Chike] will come and squeeze himself between people." The couch is a site of media and proprioceptive sensory ritual, for pleasurable pressure on muscles and joints.

Children employed verbal and non-verbal communication to solicit proprioceptive input directly from their caregivers. Noticing that Olivia was having difficulty paying attention to an episode of *Kids Baking Championship* and staying in the living room, her mom, Bailey, asked her to sit down and watch the rest of the episode together. Olivia acquiesced, but conditionally, as she asked, "Will you pat my back [while we watch]? This time you got to pat fast!" Olivia lay across the lap of Bailey, who made a hand chopping motion across Olivia's back. As Jessie and Patrick watched *Despicable Me 2* together, she gave him, she said, "deep pressure, lots of deep pressure." With her arms and legs wrapped around him in her lap, Patrick took Jessie's hands and clapped them gently in front of his face. "Where do you want me to put the hand? You want me to rub behind your ears?" Jessie asked. As she rubbed, Patrick vocalized an "ahhhhhh!" of pleasure. "Oh, that's so good," she replied. When I remarked that Patrick didn't seem to mind commercial interruptions to the movie in the version they had recorded off cable TV, Jessie explained that "[Patrick] just figures I'll give the [sensory] input while he's waiting."

Besides stimuli from other people, children also used furniture, mattresses, and mattresslike objects to generate proprioceptive input during at-home media use. Saaida's bed consisted of a mattress on the floor in the living room of her family's one-bedroom apartment. Her father, Hamza, reported that she preferred to watch videos on his tablet in "some gap between the bed and [the wall]... She tried to fit there in a very tiny space." For families with additional economic resources, a crash pad (a large air- and foam-filled mat with a nylon cover designed for people with dysfunctions in sensory processing integration) might provide therapeutic proprioceptive input. Noah encouraged his mom, Amanda, to chase him onto the blue crash pad in their living room while music from the "Toddler Tunes" Music Choice cable channel played on the TV. This was after he rebuffed her encouragement to jump on a small trampoline set up in front of their television set. "Oh, you want to crash on the crash pad, instead?" asked Amanda. "Crash," Noah replied, as he set off running across the room onto the pad.

Eli used the couch as a kind of crash pad while watching *Sesame Street*, his favorite TV show, with his mom, Julie, on Amazon Prime. While she sat on the couch, Eli climbed behind her and perched himself atop her shoulders. Julie then stood straight up, lifting Eli into the air at eye level with the flat screen TV mounted to the wall. After pacing a bit, she dumped him onto the couch and he laughed with delight. During their family's movie night, Julie said that Eli wasn't "super interested" in the films, but enjoyed "doing flips onto" their Yogibo, a bean bag-like chair often used for sensory therapy (n.d.). Sometimes materials are specially designed to provide proprioceptive sensory input (e.g., Yogibo, crash pad), and other times children make use of furniture and objects in their living spaces (e.g., mattress, sofa).

Children's unmet needs for proprioceptive input could also lead to behaviors that resulted in bodily discomfort for themselves or others. Anthony's near constant physical activity while he lay on or near his mom, Danae, while they watched Disney Junior appeared to pain and maybe annoy her: "He was trying to scratch me earlier. He was like digging his nails...He always want me to put my arm over his face. I'm like, 'Boy...'" Some parents more at ease with their children's behaviors used materials to redirect these actions and incorporated such objects into the home environment. As Patrick sat in Jessie's lap in front of the TV, he dug his fingernails hard into her hands and his thighs. In response, Jessie pulled out a squishy purple ball partly filled with sand from her side of the couch. "It's an Everlast one," she explained, "If he's trying to dig himself, we give him this." With a gentle firmness, she placed the ball in Patrick's hands and said, "You get my hands, you get the ball. You know the drill." Patrick dug in, literally, making happy vocal grunts as he squeezed. Objects that relieved proprioceptive needs could prevent a parent-child media ritual from physically paining either person.

