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Kids Across the Spectrums

Growing Up Autistic in the Digital Age

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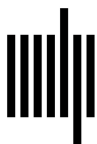
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4 FAMILY

In the winter of 2015, Boston set a record for its snowiest season ever. A January blizzard and an endless series of February snowstorms led to a massive accumulation of just over 110 inches (280 cm). Despite the funny memes shared online about the “Snowpocalypse,” that winter was an isolating time for many Bostonians. Three-year-old Alessandra (Latina, girl) was almost 2 then, and her mom, Camilla, said she “was really concerned about her social life at that moment.” Alessandra, an only child, was not attending daycare and primarily stayed at home with Camilla, an immigrant from Spain who had only been in the United States for two years and did not yet have a large network of local friends. The media that Camilla most attributed to Alessandra’s social development that lonely winter, and in subsequent years, was video chat, specifically with her and her husband’s Spanish relatives. “We are the typical family that we are using a lot the technology to communicate with family abroad,” Camilla explained.¹ Thanks to mobile apps and smartphones, they could fit video chat in around Alessandra’s intense therapy schedule. “It’s really difficult to find an open spot for [her],” said Camilla, “Sometimes instead of a Skype [on the computer], we are doing FaceTime [on the phone] in the playground.”

Video chatting with Alessandra was a learning process for everyone involved. Her relatives in Spain had to figure out how best to communicate with her. Alessandra—who was minimally speaking and had difficulties with expressive and receptive language—needed help with modeling their greetings and picking up on their conversational cues. At first, Alessandra’s relatives spoke too quickly and multitasked while they talked to her, which

overwhelmed her sensorially and disoriented her cognitively. With Camilla and her husband's help, their relatives could eventually hold Alessandra's attention for five to ten minutes. "We told them that they have to pace the interaction and . . . ask her questions that she can understand" about simple topics like letters and shapes, Camilla said. They also needed to avoid having "too much noise [in the background and] try to give her time enough to respond," she explained.

I observed Alessandra on such a Skype call at home on the computer with her *tata* (aunt), with whom she sang a Spanish children's rhyming song. In addition to the social benefits, Camilla thought that regular chats in Spanish would be helpful for Alessandra in case the family ended up moving back to Spain. The loose social norms of video chat meant that Alessandra did not have to hold eye contact if she found it uncomfortable. She could move around the living room while the camera was positioned from a distance for her aunt to observe and comment upon her play. Camilla additionally made in-person adjustments to make the chat work, like having Alessandra press the Skype call button to actively engage her in the activity from the start. For Camilla, a strong indication of social growth resulting from the regular calls was that Alessandra had begun requesting to Skype with her extended family members. The format (virtual conferencing), the content (simple conversations), and the context (talking with a familiar loved one) all supported Alessandra's social learning with technology.

This chapter focuses on the role that media and technology play in autistic children's relationships with their family members and in the daily functioning and pace of family life. In some ways, the dynamics of Alessandra's video chats were much like those of any young child or one with relatives abroad. Many little kids have difficulty sitting still and focusing on interacting with the screen on a FaceTime call. Immigrant parents urge their children to stay connected to their culture of origin, with media as one such link. Camilla is also not the only parent to worry about their child's social isolation or to attempt to use media to simulate sociality for them. Parents showed similar concerns and responses during the early months of the COVID-19 pandemic, when families were stuck at home for prolonged periods of time. There were unique considerations for Alessandra and Camilla's experiences in other respects, though. Virtual communication with an autistic child requires certain nuances, such as avoiding sensory overwhelm and scheduling video calls around therapy.

Parents and siblings are young autistic children's most frequent companions for media use. As such, they play an important role in how kids on the spectrum are socialized around and through technology, as well as what it means for them to be "social."² On the flip side, autistic children and adolescents also directly and indirectly influence their parents' media management philosophies and their siblings' media use habits. Through my fieldwork, I identified several factors shaping the family context of autistic children's technology use. Parental media management is fluid and shifts in response to changes in their autistic child's preferences and behaviors, which may be significantly more variable than those of a neurotypical child.³ Household instability caused by issues such as poverty and divorce also impact the overall trajectories of autistic children's care, including their media use.⁴ These considerations challenge the utility of broad, overly generalized "screen time" advice that caregivers, including those of children on the spectrum, regularly encounter.

MEDIA, AUTISM, AND FAMILY LIFE

I begin by reviewing current theories of autism and family well-being, what is known about media management strategies implemented by caregivers of autistic children, and how media shapes interpersonal dynamics between kids on the spectrum and their siblings.

THEORETICAL APPROACHES

Understandings of technology, autism, and family life at present are heavily influenced by historical narratives, and often in negative ways. The "refrigerator mother" theory, popularized by psychiatrist Leo Kanner and psychologist Bruno Bettelheim in the mid-twentieth century, falsely claimed that "frigid" unloving mothers caused their child's autism, and promoted the idea that an autistic child was an undesired one.⁵ For these same women, their domestic expectations were being reshaped in the postwar era by an influx of electronics and modern appliances (like home refrigerators), in addition to economic, geographic, and social shifts reconfiguring gender politics and the culture of caregiving.⁶ Starting in the 1960s, human development researchers began to empirically challenge Bettelheim's psychoanalytic theories about the origins of childhood disability.⁷ Many of these studies still presumed that disabled children were a burden to both

society and their households, and the research was explicitly motivated by “science as well as sympathy.”⁸

Contemporary research on households with children on the spectrum has tended to focus more on individual elements of the family rather than its overall functioning.⁹ This has included studies of how having an autistic child impacts dyadic relationships (e.g., marital, parent–child, child–sibling), and affects a family’s physical, emotional, social, and financial outcomes.¹⁰ Family system theory argues, though, that the sum of these relationships and outcomes does not equal the whole, and, furthermore, that the family must be understood as its own complex unit of analysis with values, beliefs, and norms.¹¹ Through a systems approach, family processes shape the developmental trajectory of the autistic child, and, in turn, the child on the spectrum impacts the broader family system.¹²

Proposals for using a family systems approach have similarly been made for the study of media and families. Children and media scholar Amy Jordan suggests that young people’s media use reflects and also shapes a family’s structural dimensions (like its organization of space in the home and time spent during the day) as well as its social aspects (such as family members’ sense of identity).¹³ Most research on families, media, and technology has centered on parent–child interactions and relationships, and less so on how siblings factor into a child’s media use, broader measures of family well-being (e.g., resilience, quality of life), and changes in familial roles and boundaries.¹⁴ Children and technology use is also a highly gendered issue; on top of other household labor, women in industrialized nations are largely tasked with being the primary managers of their child’s media activities as a form of “intensive mothering.”¹⁵

