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Kids Across the Spectrums

Growing Up Autistic in the Digital Age

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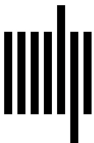
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6 SENSES

Patrick and his mom, Jessie, sat on the living room couch, engaged in their near-daily viewing of the animated film *Despicable Me 2*. Jessie is a single parent by choice, having conceived Patrick, a 4-year-old minimally speaking White autistic boy, through donor sperm and in vitro fertilization. Her deep love and singular dedication to him was evident in her attentiveness to his sensory sensitivities. Patrick giggled gleefully as Jessie ran her fingers along the soles of his feet. “He loves being tickled,” she said, loudly kissing him behind the ears. “I could eat you! I could eat you!” she exclaimed, to which Patrick responded with bursts of laughter. Jessie was not only the parent of a disabled child, but a special education preschool teacher as well. Owing to this, she employed language reflecting someone who knew quite a bit about autistic children and their unique responses to sensory stimuli. 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.

For those less familiar with terminology like “sensory needs,” while growing up you may have learned that there are five senses: visual (sight), auditory (sound), tactility (touch), olfactory (smell), and gustatory (taste). We can think of these traditional five senses as external, meaning they have to do with stimuli that come from outside of the body. However, insights from the clinical and scientific fields of occupational therapy, educational psychology, and neurobiology suggest that sensory processing also includes at least two internal senses that tell us where the body is in space.¹ These senses—vestibular and proprioceptive—have to do with body movement

and body awareness. Imagine the vestibular sense as knowing when a car speeds up or slows down, and proprioception as feeling the weight of yourself in the seat and your feet on the floor.

Humans vary in their ability to process sensory stimuli, manage its intensity, and organize bodily sensations. Sensory experiences can be not only unpleasant for some, but overwhelming and distressing enough to trigger “meltdowns” (i.e., a temporary loss of behavioral control) and “shutdowns” (i.e., a temporary retreat).² Not everyone with difficulty responding to and receiving sensory information is autistic, but sensory processing challenges are a common feature of autism. Ninety to 95 percent of school-age autistic children reportedly have some sensory issues.³ Overreactivity or underreactivity to sensory input and “unusual interest in sensory aspects of the environment” are diagnostic criteria for autism in the fifth edition of the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders*.⁴ Autistic individuals report processing sensory input in ways that can significantly diverge from those of the nonautistic population.⁵ This includes being extremely bothered by clothing tags, possessing a low or high pain threshold, and having difficulty measuring spatial proximity.⁶ Their sensory experiences can also be intensely pleasurable. For example, Ido Kedar notes in his memoir *Ido in Autismland* that blinking lights or the sun’s glare on the water are “visually harmonious sights” to him. “I see woven patterns of shapes and colors. No one who sees this isn’t amazed at the lovely details of the lights,” writes Kedar.⁷

As with the rest of the population, autistic individuals are also users of information and communication technologies. The senses play a complex role in how all of us perceive media content and interact physically with technology.⁸ However, the ways that autistic people process sensory information and how they use media and technology to create more pleasurable and less painful sensory environments tend to be understood as pathological in nature.⁹ For example, some parents and behavioral therapists consider a child’s repeated viewing and rewinding of selected parts of an animated film to be a problematic fixation in need of correction instead of a self-soothing stimulatory practice (or “stim”) that creates a pleasurable visual and/or auditory sensation.¹⁰ Some children on the spectrum reportedly have strong visual-spatial abilities and prefer processing information in a visual rather than a written form, which may heighten the appeal and ease of using screen and digital media.¹¹ At the same time, the intense sensory stimulation of interactive media might

be challenging for autistic children to filter out, particularly if that content is violent and highly arousing, and impede their ability to engage in meaningful learning or attend to others in their social environment.¹²

In this chapter, I explore how children on the spectrum like Patrick process sensory information through their media use, and, in doing so, ground the sociotechnical shaping of sociality in the sensuous study of media.¹³ The internal and external human sensory systems are interrelated in complex ways, and this sensemaking influences the design and arrangement of autistic children's domestic spaces, intimate relationships with family members, and media use when it is solitary, proximal (i.e., with others nearby), and joint (i.e., with social partners).

THEORIES OF MEDIA, AUTISM, AND THE SENSES

I start here by providing a brief background on the intersection of technology, society, and sensory differences. This includes understanding sensory processing from a neurodiversity perspective, how normative approaches to the senses are embedded in the study of media technologies, and theoretical explanations for how people regulate their senses through media.