## Vestibular

Some children sought intense vestibular input during media use, including jumping, swinging, and spinning. Skyler, for example, enjoyed *Just Dance* for the Nintendo Wii gaming system, but rather than playing the game, sought vestibular input while listening to the songs with the help of his mom, Naomi. She explained, "He just runs in circles or jumps and does headstands because he's a big sensory seeker, and I play the music." While watching TV, children primarily used bouncy surfaces like small trampolines or sofas to generate vestibular input. Amanda noted that "even when the TV's on, [Noah] won't just sit and watch a show usually. He's jumping up and down on the trampoline while he's playing." Jessie usually kept a trampoline for Patrick "in front of the TV and he'll jump on it," though it was temporarily put away when I visited due to Patrick being in a full-leg cast, the result of a recent corrective surgery.

Objects like trampolines and sofas must also be understood in relation to the space they take up, and the square footage of homes within which children roam. The small trampoline was a permanent fixture in Eli's large TV room, situated within the spacious ground floor of his suburban house. "He kind of goes in a loop sometimes," Julie noted, as Eli leaped across the love

seat, sofa, and trampoline, frequently departing and reentering the room. "We have a whole obstacle course going now," she remarked. I counted Eli doing ten such loops over the course of an hour. Anthony also made use of his couches for jumping, but within a room about a fourth the size of Eli's. His exuberance watching television, as well as the limited floor space, was marked on the wall in the form of a hole kicked through the plaster, now covered up with masking tape. Less socio-economically privileged families must work harder to support their child's sensory self-regulation in smaller living areas with closer proximity to neighbors.

Audiovisual media content depicting energetic movement also influenced the behaviors children emulated and the kinds of vestibular input they sought. While watching an episode of *American Ninja Warrior* with Kerry, his mom, Joey jumped off the couch and waved socks on his hands while the participants on-screen swung from obstacle to obstacle (Kerry: *You're going to enact your Ninja Warrior-ness. You keep on, what?* Joey: *Keep on falling.* Kerry: *You're falling?* Joey: *I was trying to fall.*) Eli's mom, Julie, suspected that the media content he liked best was also related to depictions of characters receiving vestibular input: "I do think it's the sensory. It's the episodes where characters are bouncing... There's another episode that has a pogo stick in it. He likes to jump and I think he likes these episodes about the pogo sticks." Media consumption not only concerns one's own bodily experience of consumption, but potentially also representations of experience and empathetic identification.

Ritualistic vestibular movement can itself be interpreted as expressing one's pleasure or displeasure with media content. This is true for nearly everyone (i.e., clapping after a staged performance), but especially among non-speaking and minimally-speaking children. As Eli jumped on his trampoline, Julie pointed out, "And this is classic trampoline." Eli began to jump even more enthusiastically, to which Julie responded, "Whoa, this is a good Abby! [*Sesame* 

*Street* segment of *Abby's Flying Fairy School*.]" Similarly, "when [Patrick] really likes a scene, he'll go on the floor and he'll do his dance thing," Jessie said. At one point, Patrick got up to dance along with *Despicable Me 2*, despite his full-leg cast. "He's able to get through even with the cast on. He's figured out how to get his sensory needs met even without [his trampoline]," she remarked as Patrick grooved and made pleasurable groaning sounds.

Children's body movements are also shaped by a communication technology's mobility or immobility, and the extent to which media can be enjoyed hands-free or sitting still. Ryan, for instance, used Google Chromecast to project the YouTube Kids app on his brother's old iPod to the large flatscreen smart TV in the living room. The app algorithmically automated the playlist of Ryan's favorite videos while he moved about, jumping on the sofa and running back and forth between the living room and the kitchen. Julie remarked that "one of Eli's biggest challenges is he will not sit still—actually unless he is watching television… And I should even clarify that. It's really only if he has an iPad because even when he's watching television, he is jumping." Books did not hold staying power either. Julie remarked, "As he started to move more, and it seemed his body really needed that [sensory] input, I feel like it's been much more difficult and he is no longer interested in reading books with us." Media preferences and attention levels were tied to children's vestibular sensory needs.

#### **Interconnected Internal and External Senses**

The vestibular and proprioceptive sensory experiences described above already allude to interplay with various external senses. At times, the multi-sensory nature of these media rituals was particularly pronounced. Vestibular movement, for example, could be related to a child's preferred viewing position for audio-visual media. At ten different occasions while watching *Sesame Street*, Eli exited the TV room and reentered from the adjoining dining room. Julie

hypothesized that this was not only related to his vestibular needs, but visual as well, remarking "He often circles [the dining room table], which you can still see the TV from... He likes the peripheral. He just paces."