PARENTAL MEDIATION AND AUTISTIC CHILDREN

One helpful concept for understanding how technology fits into family life is “parental mediation,” which refers to the formal and informal strategies that caregivers use to oversee, guide, control, and share in their child’s use of media.¹⁶ There are four main types of parental mediation: restrictive, social, active, and supervisory.¹⁷ In restrictive mediation, parents establish rules and enforce boundaries like time limits and website restrictions. Social mediation involves family members co-viewing or co-using media for the primary purposes of rapport building and enjoyment. Active mediation has to do

with parents' instructive inquiry and critical discussion about media content and functions with their children. Lastly, supervision includes caregivers' attempts to remain in the child's proximity and keep tabs on what they are hearing, seeing, and/or doing with media.¹⁸ Interactive media (e.g., video games) and noninteractive media (e.g., TV) may elicit different mediation forms.¹⁹ Restrictive and active parental mediation reportedly peak around age 8 and decline throughout middle childhood.²⁰

Few studies have directly examined how parents influence autistic kids' media and technology use or how kids on the spectrum shape parenting strategies around media. Caregivers of children with emotional struggles and higher levels of hyperactivity are more likely to engage in restrictive mediation.²¹ Kuo and colleagues found that parents of adolescents on the spectrum (ages 12–19) most frequently mediate their autistic child's television use with social co-viewing and mediate their videogaming with restrictive strategies.²² Engelhardt and Mazurek report that 87 percent of parents of autistic boys aged 9 to 19 have rules about video games, including restrictions on mature game content and duration of game play time.²³ In another study by Kuo and colleagues, autistic adolescents who regularly watched television with their parents reported having better relationships with them than those whose parents did not co-view with them.²⁴ Nally and coauthors additionally found that parents who ceded control of the household's media routines and rituals to their autistic child did so in order to maintain familial balance and harmony.²⁵

Since this work was conducted in the 2000s and early 2010s, though, much has changed in the way of technology and society. Over the past decade, young people's engagement with video games has extended far beyond gaming consoles to streaming websites like Twitch and videos of game play uploaded to YouTube by professional and amateur players, as well as youth themselves.²⁶ Some earlier parental concerns, such as worries about an autistic child preventing other family members' use of the shared television,²⁷ have lessened over the years with the growing ubiquity of personal mobile devices,²⁸ while the easy connectivity of these tools has also introduced new parenting challenges.²⁹ Media management can cause stress among parents of autistic kids, and their strategies may reflect worries about problematic and risky media use.³⁰ At the same time, media may offer a moment of calm and peace to stressed caregivers, a pleasurable experience to overworked children, and an opportunity for family togetherness amid busy schedules.

AUTISM, MEDIA, AND SIBLING DYNAMICS

Siblings generally spend more time together than with their parents,³¹ and their media habits reflect this copresence in several ways. They influence one another's development over their lifespans as well as the care that their caregivers provide to them and their siblings.³² Parents of multiple children may consciously or unconsciously notice differences in how media affects one of their children and adjust overall media rules and routines as a result.³³ Older siblings can be a positive force by guiding their younger siblings' media use in instructive ways, like helping them type queries into Google Search, while also influencing them negatively by prematurely introducing them to media content intended for an older audience.³⁴ The effects of media can also differ with media type, genre, and sibling gender; for instance, video games may be associated with both sibling conflict and affection, especially for brothers who play together.³⁵

There is more limited research on how siblings shape autistic children's media and technology use. One reason for this may be the higher likelihood that kids on the spectrum do not have a sibling. Retrospective studies of health records indicate that families whose first child was autistic were one-third less likely to have a second child than other families, and families with a later-born child on the spectrum were equally less likely to have more children.³⁶ The explanation for this difference is not clear; parents may be concerned about the probability of raising another autistic child or lack the support and resources to do so. Among families with an autistic child and later-born children, nearly 19 percent are estimated to have at least one other child who is also on the spectrum, though their children's conditions may be very different.³⁷

Most work on autism, siblings, and media use has been comparative studies within families of autistic children and their typically developing siblings (e.g., parent surveys comparing both children's time spent on various kinds of media).³⁸ Kuo and colleagues, for example, found that parents used similar mediation strategies for their autistic adolescent and their adolescent's nonautistic sibling(s), but more frequently applied restrictive and active strategies for videogaming with kids on the spectrum. Interaction effects were not examined, however, and the authors suggested that managing an autistic child's media use might shape parental management of their sibling's use too. No work has looked closely at families with other autistic and/or disabled children besides the focal child on the spectrum.

AUTISM AND MEDIA IN THE FAMILY SYSTEM

Parents and kids have struggles and positive experiences with digital media and communication technology—individually, interpersonally, and collectively as a family. The discussion that follows focuses on how autistic children’s everyday media use impacts and is impacted by parent–child and sibling relationships. Also discussed is the range of individual and contextual factors influencing those dynamics that affect the entire family unit.

PARENT–CHILD RELATIONSHIPS

I found that caregivers of autistic children and early adolescents engage in all four forms of parental mediation (restrictive, social, active, and supervisory) across multiple types of media. Interestingly, many of these parents also incorporate therapeutic and behavioral discourses into their discussions of media use at home. Behavior management is pervasive across childhood (e.g., “No TV until you finish your homework”), but the stakes are higher for autistic children. Rewards and punishments are often viewed as the only means of managing their behavior, while reasoning and negotiation are more prevalent with nonautistic children. Medicalized language is prominent in the parenting of neurodivergent kids and oversight of their media use, shaped in part by their child’s development, but also by interactions with clinical providers and related resources.

RESTRICTIVE MEDIATION Parents of children on the spectrum employed several restrictive mediation strategies to both promote positive outcomes and mitigate risks for their child. Strategies changed over the course of early and middle childhood alongside the move from elementary to junior high school. Restrictions included deleting or blocking access to particular apps and websites, imposing time limits or limits during certain times of the day, and monitoring mature or violent content. For some families, restriction was woven into the very social infrastructure of their home. Other parents hesitated to institute restrictions that were too rigid. Autistic children themselves sometimes expressed resistance to these rules, though several thought that it was good to have boundaries.

Parents frequently talked about the need to place hard limits on their autistic child’s media use to prevent sensory overload and overstimulation. Julie, for example, used the Guided Access feature on the iPad to lock 4-year-old

Eli (White, boy) into one app at a time because he would otherwise open and close apps every thirty seconds. “If he’s doing that for an hour, it’s like his brain is fried and the whole rest of the day, he’s grumpy and the attention span is shorter,” she said. Cathleen, mom of 6-year-old Sebastian (Latino and White, boy), turned off the autoplay feature on Netflix so that it would not advance to another episode right away. Parents also tried to limit media use to certain windows of time or with a curfew. Sara, mom of 8-year-old Isaac (White, boy), recalled that until she and her husband put an 8:30 p.m. limit on Isaac’s iPad use: “We would hear it until midnight, 1:00 in the morning because he went so far past that point of tired, he couldn’t turn his brain off.” Heavy media use outside the home also influenced media rules at home. “My sons Kahlil (age 7) and Orion (age 4) use the tablet at school every day, so no tablets on the weekdays at home,” their mother, Monisha, explained.