NEURODIVERSE APPROACHES TO SENSORY PROCESSING

Sensation affects human development, functioning, and behavior across the lifespan in complex ways. Sensory integration theory explains how 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.¹⁴ Based on these thresholds and responses, there are four types of sensory processing challenges that a person could have: (1) a high threshold and passive response (i.e., low sensory registration), (2) a high threshold and active response (i.e., being sensory seeking), (3) a low threshold and passive response (i.e., being sensory sensitive), and (4) a low threshold and active response (i.e., being sensory avoiding). Even between two autistic kids in the same family, sensory thresholds and responses can look very different. One mom, Karrie, noted that her 9-year-old son Conor (White, boy) "is very hyposensory, so he's really sensory seeking. He likes a lot of physical touch and physical input. He sometimes gets overwhelmed with loud noises," while 10-year-old Ronan (White, boy) "doesn't really have any sensory issues."

All senses are implicated in sensory regulation, but the proprioceptive and vestibular senses are lesser known.¹⁵ 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 hugged tightly. 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, 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 but are culturally and socially situated as well.¹⁶ Language reflects and generates distinctions between marked and unmarked categories, with one example being the difference between having sensory "needs" and sensory "preferences." Within the US cultural context, the prioritization of values such as independence and self-reliance effectively turns having needs and needing others into a weakness (i.e., neediness, dependency).¹⁷ This is particularly true if the needs in question are those of people with disabilities.¹⁸ With respect to autism, the mannerisms that many autistic individuals develop in order to cope with environmental sensory overload—such as hand flapping and avoiding eye contact—are often socially stigmatized.¹⁹ Autistic children may be actively discouraged or punished for exhibiting these self-soothing behaviors.²⁰ 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 increasingly pervasive.

SENSORY NORMS IN DIGITAL MEDIA

Without directly considering the lived experiences of autistic and neurodivergent people with significant sensory processing challenges, researchers have long attended to the phenomenological, social, and cultural construction of sensation. Those in the social sciences and humanities have broadened ways of thinking about the senses beyond the medical fields of physiology and neurology.²¹ Psychologists, designers, and historians

have illustrated how cultural norms, social roles, and aesthetic preferences around the senses form a basis for human interaction and differentiation.²² The anthropological and sociological study of the senses has interrogated how people have used sensory knowledge to structure culture and society²³ and how we live in and move through the world is shaped by our perception and embodiment.²⁴

In media and communication studies, the senses have provoked ongoing scholarly conversation about acuity and the body in relation to technology.²⁵ Digital and nondigital media objects have “affordances” and “constraints,” concepts that have come to encompass not only the possibilities and limitations of design features,²⁶ but how people get a feel for a given technology and perceive its potential uses.²⁷ The individual senses that media use recruit may less likely be singular modes of bodily perception and more like sensory “ensembles” of different affective, kinesthetic, and somatic ways of knowing.²⁸ Others have theorized that the sensing of media is synesthetic in nature (as in, processing information from several senses at once); for example, communication theorist Marshall McLuhan described televisual images as “tactile promptings.”²⁹ Symbolic representations of the senses have also shaped understandings of the cognitive affordances of media technologies and content. McLuhan proposed, for instance, that specific media have standardized effects on the senses (i.e., “sensory ratios”).³⁰

Disability disrupts such universalizing claims to sensory experiences and expands the broader social and political potentialities of media and technology.³¹ Normative bodies are popularly understood as ideal media users,³² or what media studies scholar Elizabeth Ellcessor terms the “preferred user position.”³³ Technological affordances are relative to diverse forms of sensory embodiment.³⁴ Research in feminist science and technology studies explores the cultural politics of sensory impairment.³⁵ Such work reveals, for example, how cognition researchers in the mid-twentieth century drew on computing metaphors like “processing,” “input,” and “feedback”—language now used to describe the senses—to position their field as more science than art (i.e., cognitive science). Cyberneticists, engineers, and psychologists at the time also designed experiments testing how tactility (i.e., touch) and haptics (i.e., force and touch) might simulate or replace the “lost” senses of sight (blindness) and sound (deafness).³⁶ These deficit-oriented sensory norms are incorporated into today’s technological developments and shape participation in and exclusion from everyday media

use,³⁷ such as the uneven quality and availability of closed (i.e., can turn off) and open (cannot turn off) captioning in user-generated online video.³⁸

MEDIA SENSORY CURATION THEORY

The various channels through which media transmits sensations—sight, sound, touch, movement, and activity—influences a user’s overall sensory experience. In the academic subfield of media psychology, media sensory curation theory proposes that media devices are tools that people purposefully use to regulate their sensory systems by amplifying input (i.e., sensory capturing) and limiting input (i.e., sensory curbing) from their surrounding environments.³⁹ Media psychologist Kristen Harrison (who is autistic) and colleagues identify three sensory environments nested within each other that people regularly manage—the natural environment (e.g., sunlight), the built environment (e.g., indoor lighting), and the media environment (e.g., the brightness of an iPad’s screen). In another example, through what media studies scholar Mack Hagood calls “sonic self-control,” a person can use headphones to increase auditory input in an environment that they find too quiet to concentrate in or, alternatively, cancel out noise in a space that is too loud.⁴⁰ In fact, Apple announced in 2021 that it would be adding a background noise reduction option for its phones and headphones explicitly “in support of neurodiversity.”⁴¹