Skyler also took pleasure from the combination of body movement and peripheral vision during viewing. An indoor home gym product called the "Gorilla Gym"—a sort of deluxe pullup bar with a swing and trapeze—was mounted to the top of the door frame intersecting Skyler's kitchen, dining room, and hallway. While sitting facing the kitchen, Skyler could see the dining room on his left side. The family used the room less for dining and more for computing, for on the dining room table stood a large iMac computer surrounded by stacks of DVDs in and out of their cases. The iMac was pivoted not only towards a seat at the table, but Skyler's kitchen-facing swinging position, from which he could peer sideways at the screen. While singing along to a kids' music DVD, Skyler swung to and fro on the thick ropes.

Other times, a child's desire for vestibular input was tied more to audio than audio-visual media. As the song "The Strawberry Shake" from the cartoon *Strawberry Shortcake* played on Toddler Tunes, Noah playfully commanded Amanda to scoop him up in her arms and spin him around in clockwise and counter-clockwise circles. "Let's do it again! Let's do it again!" Noah announced. "We're gonna go see what kind of music is coming on, it might not be spinning music," Amanda replied, catching her breath, to which Noah furthered, "I want spinning. Spinning again, mama. Spinning again." At one point, Noah flopped dizzily to the ground, but almost immediately asked Amanda to "do it again."

Zahra also derived great pleasure from continuous spinning while listening to music. As her mom, Raina, and her mom's girlfriend, Becky (who also identifies as autistic), played the song "Cheap Thrills" by Sia on Raina's phone, Zahra skipped quickly in an oval path around the living room. Raina compared Zahra's ability to seemingly spin endlessly without getting dizzy to the Whirling Dervishes of the Mevlevi sect in her former home of Turkey. "In Turkish culture, they have these people who just go around and around," explained Raina, "They find balance and spiritual something. [Zahra] can do that for hours." "More Sia!" Zahra demanded in an authoritative 4-year-old manner. "She loves that feeling," Raina responded, to which Becky agreed, "She's one of those people." Cultural traditions shaped how autistic individuals and their family members understood interlinkages of the social, the sensory, and the sociotechnical.

#### Implications of Inclusive Sensory Ethnography for Media and Communication Research

This empirical exploration of autistic children and their families has various theoretical and methodological implications for the overall sensory study of digital media in everyday life, discussed below along social, cultural, and ethical dimensions.

## **Embodiment and Socially Mediated Sensory Experiences**

Inclusive sensory ethnography expands the study of how possibilities for social coordination are enacted around and through embodied sensory rituals within mediated spaces. Embodiment is intercorporeal, according to French philosopher Merleau-Ponty (1962), in that surrounding bodies co-configure sensations, as do materials and spaces. Such objects also have affordances and constraints, concepts introduced by Gibson (1977) and Norman (1999) that have come to encompass not only the design features of artifacts, but how people get a feel for a given technology and perceive its potential uses (Nagy & Neff, 2015). Though neither Merleau-Ponty nor Gibson directly addressed disability in their work, their emphasis on contingency lends itself to imagining affordances as relative to diverse forms of embodiment (Davis & Boellstorff, 2016).

Feminist scholar Rosemarie Garland-Thomson (2011) provides further insight into how bodies of all kinds interact with environments through the critical concept of the "misfit." Fitting and misfitting reflect congruent and incongruent relationships, such as placing a square peg in either a square hole or a round one, as the metaphor goes. Garland-Thomson's misfit is useful for conceptualizing inclusive sensory ethnography because it locates conformity not in the peg or the hole, or in the sensing person and the sensory environment, but in their co-constitution, as evidenced by the conflict between Danae and Anthony while they watched Disney Junior. Each body will experience sensory misfitting, but some bodies are more likely than others to consistently misfit and face negative consequences for such misfitting in public and private spaces (as when an autistic person experiences an involuntary sensory meltdown).

Notions of the misfit and misfitting are also useful for understanding the extent to which one's surroundings accommodate variations in the human sensory experience. The children and families with whom I spent time developed active strategies for sensory fitting at home. Skyler swung from the Gorilla Gym swing to watch a DVD from the corner of his eye, Eli peripherally viewed the TV from the dining room while he continuously paced, and Patrick and Jessie used the Everlast ball for proprioceptive input on the couch. These processes were akin to what Hart (2014, p. 288) refers to as "joint embodiment," or "an improvised social choreography whereby parents and child prompt each another verbally, gesturally and physically as they together move through the social world."