Caregivers implemented strategies for limiting inappropriate content, but these attempts were not always fruitful, particularly in the case of YouTube. The introduction of the YouTube Kids app in 2015 offered parents an ostensibly more kid-friendly version of the website, but it was far from universally adopted or trusted. According to parent reports, only 24 percent of children use the YouTube Kids app, approximately the same percentage that do not watch YouTube in any format (app or website).³⁹ April, mom of 5-year-old Sofia (Latina, girl), had tried to get her daughter to use YouTube Kids so that she could better filter out inappropriate content. Sofia, however, could tell the difference between the apps and refused the junior version. To feel comfortable with Sofia still using the regular YouTube app, April was resigned to “keep reporting videos every time I hear something weird. And every time I do report, I just clear off as much as I can her history, everything she’s liked, and hope that it kind of resets everything.”

Other parents had banned all forms of YouTube for their autistic child. “We thought we were safe with YouTube Kids,” said Pamela, mom of 11-year-old Rosalita (White, girl), “and we found there was a lot of violence and underlying sexual content that really shouldn’t have been there that was masquerading as kids’ stuff and so we nixed all of YouTube.” When I talked to Rosalita, though, she had interpreted her mom’s rule a little differently. “My [younger] brothers aren’t allowed to watch YouTube because sometimes they watch unexpected things,” she said, “but I can tell. I can tell if this video is okay, then make sure it doesn’t have bad language.” Unfortunately, not all autistic children were as capable as Rosalita in their ability to tell the difference

between appropriate and inappropriate videos for children, nor had YouTube fully addressed the problem; hence, vigilance was required on the part of parents whose autistic kids were mass YouTube consumers.

A few parents had very concrete media rules at home around which children's behavior was organized as a form of social infrastructure. Jamie and Jesse, parents of 10-year-old Levi (Latino and White, boy), had instituted a set of "Family Rules," which were visualized on a poster that hung in their playroom. It listed various policies and consequences for violating them. The first consequence was "Loss of Screen Time," with the description, "Could be for 15 minutes, could be for a week or could be for a different amount of time." Not only could Levi have his screen time taken away by his parents, but he had to earn it in the first place by completing household chores and doing nonscreen activities. Jamie and Jesse had made a very intricate chart (figure 4.1) detailing which tasks earned Levi and Abigail which type of media and for what duration of time, using a unique calculus. For example, "3 Full Bites New Food" equaled a "Half Episode" and "20 Minutes of Work on New Skill" earned "1 Episode." Once a day, Levi and his sister could also trade in a full TV episode for 15 minutes of watching an approved kid-influencer channel on the YouTube Kids app. Levi was not a fan of this reward and reinforcement system. "I get to earn screens, which is terrible. And Abigail thinks that, too, she just doesn't want to do anything about it," he remarked with some bitterness.

Part of the reasoning as to why Jamie and Jesse had created such a firm structure around Levi's media use was because his current elementary school, unlike his former one, did not give homework. Jamie suspected that this led to him requesting screens upon arrival at home without another way to break up his afternoon and evening. His parents were also influenced culturally by their time living in a heavily religious Christian community in the South. The idea for the screen time reward system came from a time when "we went to this one parenting thing that talked about kids that are entitled," Jamie said. She and husband did not like the idea of building their children's moral character by having them earn money for chores, so they used media as a reward instead. Levi's autism factored into the extensive screen time rules in his home, though his disability was far from the only element influencing his parents' caregiving style.

Other kids felt that there were benefits to having some boundaries on their media use or were at least more ambivalent than Levi. Raul (Latino,

<u>TASK</u>	<u>TIME EARNED</u>
Get dressed, Potty, Make Bed <i>Brush Hair</i>	1 Episode w/choomilk
Breakfast/Clean-up/Brush Teeth	Half Episode
Timed 10 Min Clean-up (LR/PL/Kitch/Office) (up to 3X)	Half Episode
Timed 10 Min Clean-up (Bedroom) (up to 3X)	Half Episode
30 Min Reading	Half Episode
30 Min Outside	Half Episode
30 Min Inside Play with Sibling (No Complaining)	Half Episode
1 Board Game (Start to Finish) (up to 2X)	1 Episode
Clean Plate Dinner club	1 Episode w/dessert (HW must be finished)
3 Full Bites New Food	Half Episode
Laundry (Start to Finish)	2 Episodes
Laundry Incomplete (starting it, or putting clothes away)	Half Episode
20 Minutes of Work on New Skill	1 Episode
1 Assigned Chore	1 Episode
FREE (Morning)	30 min Video Game Time
FREE (Afternoon)	30 min Video Game Time
Daily Trade-In	1 Episode = 15 Min of Channel Time

FIGURE 4.1

Levi and his sister's chart for earning screen time. *Source:* Meryl Alper.

boy), who was 11 at the time of our interview, wrote that his parents “limit my amount of time with tech depending on my behavior each day.” As for what he did or did not like about these rules, Raul said, “I like that they are showing me how to appreciate the technology. I don’t like when it’s time to get off.” Autistic kids thought more positively about their parents’ rules when they were aware of how media use could affect their sleep quality, which many autistic people report struggling with.⁴⁰ Twelve-year-old Brendan (White, boy) said that his mom had a rule about “no electronics from 8 p.m. to 8 a.m.” He had “no opinion whatsoever” about the rule, though he said that when he used to go on his laptop at night, he “slept through half the school day.” Now, he said, “I sleep less during the school day. Note, I said ‘less,’” suggesting that his difficulties paying attention in school were not entirely related to screen media. Media did not just impact children’s sleep; it could also be a tool for nonspeaking kids to communicate their needs at nighttime. April, for example, noted of Sofia, “When it’s bedtime, she’ll put lullabies on when she’s tired.”

Some parents were hesitant to restrict their autistic child’s media use too heavily due its potential benefits, both for themselves and their kids. Raul’s mom, Nina, said that there had been days when her son had met his three-hour iPod quota and found a loophole by watching YouTube on their smart TV. She did not punish him though: “I pick my battles, right?” she said. Kerry, mom of 6-year-old Joey (White, boy), worried that constraining her son’s leisurely and creative use of digital media would confuse him, since she envisioned a future in which he would likely need a computer for notetaking and test accommodations. “We have to some way teach him how to use that tool and not fall into the black hole of all the options he has in using that tool, [so] we try not to set limits,” she explained. Overall, restrictive mediation was commonly employed by parents of kids on the spectrum, but caregivers had difficulty balancing their child’s desires for autonomy and challenges with self-regulation.