Media sensory curation is reportedly higher among children with disabilities that may cause sensory dysregulation (e.g., autism, ADHD) than those without.⁴² Within a household, different thresholds and regulatory responses to media sensory stimuli can generate conflict between family members (i.e., turning the volume up too high), particularly between neurotypical parents and neurodivergent children.⁴³ Conflict may be preemptively avoided through physical, social, and symbolic modifications that autistic children and their caregivers make to the home environment that can reduce sensory challenges and contribute to well-being.⁴⁴ Cathleen, for example, placed media in the same category as objects she had purchased for 6-year-old Sebastian (Latino and White, boy) that were designed for sensory regulation purposes. “I think [media is] a tool that we use just like we use a swing or a rocking chair or a body sock,” she said. “[It’s a] way for him to decompress and reorganize himself.”

Home environments and their sensory features can look very different among autistic children. Few parents have the social, cultural, or economic

means to install sound insulation for reducing noise if their autistic child screams or pounds on the floor during high-stress times.⁴⁵ Families who live in neighborhoods with spaced apart homes are privileged in this respect. For instance, Hamza, father of 8-year-old nonspeaking Saaida (Asian/Bengali, girl), was worried about what would happen over Saaida's winter break from school when it was too cold to take her outside to play. The lack of vestibular input would likely lead to her having a meltdown inside their apartment. "In snow time, when school close," Hamza said, "sometimes this situation will make us so much trouble to control her. The other people in this building . . . I know if police come . . . somebody told me they'd call police." This fear of law enforcement being summoned was compounded by Hamza's status as a Bangladeshi citizen living in the United States with his family on a temporary visa. Saaida and her parents were not only managing the natural, built, and media sensory environments within their home, but also an ableist, racist, and xenophobic world outside it.

SENSING SOCIALITY AND MEDIA

Media plays some role in autistic children's sensory seeking and avoiding at home and their encounters with pleasurable and painful sensory stimuli. But what does this look like up close? I found that the external senses (auditory, tactility, visual, and gustatory),⁴⁶ the internal senses (proprioceptive and vestibular), and their complex interrelation are central to autistic children's media and technology activities. These mediated behaviors are integrated into how they interpret their physical environment, the people around them, and their own sensoria.

AUDITORY

Autistic children can have challenges with auditory processing in at least two ways that shape their media use: sound volume and types of sounds. With respect to volume, loud media causes extreme discomfort for some. Nelson, father of 10-year-old Stephanie (Latina, girl), said that she would accidentally "put the volume all the way up to a hundred" using the TV remote, "and she would be freaking out because she was trying to adjust herself." Because Stephanie also did not have an effective way to communicate, this sudden auditory overload caused her increased stress. A number of children, though, preferred the volume to be very loud, which could be a source of minor or

major conflict between the child and their family members. During my interview with Kerry in the family's living room, her 6-year-old son Joey (White, boy) sat down on the sofa and turned on the television set. The TV show began to play very loudly, to which Kerry remarked, "Where are the remote controls? Here they are. Let's turn them down, let's turn this down a little bit, okay?" She explained that Joey's grandmother, who babysat him and his brother afterschool, "lets them put it on like, 40, and I keep it on 12."

While Joey was not visibly bothered by Kerry lowering the volume, 4-year-old Bennett (White, boy) was resistant to a similar intervention from his mom, Shelby. Bennett (who is autistic) and his twin brother, Kyle (who has a sensory processing disorder) were playing games on their tablets in the living room. When Bennett turned the volume up on his device, Kyle left for the adjacent sunroom on the first floor of the house. Shelby walked over to Kyle to ask if he had left "because Bennett's [tablet] is loud?" to which Kyle replied, "Yeah." A few minutes later, Bennett went to join his brother but with his tablet still set at the higher volume. Kyle protested Bennett's intrusion, causing Shelby to intervene. "Bennett," she asked, "can I turn you guys down just a little bit?" "No," said Bennett, his voice slightly rising in anger and his body tensing. Kyle, sensing conflict, moved further away from his brother toward the other end of the sofa. "[Bennett] likes everything loud," Shelby shrugged, the tension defused, "Last night, he turned the TV up to 90. I'm like, 'Really?'"

Mobile technologies with simple volume controls allowed kids like Bennett to put auditory pleasure into their own hands, both for better and for worse. While I interviewed Stephanie's parents on a weeknight, she held the speaker of the iPad close to her ears as she sat nearby bouncing on an exercise ball, creating a sensory experience more to her liking than the incident with the TV remote. Nina said that her son Raul (Latino), who was 11 years old at the time of our second interview, liked to "keep the volume on low, but he will press the phone or the iPod against his ear during certain parts. . . . No visual, just listening." April, mom of 5-year-old Sofia (Latina, girl) put tape over the speaker of her daughter's iPad to muffle the sound because Sofia preferred it loud but also refused to wear headphones.