In this way, inclusive sensory ethnography departs from the agenda of haptic media studies (Parisi & Archer, 2017), a recent intervention in sensory approaches to media research, as it is less focused on creating the sensory category it wishes to explore through media, and more so on employing grounded theory to let such categories emerge from the ethnographic context. Attending to how new media objects stimulate the proprioceptive and vestibular senses (such as with virtual reality systems and wearable technologies) may obscure how people *make* ordinary print, screen, and interactive media tools proprioceptive and vestibular through rituals and routines. Inclusive sensory ethnography enables documentation of how material changes might be made in the sensory environment, relative to a normative culture that makes bodies conform to sensory spaces.

## **Sensory Culture and Digital Anxieties**

Inclusive sensory ethnography can also illuminate normative assumptions about the body that underlie cultural tensions regarding the negative effects of media and technology on attention, hyperactivity, and sensory regulation, particularly among children (Newman, 2010). Adult sensibilities often characterize children's media culture as an assault on the senses. Sensory studies scholar Waskul, for instance, frames his broader discussion of media, consumer, and material culture by expressing his annoyance at how his "sociological sensibilities are severely aggravated" each time his children watch the preschool series *Dora the Explorer*. He writes that "Dora is hard of hearing; she constantly asks her viewers to 'say it louder!" (Vannini, Waskul, & Gottschalk, 2012, p. 148)—so much so that Waskul finds he must leave the room when his children fervently follow Dora's commands.

Most of the children with whom I spent time derived great pleasure from aspects of sensuous media culture that provoke adult concerns about addiction and distraction. Sensory objects and toys for proprioceptive input regulation such as gyroscopes, Therapuddy, and weighted blankets are now repackaged respectively as fidget spinners, slime, and gravity blankets (Martin, 2017). YouTube videos, Pinterest pages, and Etsy stores contribute to the popular mainstreaming and profitability of these products. On the one hand, there is greater

awareness of sensory differences and easier distribution of information on how to obtain or make sensory toys. Amanda and Jessie, for instance, learned of crash pads and sensory balls from Facebook groups for parents of children with disabilities. Yet these fads do not automatically translate into greater disability acceptance. Stigma has long been associated with technologies considered "assistive" when used by people with disabilities but merely "helpful" for a general population (Alper, 2017; Moser, 2006). The boundaries maintained between materials designated "for sensory needs" and "for play" are inherently political because acceptable use is contingent on compulsory able-bodiedness (McRuer, 2006) and cheap mass production (Bailin, 2017).

#### **Researcher Reflexivity and the Ethics of Sensory Privilege**

Pink (2015b) calls on sensory ethnographers to reflect on their own participation and privileges in sensory cultures. As someone versed in intersectionality, I knew I could walk into strangers' homes more easily as a young upper-middle class white woman, especially considering the predominant racial, gender, and socioeconomic backgrounds of in-home speech, behavioral, physical, and occupational therapy providers.<sup>4</sup> Similarly, I became aware that I could walk into houses with barking dogs and fluorescent lights because I processed sensory input in a manner that "fit" with these stimuli. Numerous times when I opened the car door of my rented Zipcar or entered a Lyft to travel to participants' homes, I was hit with the aggressive waft of car deodorizer or a driver's heavy cologne. If I had chemical sensitivities to these scents, this would constitute more than a mere annoyance; it could have prevented me from using these cost-effective means of transportation altogether.

Inclusive sensory ethnography requires reflection on the part of neurotypical researchers such as myself with respect to the entwinement of social, cultural, and economic privileges they

<sup>&</sup>lt;sup>4</sup> For instance, upon entering Emma's home, her brother Mikey asked, "Are you here to teach Emma how to talk?" mistaking me for a speech-language pathologist.

may benefit from over the course of fieldwork due to their own abilities to process sensory information, as well as their own relationship to the privileges that research participants do or do not similarly experience. I recall, for example, feeling slightly nauseous watching Ryan's favorite YouTube Kids videos with him on the large flat screen TV. Such videos take hacks of the video game *Grand Theft Auto* and combine them with animated graphics from Disney's *Cars* franchise and dancing DC and Marvel superheroes, all set to children's nursery rhymes (e.g., CARS 4 KIDS, 2017). I found these videos jarring to watch, yet they provided Ryan with great delight. He curated an optimal sensory environment using media, allowing his "challenges" to become less of an obstacle, whereas I needed to adapt if I was to observe him.