SOCIAL MEDIATION Social mediation was a popular way for parents to connect with their autistic child, but activities did not always go as planned. For instance, Francesca, mom of 12-year-old Diego (White, boy), mentioned a time when she had gotten the new *Postman Pat* movie, a spinoff of the children’s TV series beloved by Diego, with the idea that he, Francesca, dad Santos, and younger brother Paolo could all watch it together on the projector

in their living room. Diego though could not sit for the film for very long. Francesca found it “frustrating, because when you want to do something as a family, . . . there’s no way.” Shared viewing sometimes required altered expectations and arrangements. In Eli’s home, family movie nights were held a few times a month. At a certain point during the viewing, however, the group often split in two. “Sometimes [it] turns into one parent with Dean and Caila [Eli’s older brother and sister] and the other one running after Eli,” said Julie, his mom.

In some cases, collaborative media use allowed autistic children to teach their parents and take on a more expert role than usual. Natasha, for example, had taken it upon herself to read up on Minecraft and download the game onto her personal computer when her 8-year-old son Jeremiah (White, boy) expressed interest. Noticing his mom’s enthusiasm, Jeremiah encouraged her to learn more. Said Natasha, “I think at some point I finally went and got a YouTube video called ‘Minecraft for Kids.’ I was watching it and Jeremiah looked over my shoulder and watched along. Then he helped me figure out how to play.” Though Jeremiah sometimes had difficulty managing his emotions while playing, Minecraft brought the family together in a special way. Natasha reflected, “[It’s] a good example of the family at its best. It’s a lot of fun. And also, it’s the worst. We have moments [with Jeremiah and his younger sister, Chloe] where it’s, ‘Chloe, you cannot put that there! This is my world, my rules!’” Caregivers wanted to jointly partake in media as a leisure activity with their child, but there were logistical and personal challenges.

ACTIVE MEDIATION In terms of active (or instructive) mediation, parents of autistic children found it beneficial to talk through media content with their child, including conversations explaining content and appraising it as positive or negative.⁴¹ For example, the parents of 3-year-old Oscar (White, boy) spent a lot of intensive time with him while he watched YouTube letter videos on the living room TV. “We just don’t turn it on and let it play and leave the room,” said his dad, Abe, a linguist who suspected that he was likely on the spectrum himself. He shared Oscar’s fascination with words and curated related media content for them to discuss together. “I might show the Russian alphabet or the Greek alphabet or I’ll find a French song or Spanish song, just to introduce him to these things,” he said. Norah, mom of 5-year-old Max (Asian/Vietnamese and White, boy), described how her son initiated active mediation with her while watching one of his

favorite TV shows, *Curious George*. “It’s very social. He wants to discuss the show and tell me all about it and ask me questions,” she remarked. Parents engaged in active mediation with an awareness of their child’s cognitive challenges and strengths. Karrie, for example, played the Nintendo game *Scribblenauts* with her 9-year-old son Conor (White, boy). In *Scribblenauts*, players spell objects they wish to make appear. Because Conor struggled with reading, Karrie joined in so that she could help him with the game.

Active mediation sometimes looked different for families with nonspeaking autistic children who communicated using speech generating devices. For instance, Julie engaged in dialogic viewing and questioning with Eli as he watched an episode of *Sesame Street*.⁴² “Is that a hexagon?” she said pointing to the screen, then after a few seconds, answered her own question by saying, “No. That’s a circle. That’s a circle.” Afterwards, she went to look up words for shapes in Eli’s augmentative and alternative communication device, an iPad with an assistive speech app called Proloquo2Go, with the idea that maybe someday he could comment himself. Julie discovered, however, that Eli’s teachers and speech therapists had not made a file folder on his tablet for terms like “hexagon” or “circle”—just a button for the word “shape” itself. “I feel like they’re missing vocabulary sometimes,” said Julie, as she added the words to Eli’s app on her own.

Besides parents’ comments on educational material, they also spoke with their autistic children about questionable content (i.e., negative active mediation). Jennifer, mom of 6-year-old Casey (White, girl), enjoyed showing her daughter TV shows and movies that she herself enjoyed as a child. She had to keep an eye out, though, for outdated stereotypical portrayals that Casey might accidentally model. Drawing attention to these depictions could also have the unintended effect of Casey being more likely to mimic them. Jennifer explained one occasion when they were watching a movie in which “they stereotype someone Asian with music.” Jennifer paused the film and told Casey, “You know, . . . they didn’t have to do that, and they did it because she was Asian and that’s racist and you don’t do that.” Thinking the problem was resolved, Jennifer pressed play again. “But then I heard her sing the song part,” she said, “so I just turned off the movie entirely.”

Caregivers subjectively make such determinations about content being appropriate or inappropriate for their autistic child. These decisions and conversations are shaped by factors such as race, cultural background, class, and socioeconomic status. Kimberly, for example, thought that it was

okay for 8-year-old Amaya (Black, Latina, and White; girl) to watch what she called “teenager cartoons” like *The Simpsons* and *Family Guy* if it made Amaya happy and she did not mimic what she saw and heard. “I don’t think I’m a bad parent for letting her watch it as long as she doesn’t repeat it or start acting like it,” Kimberly said. She also attributed agency to Amaya as a viewer. “These things are not good for her little brain,” said Kimberly, “so I told her, ‘Hey—what they say, you can’t say it,’ so she respects that.” Amaya’s recent consumption of the cartoons was also tied up with Kimberly’s current inability to afford a cable television subscription and exclusive reliance on broadcast TV channels, on which *The Simpsons* and *Family Guy* air in the United States. “I think she’s just bored and misses her cable channels,” Kimberly surmised. The instructiveness of active mediation was relative to the material and institutional conditions surrounding an autistic child’s learning from media at home.

SUPERVISORY MEDIATION Caregivers also oversaw their child’s media use by taking on a more peripheral role, like supervising while doing chores. “I’m usually cleaning up, so she can pick up the tablet on her own,” said Crystal, mom of 3-year-old Aaliyah (Black, girl), and “if I’m frying something, I don’t want her in the kitchen.” Sebastian’s mom, Cathleen, found that “the only way that I’m able to like make dinner or do some household chores before [Sebastian and his brother] go to bed is to put the TV on because then . . . I know they physically are not going to get on each other.” These mothers kept an eye on their children’s media use in the same or adjacent room while attending to household tasks. Some parents alternated between supervisory and more active mediation. Oscar’s mom, Leslie, noted that she and her husband often oversaw his viewing of alphabet videos in the living room. “This is why pretty much we bring reading material, because we’re not too interested in watching these videos,” said Leslie. Abe added, “You look up now and again but generally don’t pay attention.”