Other children had no issue using headphones with mobile devices, which enabled them and other family members to each maintain their preferred sound levels while remaining in the same room or enclosed space. "When we are all together and it's getting too loud," said Esosa of her 7-year-old

son Chike's (Black, boy) preference for loud music on his iPod, "we are like, 'Here. Put this on.'" Kameelah mentioned that she and her husband had purposefully turned the volume setting on 6-year-old Talen's (Black, Latino, and White; boy) headphones down low so that he could raise the volume on his iPad as high as he wanted. "He ideally likes both loud," said Kameelah. Limiting the headphone's audio output bounded Talen's volume control to just one device.

Headphones were also actively chosen by children, sometimes in tandem with other objects, to curate a more comforting auditory environment. Six-year-old Olivia (White, girl) hung out on the couch while I jointly interviewed her and her mom, Bailey. Olivia had turned the volume up high on the Spotify app on Bailey's phone, and since the music was interfering slightly with our conversation, Bailey initiated a negotiation process with Olivia. She offered Olivia the option of taking a break in her bedroom upstairs, to which Olivia responded, "I think I'm going to stay here and put the blanket on me." As that did not address the issue of volume, Bailey replied, "If you want, you can go up and get headphones and put them into the phone and you can listen to it that way, okay?" Olivia agreed and the interview kept going, with the blanket and headphones allowing Olivia to meet both her social and sensory needs.

In addition to volume, certain sound qualities could also set off meltdowns. Three-year-old Aaliyah (Black, girl) was unable to bear one particular video in a series of short, educational videos about careers that aired between TV shows on PBS KIDS. Her mom, Crystal, explained, "There's a pilot, there's a scientist, and there's a teacher. But the teacher [video] bothers her." Crystal did not know what about the male teacher's voice disturbed Aaliyah, but she knew how to identify warning signs. "[Aaliyah will] get a sense when it's coming on," said Crystal, "Like the show will end and she'll think it's coming. She'll block her ears or curl her body into [her] mind." Those behaviors alerted Crystal to immediately change the channel or mute the TV in response to what Crystal described as Aaliyah's physically painful response to the auditory stimuli. "It's like a fear in her eyes," Crystal said, "when that commercial comes on. It's like, ugh. I want to save you from that pain."

TACTILITY

Autistic children incorporated tactile feedback into their media routines in a number of respects, including by playing with "fidget toys" during television viewing, using game controllers to keep their fingers busy, and

watching YouTube videos of other people's hands manipulating objects. One pervasive fidget object in children's homes were "mermaid pillows," named for sequins affixed to pillows that shimmer like scales on the mythical creature's tail. The sequins are sewn as to be flipped in two directions, with each side of the sequin reflecting a contrasting color. With the sequins, one can write messages, play with the reflecting colors, or enjoy the smooth feeling. While the low-cost trend is enjoyed by both disabled and nondisabled children,⁴⁷ the pleasure of a mermaid pillow might be felt more intensely or differently by those on the autism spectrum. In fact, on craft websites like Etsy, they are often listed for sale as a "sensory fidget."⁴⁸

Amanda worked part-time at a home decor store where she came across the mermaid pillow and purchased it because she thought her son 3-year-old son Noah (White, boy) might enjoy the feel. "He has a lot of textural aversions," she said, "so this is just kind of like a funky texture for him to play with." The mermaid pillow stayed in the living room, but instead of being placed on the couch, it was kept atop a small table in front of the large flatscreen television. Amanda said, "He's usually not sitting. He doesn't sit very often. He's usually standing over here going—" at which point she rubbed her fingers along the sequins. Jessie had also purchased an inexpensive mermaid pillow on Amazon for Patrick to play with "when he needs to fidget" while sitting in front of the TV. She had learned about the pillowcase on a sensory processing disorder Facebook group. "It's like a disco ball," said Jessie, "That's like a sensory thing that he'll use while he is watching things."

Not all moms, though, spend significant time on Facebook groups, make Amazon purchases, or even have internet, like Danae, mother of 5-year-old Anthony (Black, boy). As an episode of the animated Disney Junior show *Doc McStuffins* played on the TV, Anthony and one of my research assistants sat next to each other on a small sofa. When Anthony began to play with her coat, Danae reprimanded him, saying, "Anthony, leave her buttons alone." Danae explained of her son's behavior, "He like the feeling. You know, if I have a shirt on and it have the thing, he be like scratching it." A few minutes later, Anthony affectionately sat in Danae's lap facing the TV set, his arm laid behind his head and his fingers lingering on the raised printed design on her T-shirt.