Being a neurodivergent researcher can also serve as an advantage in this space, as one might understand more about which behaviors are being enacted by participants to fulfill proprioceptive and vestibular needs. Several autistic scholars and self-advocates contend that autism is itself a uniquely sensory language that cannot be comprehended by non-autistics (e.g. Baggs, 2007; Yergeau, 2017). Yet, neurodivergent people are neurodivergent in different ways, such as being hypo- or hypersensitive to the input that certain media or media environments provide. Neurodivergent researchers can make important contributions to inclusive sensory ethnography, as can researchers who accept the very different ways in which others diverge.

#### Conclusion

In proposing inclusive sensory ethnography, this article draws attention to where social and technical possibilities converge and diverge around the senses at the overlooked intersection of media studies, critical disability studies, and sensory studies. Inclusive sensory ethnography intervenes in the ethnographic study of everyday technology use by attending to users at the sensory margins of a largely neurotypical world. Such ethnographic work demands that researchers ethically consider how they approach sensory aspects of the environment during fieldwork and how this differs from participants' individual needs.

Inclusive sensory ethnography prompts an array of initial questions for both qualitative and quantitative researchers as they approach the study of media, technology, and social life:

- How might sensory language already underpin common theories and concepts in communication, technology, and society? In what ways does this language privilege a normative conception of sensory processing?
- Have studies of "haptic" technologies fully explored aspects of their use that are proprioceptive and vestibular in nature? To what extent has haptic media studies accounted for sensory dysregulation among media users?
- How would one's own ethnographic practice adapt if a research assistant, graduate student, or collaborator with sensory processing differences came on board?
- Relatedly, as ethnographic practice requires researchers to be transparent about their cultural biases and experiences related to their particular community of scholarly interest, how do we protect neurodivergent ethnographers who self-identify as such from stigmatization and marginalization?
- What is the relationship between sensory regulation during media use and one's ability to process messages in those media? How might sensory regulation behaviors serve learning and other cognitive processes through media use?

As this incomplete list demonstrates, inclusive sensory ethnography generates new possibilities for understanding the role of the proprioceptive and vestibular sensory systems, their interconnection with the external senses, and their regulation and dysregulation. For sensory ethnography of media and communication technology to present a more complete view of human sensory systems, greater attention needs to be paid to the role of the proprioceptive and vestibular senses, and their relationships to the other senses in how media is experienced. This approach has the potential to orient media and technology studies towards a more critical awareness of conventional assumptions regarding sensory processing and perception in ethnographic research as broadly construed.

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# Appendix

Name	Age	Gender	Race/Ethnicity	Diagnosis	AAC User*	Yearly Household Income
Abbey	4	Girl	White	ASD (Autism	Ν	\$25,000-\$50,000
				spectrum disorder)		
Anthony	5	Boy	Black	ASD	Ν	Less than \$25,000
Chike	7	Boy	Black/Kenyan	Autism	Y	\$100,000 or more
Eli	4	Boy	White	ASD	Y	\$100,000 or more
Emma	3	Girl	White	ASD	Ν	\$100,000 or more
Joey	6	Boy	White	Autism, PDD-NOS (pervasive developmental disorder, not otherwise	N	\$100,000 or more
Noah	3	Boy	White	specified)	N	\$25,000,\$50,000
Olivia	6	Girl	White	ASD	N	\$100,000 or more
Patrick	4	Bov	White	Autism	Y	\$50.000-\$100.000
Ryan	3	Boy	White	Autism, ASD, mixed receptive- expressive language disorder	Y	\$50,000-\$100,000
Saaida	8	Girl	Asian/Bengali	ASD	Y	Less than \$25,000
Skyler	6	Boy	White	Autism, ADHD	Ν	\$100,000 or more
Zahra	4	Girl	White/Azerbaijani	ASD	Ν	Less than \$25,000

Table 1. Descriptive data of selected child participants

\*Non-speaking or minimally speaking child who uses augmentative and/or alternative communication methods, tools, and/or strategies (e.g., a speech-generating device).

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