The fact that autistic children could easily occupy themselves with media without the need for active or social intervention by adults was also a source of worry for some caregivers. Angelica resented the implication that her daughter, 4-year-old Bella (Cape Verdean, girl), could be babysat with media, because it let others off the hook for engaging with her. It made her angry when people, albeit well-meaning, told her that Bella was “so easy to watch [because] you just give her the phone or the tablet and she’s just

quiet and she just sits there.” Angelica found comments like these dehumanizing because they seemed to prize compliance in autistic children and to justify denying them other social opportunities. “I don’t want that to be the reason why you think my daughter is ‘easy to watch,’ because she just sits on the phone and on the tablet,” Angelica said. Media supervision was a valid and necessary form of mediation, but one that could be misused by caregivers of autistic children if it rationalized their social isolation.

THERAPEUTIC DISCOURSES Beyond the interpersonal communication strategies that parents used to manage their autistic child’s media use, and children’s own perspectives on these techniques, some of the concerns mentioned by parents did not fit neatly into the categories of restrictive, social, active, or supervisory mediation. One main reason for this was that parental mediation assumes that a child’s parents are the sole adults influencing how media is managed at home. For many children on the autism spectrum, however, applied behavioral analysis (ABA) therapists are a constant presence, as such therapy is often intensive and long-term.⁴³ The primary focus of this clinical field of work is to modify an autistic child’s measurable behavior, including increasing “helpful” behavior and decreasing “problematic” ones. Behavioral therapists influence the role that media plays in autistic children’s lives by shaping parental conceptions of media as a behavioral reward and reinforcement tool. This influence goes beyond the level of the individual therapist, as behaviorism pervades cultural conceptions of autism more broadly.⁴⁴

For example, many parents absorbed the idea that media was something with which to reward desired behaviors and to withhold until said behaviors were exhibited. “I use [the computer] as leverage against them,” said Pedro, dad of 7-year-old Bryan and 9-year-old Matt (White, boys). “It’s his reward system at the end of the day,” said Gail, mom of 5-year-old Robert (Black and Asian, boy), “I make him work for it.” Nelson, father of 10-year-old nonspeaking girl Stephanie (Latina), borrowed clinical language when talking about how he and his wife managed Stephanie’s screen media use. “We use it also as a positive and negative reinforcer,” he explained, “The positive reinforcer, she can play with it for a certain amount of time and then if she’s not compliant or something, she’ll be timed out from an iPad.” Employing media as a behavioral reward was difficult for some parents to maintain, though. Eli’s mom, Julie, explained that “it’s a constant balance because we

need it to remain motivating, and so there's some measure of withholding it so that when he earns it, it's a big deal and it feels special."

Tara, a stay-at-home mom of 3-year-old Ryan (White, boy), discussed how her son's behavioral therapists used media as a reward with him and how this provided structure to her family's life. "He will get to watch a minute of one of his favorite videos, which keeps him going to the next task," she said, "We use media in a lot of different ways for him to reinforce good behavior." Tara was particularly invested in the assistance provided by her son's therapy team, in part because they personally provided her with stability that was missing in her life. She said that she had "cried" when Ryan aged out of early intervention when he turned 3. "What am I going to do?" she thought, "Because [his early interventionists] were just really, really involved." Tara's husband, Ryan's father, served in the US military reserves and was set to deploy again soon. He was not very active in Ryan's day-to-day life, as he worked a full-time job on top of his military duties and struggled with posttraumatic stress disorder (PTSD). "Unfortunately, my husband's not here a whole lot," she said. Tara instead focused her energies on turning every media moment with Ryan into a therapeutic one. "Where people might just have their kids watching something to keep them busy," she said, "usually whatever he is watching, we're talking about. I'm making him tell me who it is, use his words, what color, what shapes."

Another parent, Nina, pushed back against the guidance of behaviorists and the medicalization of autistic children's screen time because it centered a normative conception of child development. Her son, Raul, enjoyed repetitively watching short portions of videos and cartoons. Nina felt judged by clinicians for allowing her son to do so, particularly behavioral analysts. "People have expressed to me that he really should be watching the whole episode, so it sustains his engagement because it feels, quote unquote, normal to them," she said. Nina did not appreciate their judgement, as media allowed Raul to control his time and for her to have a break. Moreover, she thought that such clinical advice was detached from reality: "Behavioral therapists try to set the same benchmarks for our kids as they do for neurotypical kids. So, if the [American] Academy of Pediatrics says you should only have one to two hours of screen time a day, and a behavioral therapist who doesn't know your family or your habits or your daily practices walks into your home and says the same thing . . . , it's really jarring as a parent in my position." Research suggests that children on the spectrum far exceed

the American Academy of Pediatrics' screen time recommendations.⁴⁵ The ethos of ABA therapy might lend itself well to enforcing clear media rules, but Nina wished that more health-care providers met her family where they were, which meant much more than two hours of daily screen time for Raul.

Not all clinical interventions for autism are identical. Besides behavioral therapies, there are a growing number of relationship and noncompliance-based options, like the Developmental, Individualized, Relationship-Based model (also known as DIRFloortime or Floortime) and Relationship Development Intervention (RDI). These alternative approaches shaped how other parents approached media management. Norah, for example, thought that Floortime, which involves parents physically getting onto the floor and playing with their young autistic child,⁴⁶ influenced her approach to using media with Max. She said that when she did "Floortime stuff [with Max]" when he was 2 years old, "it was really just about getting into that space with him all the time." That interactivity extended to the family's leisure activities. "Max and I do everything together," said Norah, "we play iPad together, we'll watch a movie together, we play stuffed animals together. We're really like playmates." Max, an only child, in turn initiated social uses of media with his parents. I observed him and Norah working on the game *Plants vs. Zombies* together, with Max playing and Norah commenting, Norah and Max jointly playing, and Norah playing while Max watched and sometimes commented or took over for her.

Besides being a parent, some caregivers also took on the role of assistant therapist in how they guided, limited, and shared in media with their autistic child. Such parent-mediated interventions have been intensified by school closures during the COVID-19 pandemic, shifting many of the responsibilities of full-time, one-to-one school aides onto caregivers. For example, Nour, mom of 8-year-old Karim (Middle Eastern/Algerian, boy), described regularly engaging in a media activity that sounded a lot like active mediation but with a more therapeutic purpose. She said that much of her screen time with Karim was "focused around watching things together, just getting the declarative language from him. Because we're doing RDI, which is Relational Developmental Intervention." Nour said further, "We would watch either mute things or cartoons without any words and we just comment on them and share things like that. It's also therapy-based." Besides being a mom watching and commenting on media with her child, Nour became a sort of part-time therapist through this shared media activity. "I'm trying to

substitute for his speech therapist or whatever assignments she gives me,” Nour said. The many developmental and behavioral intervention approaches to autism have very different therapeutic paradigms, which in turn impacts mediated parent–child relationships in varied ways.