For some children, their media viewing habits involved seeking or avoiding certain textures. As 4-year-old Eli (White, boy) watched *Sesame Street*, he rubbed his hands over the green bristles of a toy wooden broom and

pressed his palm into the cold prickliness of a pin screen, a toy in which hundreds of flat metal pins are arranged to create a three-dimensional relief when an object is pressed against the pins. Eli also placed the pin screen on his head and under his T-shirt while he watched. Sometimes the physical texture of technologies themselves shaped children's sensory experiences. When I commented on the fact that Patrick's tablet did not have a case on it, considering the high cost of the device and good chance of it breaking in a child's hands,⁴⁹ Jessie explained that the tablet was caseless because Patrick "does not like the feeling. He has wrecked tons of them. The ones that have more of the rubber feel, he has bit off."

Computer and console video gaming offered added tactility for autistic children. During my interview with then-12-year-old Saylor (White, girl), she was constantly doing something with her hands, be it rolling a tube of lip gloss around or fiddling with a Band-Aid on her toe. Saylor explicitly identified haptic feedback as part of what made gaming pleasurable to her. Besides the fun of building and playing with friends, Saylor said that she liked Minecraft and Roblox because "it was just a good way to get your hands working." In fact, the minute after she put down the Xbox controller after showing me the video game *Fortnite*, she picked up her iPhone—adorned with a *Fortnite*-branded PopSocket grip accessory—without looking at the screen and held it in her lap. These behaviors and reflections from Saylor suggested that her need to hold the phone was partly about the materiality of the object and not just the media content or social connection it provided.

Children's fascination with YouTube videos of hands manipulating objects was also an extension of their cravings for tactility. It is well documented that children and adults alike are fascinated by product unboxing videos and Kinder Surprise Egg toy videos that show close-up shots of hands twisting and turning pieces. Media studies scholar Sharif Mowlabocus writes that "the hands . . . offer a sense of vicarious touch."⁵⁰ For children who process sensory stimuli differently, these videos are appealing not just for their commercial or noncommercial content, but also for their tactile simulation and stimulation. Three-year-old Oscar (White, boy) watched hours of videos on repeat of hands making letters out of Play-Doh. Rosie pulled out her phone to show me a photo of 4-year-old Spencer (Black, boy) "making the time with Play-Doh" as he watched YouTube videos of timers counting down. "This is an example of sensory," she said, explicitly referencing the visual and tactile stimulation that the activity produced.

VISUAL

Irrespective of content or messaging, the formal features of visual media can provide sensory stimulation favored by some autistic children. This includes adjusting proximity to the screen, amplifying color contrast, and shifting visual perspectives. Various parents reported that their children preferred to keep screens very close to their faces as they watched. Nina said that Raul will “press his face up to a specific spot in the TV screen” and the screen will fill his entire field of vision. Molly reported that 4-year-old Abbey (White, girl) “has to get so close to the TV. I’m like, ‘Back up,’ but she gets so excited that she gets way too close to it . . . especially when they sing.” With a smaller screen, I watched Abbey hover over her mom’s iPhone, her face two inches from the device. Nikki, mom of 3-year-old Emma (White, girl), noted how unlike Emma’s neurotypical siblings’ tablet use, “Everything is close. Her eyes are fine. They were tested. But I know that there’s a word for it, and I can’t think of it right now, where she tends to put a lot of things up close.”

A few children were visually drawn to digital media content that had been altered through device settings or effects to amplify the contrast between colors. During my interview with Esosa at her dining room table, Chike walked over to us with her iPhone. He had switched the Accessibility setting on iOS in order to play the mobile gaming app *Temple Run* in an inverted color mode. “He likes to put it in negative mode,” said Esosa, “He likes the visual.” Among the array of YouTube videos that I observed Abbey watching on her mom’s iPhone, three of them consisted of screen recordings of apps and animated shows (e.g., *Talking Tom Cat*, *Pocoyo*), arranged in a grid on screen of anywhere from three to ten small video screenshots, with a different color filter added to each video so that the recordings moved identically but in assorted colors.

Mobile devices also afforded children easy manual control over the visual pace of video platforms and playback modes, including pausing, rewinding, and fast-forwarding video clips in a repetitive manner. Eight-year-old Amaya (Black, Latina, and White; girl) enjoyed the blurred visuals of scrolling up and down through YouTube’s list of recommended videos on her iPad without necessarily clicking on one to watch. While watching *Sesame Street* on Jessie’s iPhone, Patrick would repeatedly flip the phone 180 degrees back and forth in his right hand while viewing, a one-handed move that would have been hard to pull off with a tablet. When he turned it around, the picture on the phone shifted between vertical portrait mode and horizontal landscape

mode. There were many levels of sensory pleasure for Patrick: the moving of his hands, the jostling of the screen, and the activity taking place within the *Sesame Street* content itself. Some parents, though, actively worked to limit their child stimming with mobile video. Stephanie's dad, Nelson, reported that "we started working with this new therapy where [Stephanie is] not repeating the video over and over again. She can see the whole video, but she needs to start getting out of that, going over and over it."