SIBLING RELATIONSHIPS

Besides interactions involving parents and their autistic children, either one-on-one or with other family members, kids on the spectrum also used media with their siblings while their parents were nearby or not copresent. These sibling dynamics were in some ways just like those of nonautistic kids (e.g., fighting over viewing choices on a communal screen). In other respects, they could be more dispassionate or, alternatively, more intense. Relaxed media use rules for an autistic child, for example, might elicit sibling jealousy. Julie noted that “if Eli is watching TV,” then his brother or sister will say, “‘Well, I want a show then.’ And so then suddenly you’re like, ‘I don’t want us all watching TV all day. That’s not the plan.’” Parents did not necessarily want to limit their autistic children more than their nonautistic child, either. Brianna said that she sometimes needed to remind Adrian when his video game time was up, but it was not so different with his older brother. “There are certainly days he would play too long,” she said, “but both my kids would.”

Watching videos and TV together were activities that autistic kids, particularly younger ones, could share in with siblings. Talking about her 3-year-old daughter Emma (White, girl) and her two siblings, mom Nikki said that “socially, that’s her way sometimes with them, to draw them to be with her, is to sit with an iPad.” Among older children, gaming was a popular sibling activity. Rebecca said that the few times her minimally speaking son Kevin (age 13, Asian/Japanese and White) uses “purposeful speech is when he’s watching his brother playing [video games]. ‘Oh! Watch out! Watch out, you’re going . . . Oh, good job!’” Joey was introduced to Minecraft by his 8-year-old nonautistic older brother, Brian. When I initially visited their home, the brothers were sitting side-by-side in the dining room/office on separate computers but playing on the same Minecraft server with their respective avatars. The server itself was a domestic space, as the brothers had built their own homes and their avatars were currently together in Brian’s abode. “These two buildings are our houses,” Joey explained, “Our houses are connected together.” While their media use was intertwined, there were also major behavioral differences between them. “Brian can better self-regulate

his screen time,” said Kerry, “whereas Joey, if you did not tell him to turn it off, he never would.”

Siblings who were each on the autism spectrum could both instigate and empathize with one another in unique ways, while their overall relationship and how they used media together also reflected general sibling dynamics. Ten-year-old Ronan lightly supervised the media use of his younger brother, Conor, who had greater socioemotional and communication challenges and was more mischievous. Describing the difference between them, and how it shaped their media use, their mom, Karrie, explained, “Ronan will be trying to build this very elaborate thing [in Minecraft] and get it all exactly the way he wants it, and Conor will come around and blow it up.” This attraction to chaos fed into Conor’s interest in gory video games like *Five Nights at Freddy’s* and *Bendy and the Ink Machine*. Though he had never played the games himself, Conor enjoyed watching others’ recorded play on YouTube, videos which Conor’s parents subsequently told him he was not allowed to watch. “I was banned from horror games,” he relayed to me. Despite being aware of the rule, he had a hard time obeying it. Ronan talked about how the videos that his younger brother was drawn to were “actually pretty creepy” and would “make him say scary things. . . . Sometimes I have actually caught him trying to watch them when he was not supposed to.” Ronan notified his parents when he discovered Conor attempting to view the videos, motivated to do so out of obedience and genuine concern for Conor’s well-being, but, also, as Karrie joked, because “nothing makes him happier than tattling on his brother.”

Some children on the spectrum had a behavioral tendency to act out in ways that could negatively affect their siblings. Even though Adrian was better now at self-regulating, Brianna said that when he was younger, he would become agitated by the competitiveness of video gaming. “I’d always be extremely anxious when he was playing with his brother and I’m glad that’s changed because it would be hard on his brother,” she shared. Physical conflicts over media could also escalate for some children. Part of 6-year-old Katie’s (White, girl) aggression stemmed from her receptive-expressive language disorder. She had difficulty understanding the messages and information that she received from others, as well as expressing her own feelings and thoughts. At one point during my visit, Katie’s younger brother, Julian, requested to look at her iPad while she was playing a game, which she did not want him to do. In response, she went into a pop-up tent set up on the living room carpet. When Julian tried to enter, Katie pushed and kicked

him hard, leading their mom, Annemarie, to intervene. When I asked her how this event rated in terms of violent encounters on a scale of 1 to 10, Annemarie rated it a “2 or 3 . . . I was kind of pulling them apart but there was a barrier” at least with the tent between them.

Autistic children and their siblings could also have a more distant relationship, through which media did not facilitate social interactivity. During my hour-long observation of Robert and his older brother, 7-year-old Stefan (who had ADHD), the brothers did not interact. Robert watched animal videos on a tablet and Stefan glanced periodically at an episode of a nature reality TV show on in the background, while each talked to themselves and played with their own toys. Their mom, Gail, said this was typical behavior: “They don’t really play together. They play side-by-side.” Meena, mother of 5-year-old Eashan and his 9-year-old brother Adhi, both of whom were autistic, discussed the boys’ video game play together, which I also observed them doing on a Nintendo Wii. “There’s no interaction there,” Meena said of the game play, “You are running on two parallel tracks. With my kids, the only interaction is when we tell them they have to take turns.”

These autistic children and their neurodivergent siblings were copresent but did not consistently co-use media in a manner that required interpersonal interaction. Interactive play is generally more valued than parallel play in social skills interventions for children on the spectrum.⁴⁷ Nonetheless, parents like Meena and Gail did not force their neurodivergent children to alter the play patterns with media and technology that came more naturally to them at home. Media provided an important relational touch point for autistic children and their siblings, though watching and playing were not always experienced communally or cooperatively.

INDIVIDUAL AND CONTEXTUAL FACTORS

The different roles that media played in autistic children’s relationships with their family members and in their parents’ management of their technology use were heavily affected by a variety of individual and contextual factors. These influences included the child’s own interest and skills, parents’ personal priorities and values, and household-level considerations shaped by neighborhood, employment, and other institutional forces.

CHILD Overseeing autistic children’s media use required parents to weigh the benefits and risks of giving their child a device, especially kids with

communication, sensory, behavioral, and impulse control challenges. Numerous parents referred to their child as “addicted” to technology and as having difficulty focusing on anything else once in its presence. “If Eli sees an iPad,” said his mom, Julie, “there’s no sharing. He’s not giving it up.” As a result, she and her husband had purchased two iPads for their three children to share. Mom Angelica said she had to be careful using her phone when out with her daughter Bella because if “I don’t give it to her right away, she sometimes will flip out.” Meena hypothesized that autistic kids were not so different from nonautistic kids when it came to an attraction to screen media. “They are all addicted to it,” she said. But whereas a typically developing kid might follow a parent’s order to put a device away, a child on the spectrum may not as easily obey the request, as Meena described: “I tell them not to touch it and it becomes an anxiety issue. That’s the single thing that’s running in their mind. When will I get to touch the iPad? When will I get to play the iPad?”