GUSTATORY

The gustatory system, associated with eating and taste, can also be a part of children's sensorial media experiences. For example, 13-year-old Pargev (Armenian, boy) routinely liked watching *High School Musical* on Netflix while moving potato chips back and forth between four blue plastic bowls as he ate. Media could also distract autistic children from aversions they had to particular foods.⁵¹ Rosie recalled that Spencer will "multitask no matter what he's doing . . . [so] one of the strategies to actually get him to eat when he was younger was to put something on, because he had so many sensory things." Norah said that she will sometimes put her son Max (Asian/Vietnamese and White, age 5) "in front of the TV to get him to eat something healthy" because he will "just blindly eat whatever is in front of him," whereas he will not eat vegetables at the dinner table. "One way I rationalize this is like, 'Well he's going to eat carrots, so it's okay for him to watch *Curious George* again,'" said Norah.

When placed into one's mouth, media objects themselves could become a problematic gustatory stim. Like Saaida in chapter 1, Patrick had an issue with trying to consume paper, leading Jessie to avoid buying print books or borrowing them from the library. "Sometimes if you're not looking, or you turn your back for a second, . . . he'll eat paper. We've had some paper issues with books," said Jessie. April mentioned that Sofia "loves puzzles, but she's been eating them lately so we've kind of put them away for now until this phase is over." They also had difficulty locating a tablet case that Sofia would not chew on. "It's kind of hard to find a case that's not edible," said April, "because anything soft is edible for her. But if we kind of just go, 'No you can't eat that, you can't eat that,' eventually she'll stop because she's like, 'They're just going to keep getting on my nerves.'"

Children found other ways to have their gustatory needs met while (metaphorically) consuming media. I found it ironic that one of the books

that Sebastian repeatedly wanted renewed from the library was *The Magic School Bus Explores the Senses*, considering his own sensory issues. His mom, Cathleen, noted that he will wear a sweatband on his wrist at all times, including while watching TV, because he will otherwise chew on himself. For Patrick, the mermaid pillow provided a solution to some of his self-harm behaviors by redirecting his need for gustatory sensory stimulation. He “will bite his hand,” Jessie said, “It’s not anxiety related. It’s just sensory seeking and behavioral. . . . [The mermaid pillow is] great because when he’s watching or playing, he’ll have one hand here [instead].”

PROPRIOCEPTIVE

Media additionally provided opportunities for proprioceptive input and close physical intimacy for autistic children at home. The sofa was one site of sensory ritual and pleasurable pressure on muscles and joints. Molly 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 enabled sitting side-by-side 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, curling up next to Molly, who rubbed Abbey’s leg, arm, and back. Chike also preferred this sensation, as Esosa explained, “If everybody is down here [watching television],” pointing to the living room, “[Chike] will come and squeeze himself between people.”

Children employed verbal and nonverbal communication to directly solicit proprioceptive input from their caregivers. Noticing that Olivia was having difficulty paying attention to an episode of *Kids Baking Championship* and staying in the living room during my observation, 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, 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 in response to Patrick’s gestures. As she rubbed, Patrick vocalized an “ahhhhh!” of pleasure. “Oh, that’s so good,” she replied.

Besides stimuli from other people, children also used furniture, mattresses, and mattress-like objects to generate proprioceptive input during media use.

Saaida's bed consisted of a mattress on the floor in the living room of her family's one-bedroom apartment. 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 room and resources, a crash pad—a large air- and foam-filled mat—provided proprioceptive input. Noah encouraged his mom, Amanda, to chase him onto the blue crash pad set up in their living room while music played on the TV. "Oh, you want to crash on the crash pad?" 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* with Julie. As she sat on the couch, he climbed behind her and perched himself atop her shoulders. Julie then stood straight up in a pretty remarkable feat of strength and balance, lifting Eli into the air at eye level with the flatscreen TV. After pacing a bit, she dumped him onto the couch, and he laughed with delight.

As with gustatory sensations, 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 Danae while they watched TV appeared to pain and maybe annoy her. "He was trying to scratch me earlier. He was like digging his nails," said Danae, "He always want me to put my arm over his face. I'm like, 'Boy . . .'" Parents who were more permissive of their children's sensory seeking 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 [fitness brand] one," she explained, "If he's trying to dig . . . , 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.

VESTIBULAR

Some children sought intense vestibular input during media use, including jumping, swinging, and spinning. Six-year-old Skyler (White, boy), for example, enjoyed *Just Dance* for the Nintendo Wii gaming system, but rather than playing the game using the controller, he moved along 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



FIGURE 6.1

Small trampoline set up in front of the television set in Noah's living room. *Source:* Meryl Alper.

I play the music." While watching TV, children 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" (figure 6.1). 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 because Patrick was in a full leg cast as the result of a recent corrective surgery.

Similar to proprioception, vestibular input must also be understood in relation to the room that sensory objects take up and the square footage of homes within which children roam. Conor and Ronan had a dedicated playroom in their large suburban home. Karrie noted how "when watching TV or playing video games, [Conor is] very mobile. . . . He climbs up onto the arm of the couch and then jumps off and runs around." 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. Anthony also made use of his couches for jumping, but within a small apartment in one of Boston’s poorest neighborhoods. His exuberance while watching television in the limited floor space was marked on the wall by a hole kicked through the plaster, now covered with masking tape.

And as with YouTube videos of hands manipulating objects and simulating tactile pleasure, audiovisual media content depicting energetic movement also influenced the behaviors that children emulated and the kinds of sensory input they sought. Crystal said that if “someone is upside down in a video, [Aaliyah] wants to be upside down. Running, bumping into things intentionally because of something that she watched.” While viewing an episode of the TV show *American Ninja Warrior* with Kerry, Joey jumped off the couch and waved socks on his hands while the participants on-screen swung from obstacle to obstacle. Said Kerry, “You’re going to enact your Ninja Warrior-ness. You keep on, what?” “Keep on falling,” responded Joey, “I was trying to fall.” Julie suspected that the media content Eli 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,” she said, “There’s another [*Sesame Street*] episode that has a pogo stick in it. He likes to jump, and I think he likes these episodes about the pogo sticks.”

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 nonspeaking and minimally speaking autistic children. As Eli jumped on his trampoline, Julie pointed out, “And this is classic trampoline.” Eli began to jump even more enthusiastically while watching a *Sesame Street* segment of *Abby’s Flying Fairy School*, to which Julie responded, “Whoa, this is a good Abby!” 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 said.

Children’s body movements are additionally shaped by the mobile affordances of communication technology and the extent to which media can be enjoyed hands-free or sitting still.⁵² Three-year-old Ryan (White, boy),

for instance, used Google Chromecast to project the YouTube Kids app onto the large flatscreen TV in the living room. The app algorithmically automated a playlist of 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.”

INTERCONNECTED INTERNAL AND EXTERNAL SENSES

The internal and external sensory experiences that I have described allude to the interplay between various senses. At times, the multisensory nature of these media rituals was particularly pronounced and manifested in complex cultural, spatial, and social relations within a given child’s environment. With respect to culture, 4-year-old Zahra (Azerbaijani, girl) derived great pleasure from continuous spinning while listening to music in a manner that conveyed cultural meaning for her mom, Raina. As Raina and her girlfriend Becky (who also identifies as autistic) played the song “Cheap Thrills” by musical artist Sia on Raina’s phone, Zahra skipped quickly in an oval path around the living room. Raina compared Zahra’s ability to seemingly turn around 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 manner befitting a preschooler. “She loves that feeling,” Raina responded, to which Becky agreed, “She’s one of those people.”

Spatially, vestibular movement could be entwined with a child’s preferred viewing position for audiovisual media. On 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 pull-up 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 toward 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.

REFLECTIONS ON THE SENSES

Autistic children’s engagement with new media, at home and among family members, reveal normative assumptions about the senses and sensory processing that underpin prevailing ideas about media, sociality, and neat distinctions between minds and bodies.⁵³ Their solitary and shared rituals and routines demonstrate how the external and internal sensory systems are connected to one another as well as complexly entwined with ordinary media use. Their stories also illustrate how intimate associations with others are co-configured not only by joint technology use, but also by the senses. Two concepts from the field of critical disability studies—“misfitting” and “access intimacy”—further highlight the centrality of sensation in the socio-technical shaping of sociality.

According to philosopher Maurice Merleau-Ponty,⁵⁴ embodiment is intercorporeal, which means that surrounding bodies shape our sensations and that we shape the sensory experiences of other people. Feminist disability scholar Rosemarie Garland-Thomson extends this social view of embodiment to nonnormative bodies through the critical concept of the “misfit.”⁵⁵ The term misfit usually has a pejorative connotation, meaning a person who is set apart from others and is not accepted based on their behavior or attitude (e.g., “social misfit”). Garland-Thomson reframes the word as neither inherently negative nor based on individual deficiency. Fitting and misfitting, Garland-Thomson explains, reflect congruent and incongruent relationships, similar to placing a square peg in either a square hole or a round one, as the metaphor goes.