For some parents, restricting access to media was less important than avoiding an upsetting transition away from a screen-based activity. “One of our biggest struggles with him is ending media use and getting off the screen,” said Meg, mom of 9-year-old Cody (White, boy). She bemoaned the fact that “media is designed to keep you sucked in and [Cody just wants] to keep going a little bit more.” Having to step away was “the biggest source of meltdowns for him,” Meg said. One strategy the family had used was setting an alarm with an Amazon Alexa placed in the kitchen. “He needs a countdown, he needs timers, he needs a reminder,” said Cody’s dad, Bobby. Technology is only helpful, however, if you actually use it, and “a lot of times unfortunately, we’re running around and don’t remember [to set it],” said Meg.

In terms of physical factors, several children had difficulties with toileting and interoception, or the sense that helps a person feel what is happening inside their body. Interoceptive dysregulation impacted autistic children’s media use in different ways. “She’ll use it to the point of wetting her pants,” Jennifer said of Casey’s attachment to the iPad. Bella often felt great discomfort when going to the bathroom, so her parents gave her the phone while on the toilet to help relax her. This strategy sometimes did not work as planned, though. Bella’s mom, Angelica, recalled a family visit to Disney World in which Bella requested to go to the bathroom and use Angelica’s phone. After 20 minutes of watching videos, Angelica realized that Bella did not need to go, but rather “did it as a kind of way to escape

what was going on” sensorially at the busy amusement park. Annemarie similarly discussed the complexities of involving media in toilet training for first grader Katie, which was an ongoing process. Using the tablet as an incentive to sit on the toilet “was starting to backfire,” said Annemarie, because her daughter had begun refusing to go unless given a video first.

Lastly, in terms of child factors, multiple parents mentioned concerns about their child engaging in physically risky behavior and saw media as a way to keep them still, safe, and occupied. “We cannot leave these kids off by themselves all the time like other parents can,” said Nina, “So it’s super unrealistic to think that you can take away electronics or you should limit their screen time and have faith that they’ll be safe.” Four-year-old Bennett (White, boy), for example, had, on many occasions, run away from his caregivers and into the street in their suburban neighborhood. On one such occasion, he and his twin brother were being watched at home by their grandmother when she realized that Bennett had bolted out the front door. While he had not gotten far, his grandmother had a bad knee and could not run after him. From the porch, Bennett’s mother, Shelby, said, “she was like, ‘Oh Bennett, we got to see what’s on Grandma’s phone. Come look what’s on Grandma’s phone.’ And that got him in the house.” An autistic child’s personal screen time was safer than the physical danger that they could easily get into, which gave their caregivers some peace of mind.

PARENT Parents significantly varied in the degree to which they found managing their autistic children’s media use to be stressful. For example, Natasha, mom of 8-year-old Jeremiah (White, boy), claimed to have “never worried about screen time” due to her children being overscheduled. “The amount of free hours anyone could potentially have [is] so small,” she explained, “that when we do have free hours, people can decide what they want to do.” Other mothers, though, had internalized guilt over letting their autistic child frequently use screen media, and this weighed on their parenting decisions. Nina, for example, felt “like there’s this little voice saying I should be doing more with my son [Raul] than giving him the iPod for seven hours on a Saturday.” Nina saw no other way for her to stay mentally sane and for Raul to be happy, especially considering that he could not independently occupy himself with sports or other hobbies.

Some parental guilt was rooted in a lack of clear medical guidance and assurance regarding autistic kids and technology. Annemarie was concerned

about Katie's reliance on the iPad because "there isn't research that shows how it's going to affect their brains." Crystal worried that she had somehow induced autism in her daughter, 3-year-old Aaliyah (Black, girl), by allowing her to use a phone and tablet at an early age. "There's guilt that I caused her to be . . . who she is, because of the device . . . [that] me giving her the device this whole time was creating her antisocial," said Crystal. At the same time, Crystal mentioned several personal issues that exacerbated Aaliyah's social isolation and her own. Her husband and Aaliyah's father, Mike, had been on disability leave and not working when their daughter was younger. Instead of sending Aaliyah to costly daycare at that time, Mike watched her during the day while Crystal worked, prior to her current unemployment. The situation weighed on Crystal, who blamed herself, though not her husband. "I went to work, and he stayed with her giving her the device all day long, and I thought, 'Nobody is talking to her,'" she said regretfully.

As with caregivers more generally,⁴⁸ parents' personal media habits also influenced their mediation strategies, and their autistic children's media preferences shaped their own use as well. For example, April had signed Sofia up for her own YouTube account because she was starting to receive algorithmic recommendations for content geared toward her daughter's preferences instead of her own. "It used to be on mine," April explained, "but then I would just try to watch YouTube to relax and it would be like Clifford, Clifford, Clifford, ABC." Six-year-old Skyler (White, boy) and his mom, Naomi, regularly co-viewed YouTube videos that users had recorded of themselves reading books. Naomi was a former librarian and had felt discouraged when Skyler rejected reading physical books with her. "It's really, really important to me that he loved books, and he wasn't loving books," she recalled, "so this is how we kind of brought books back into his world." Mothers factored their own needs into how they managed their child's media use, despite living in a world that largely requires women to subjugate their feelings and emotional well-being for the sake of others.⁴⁹

HOUSEHOLD Finally, families of autistic children contended with several home, environmental, and family considerations that impacted how media was integrated into their lives. Extended family could have a meaningful role in autistic children's regular engagement with media, as is highlighted by Alessandra and Camilla's story at the start of this chapter. For instance, the immediate and extended family of 8-year-old Isaac (White,

boy) practiced a modern form of Orthodox Judaism that restricted the use of electronics from sundown on Friday to sunset on Saturday (i.e., Shabbat), a time usually spent in prayer and with family. His mom, Sara, said that despite being very religious, her aunt and uncle would “literally will go run to find what their Wi-Fi password is” during Isaac’s Shabbat visits to their house “because they know Isaac needs to be on YouTube. . . . [My family is] so supportive.”

A lack of consistent high-quality childcare outside of school hours was also a major concern for many parents. When talking to Annemarie, I was struck by how she truly had no one to watch her children besides herself, her husband, or the TV-as-babysitter. All of the other adults who could have potentially cared for Katie and Julian, including a hired regular babysitter and Annemarie’s in-laws, had quit. They had done so on account of Katie’s physically aggressive outbursts, which included past incidents of kicks to the head and choking her family members, all over relatively minor things. The sitter “doesn’t want to come anymore,” said Annemarie, and “my husband’s parents, they had to take a break because it was too hard, stressful for them.”

To get through the day, screens could allow parents to run errands with their autistic child that would otherwise have been difficult to do. Stephanie’s parents used a free grocery app when shopping to keep her calm and engaged. She could visualize which items were still needed and check off each item once it was placed in the cart. Other apps that worked offline, like the camera, were also useful in locations without Wi-Fi. Stephanie’s father, Nelson, recalled taking selfies with his daughter in the big box store Costco, a location that could be sensorially overwhelming for her. He explained, “We’re trying to do as much as we can to get her involved. If she gets bored, she’ll start walking around the store, and she’ll run away from us.” Parents of young kids might use their phones in a similar way in public places,⁵⁰ but the caregivers of autistic children with behavioral and communication challenges felt a heightened sense of anticipatory concern.