Garland-Thomson’s idea of the misfit locates conformity not in the peg or the hole, or in the sensing person and the sensory environment, but in their

co-constitution. The concepts of misfit and misfitting are useful for understanding the extent to which one's immediate surroundings accommodate variations in the human senses. Autistic children and their families developed active strategies and designed accommodations for countering sensory misfitting at home, what some have called "therapeutic landscapes"⁵⁶ or "prosthetic environments."⁵⁷ Some of these materials, like crash pads, were specially designed to provide sensory input; in other cases, children made use of preexisting furniture and objects such as mattresses in their living spaces. Children and parents developed creative ways to work with sensoria that "misfit" their environments and enabled the child to interact with media and with their family members in a more comfortable manner.

Beyond children's immediate environments, these alterations are also relative to the wider sensory culture.⁵⁸ Some of the very therapeutic objects and toys used by autistic children—such as gyroscopes, Therapuddy, and weighted blankets—are increasingly repackaged for a mass audience as fidget spinners, slime, and gravity blankets.⁵⁹ Autonomous sensory meridian response (ASMR) videos on YouTube, which generate a pleasurable tingling sensation for some through recorded sound and movement, have gone from fringe internet content to a profitable global phenomenon.⁶⁰ There are obvious benefits for neurodivergent people to these tools becoming cheaper, more widely available, and less socially stigmatizing, especially for those without official diagnoses. 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 the general population.⁶¹ The boundaries maintained between materials designated "for sensory needs" and "for play" are inherently political because acceptable use is contingent on compulsory able-bodiedness and the idealization of nondisabled bodies.⁶²

Sensory cultures also exist within wider social structures. Though each body will experience some sensory misfitting, certain bodies are more likely than others to consistently misfit and face significant consequences for doing so in public and private spaces. Less socioeconomically privileged families like Saaida's must work harder to support their child's sensory self-regulation in smaller living areas with closer proximity to neighbors. Autistic people of color may be at a higher risk of physical victimization and deadly encounters with law enforcement if their behaviors, stims, or sensory meltdowns are interpreted as threatening, which may explain Danae's

urge to discipline an energetic Anthony.⁶³ Rosie, who is White, expressed grave concern for her son Spencer, who is Black. “What if he has a meltdown in society?” she wondered aloud, “This society is very frightening right now with a Black son. It is. He has a meltdown and ends up in jail and they don’t know that he has autism.” The potential for autistic children to self-regulate their senses through media is relative to other degrees of freedom, autonomy, and mobility within and outside their homes.

In addition to misfitting, the concept of “access intimacy,” developed by disability justice activist Mia Mingus,⁶⁴ also helps to understand the political and social dimensions of sensory engagement with media and technology. Access intimacy is “produced when interdependence informs the making of access.”⁶⁵ In other words, access depends not only on accessible infrastructures and built environments, but on disabled people who are cared for and who care for others.⁶⁶ People with disabilities have long developed practices of mutual aid within systems that actively work to isolate them from one another and deny them care.⁶⁷ In addition to technologies, people become affordances for each other when there are no readily available tools, devices, systems, architecture, or infrastructure to address their needs.⁶⁸

Autistic children and their families illustrate how media and technology are in many ways central to access intimacy in the context of sensory sensitivities. They use media content, devices, and settings as “care structures” to actively cope with a world that is often sensorially chaotic and painful.⁶⁹ Mediated relationships, practices, and intimacies are forged around and through family members with different sensory processing capacities.⁷⁰ These processes are akin to what clinician and social anthropologist Brendan Hart refers to as “joint embodiment,” or “an improvised social choreography whereby parents and child prompt each other verbally, gesturally, and physically as they together move through the social world,”⁷¹ epitomized by Patrick and Jessie at the start of this chapter.

Caregivers balance the competing sensory needs of different family members, though not without conflict. Tension emerges when there is a mismatch between individuals inhabiting the same mediated space. One person’s sensory comfort may cause discomfort to someone else. The unique adaptive functions that children develop through media sensory curation may not be fully understood by parents and caregivers.⁷² Disabled people are intimately aware that access needs can conflict and need to undergo a

negotiation process to reach a resolution, which is not always possible.⁷³ Sensory needs can be temporarily met through media and technology, but maintaining a sense of comfort also means regular negotiation and trade-offs. Media may be an effective method for reducing sensory overload, but it can also become problematic if it becomes a primary coping strategy.⁷⁴

In closing, media does not just inform, entertain, and connect us to others; it also soothes and comforts sensorially. All of us have preferences for media content, settings, devices, accessories, and spaces that allow us to adjust sensory input and maintain a sense of physical and emotional well-being. By observing autistic children and their caregivers at home, as well as by talking to them about their favorite media routines and layered stimulating practices, I found that responses to sensory stimuli are shaped not only by immediate social partners (e.g., parents, siblings) and social environments (e.g., living rooms, bedrooms), but also by broader social structures (e.g., immigration, housing, policing). Richer consideration of the senses allows for deeper, more critical understandings of the social norms at play and power dynamics around everyday media and technology use. Next, I conclude with this book's final body chapter, connecting autistic children's sensory experiences to their embodied emotions and how they use media to navigate complex feelings.

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