Beyond the day-to-day, autistic children face the same destabilizing life events that other kids do, including parental divorce, parental separation, or the long-term absence of a parent. Media may be more core to these young people’s well-being by offering consistency, routine, and familiarity. Brendan’s mother, Marcia, was divorced from his father and shared custody of Brendan and his siblings. “He has to go back and forth between me

and his father, which is not easy," she said. What made these transitions smoother was that Brendan could take his laptop with him, a device that held significant affective meaning. "It's his connection, it's his comfort," said Marcia, "He would carry that whole thing with him everywhere." She even recalled times when they would be in the car, about to drive away, and Brendan would ask for five more minutes to finish something on the laptop while connected to their house's Wi-Fi network.

Another single mom, Audrey, was raising Caleb (Black/Haitian, boy), who was 9 years old at our first meeting, and his younger sister, Erika (age 6), having kicked her husband out of the house after nearly 15 years of marriage for being physically and emotionally abusive. Audrey had some relatives in the area, but all were elderly and could not provide consistent childcare. In the small quarters of their apartment, Audrey and her children created both communal and private media spaces. Caleb and Erika had a smart TV in their bedroom so they could view Netflix or YouTube while Audrey watched news in the living room. She kept their remote control outside the door though, on top of the refrigerator in the kitchen, so the children were not able to watch without permission or late at night. Caleb brought up his dad in passing when talking about the TV shared by him and his sister. "Usually, me and my sister fight a lot over the television and usually my sister wins because my father's not here. And I do not want to talk about that," he stated, which I assured him I would not make him do.

Parents of limited financial means additionally balanced their autistic child's access to media with other expenditures. Nour, for instance, said that Karim (who was 11 at the time of our follow-up interview) "had his own phone for a year. Then, you know, expenses were a lot, so I cut on that." Five-year-old Anthony (Black, boy) had his own smartphone from MetroPCS because a family data plan through the cellular provider was cheaper than paying for home internet. Said his mom, Danae, "He don't use the phone. I just get it for the YouTube." Gail downloaded YouTube videos to Robert's tablet for offline viewing because "we don't really have the internet," she said, "Sometimes I'll turn it on from my phone, but it gets pretty expensive, so I don't leave my phone as a hotspot."

When I visited Sofia and her family, it was a particularly hot day during a summer that had already caused frequent power outages in her low-income Boston neighborhood. April had thought of various contingency plans if the electricity and internet were to cease functioning. The family paid for

a data plan from a cellular provider on Sofia's iPad in case the Wi-Fi went down. If that were to run out of battery, April made sure that her laptop, which had a DVD player, was charged so that Sofia could watch episodes of her favorite TV show. If worse came to worse, April told the other family members in her intergenerational household, "Next time the power goes out, we're going to a hotel. I don't care if you have to use credit cards; it's just better to not be miserable. She'll be good, she'll have her stuff, and we'll have AC." The economic and infrastructural conditions around autistic children and their families directly shaped their priorities, including their investments in media and technology.

REFLECTIONS ON FAMILY

Among families with children, there is no single factor that determines the role that media and technology play in their lives, including a child's disability. Households with kids on the spectrum are both different from and similar to other families in their joys and struggles. For example, most parents try to balance firmness and looseness in the rules they make and the examples that they set. Medical discourses of behavioral intervention (i.e., rewards, reinforcement), however, are more likely to be woven into media management strategies for the caregivers with whom I spoke. Parents of autistic kids must also handle distinct—and sometimes competing—sensory, behavioral, and socioemotional needs of household members, including siblings.⁵¹ There were significant differences in personal parenting philosophies around media, and there were multiple contextual factors impacting families' everyday technology routines and habits. Media can additionally be a constant, reassuring presence for autistic kids when there is major upheaval in their family life. Below, I discuss theoretical implications of this work for studies of parental mediation, recommendations for clinicians and therapists who work with children on the spectrum, and industry suggestions for better implementing technological guard rails to support parents in keeping their autistic kids safe online.

Concurrent with existing research, I found that parents of children on the spectrum employed active, restrictive, and social mediation with their children; they also engaged in media supervision, which is a more recently identified parental mediation strategy.⁵² Yet current theories of parental mediation do not neatly map onto autistic children and their families. For

example, in a 2015 study by Kuo and colleagues, parents identified six main strategies for mediating their autistic child's television and video game use.⁵³ Three were characterized by the researchers as restrictive mediation (removing/limiting access to media, setting rules and being consistent, using monitoring software) and one aligned with active and social mediation (engaging in media activities together). However, within the existing types of parental mediation, the authors observed two strategies that they could not categorize: first, keeping the adolescent busy doing other activities and second, using media as a motivator and removing media as a punishment. These parenting strategies reflect not only individual choices, but also the lack of affordable and accessible leisure activities for children on the spectrum outside of school and the entwinement of behavioral intervention principles in the parenting of autistic kids.

The intersection of autism interventions and parenting strategies around autistic children's media use is complex, as illustrated by the varied experiences of Ryan, Max, and their mothers. Behavioral therapies for kids on the autism spectrum are far more likely to be covered by public insurance providers in the United States than developmental and relationship-based interventions.⁵⁴ One of the major critiques of ABA, the most dominant form of behavioral therapy, is that it overfocuses on compliance and that this emphasis leads to deprioritizing the emotional needs of autistic people. In ABA, for example, parents are often encouraged to withhold a reward from their child unless a desired behavior is exhibited, like asking verbally for a toy or snack. Strict ABA programs teach parents to ignore their child's protests and cries. Autistic self-advocates have argued against taking away something extremely pleasurable from an autistic person as a form of punishment due to the disproportionate stress and anxiety it may cause.⁵⁵ For many autistic children, media is not ancillary to their lives and something they can manage without; it is a comfort blanket in a highly discomforting world, such as with Brendan's laptop.

Prior work has found that pediatric autism medical providers are advising families on their child's recreational technology use—assistance that could help parents like Annemarie and Crystal—but that the utility of this guidance is mixed.⁵⁶ Moving forward, I encourage clinicians to take a family systems perspective on both autism and children's engagement with media. This requires understanding not just individual relationships—like that of kids on the spectrum and their siblings—but the family unit as a

whole, along with social and ecological factors beyond the household. For example, a lack of homework from school shaped Levi's parents' family media rules. Many parents, especially mothers, shoulder significant guilt about their child's time with screens.⁵⁷ For mothers of autistic children, this shame is intensified by the modern spin on the ableist refrigerator mother theory: that screen media (disproportionately managed by moms) causes autism, which is assumed in such a theorization to be an unquestionably negative outcome.⁵⁸ Clinicians should listen to parents to understand the tradeoffs they make when they give a screen to a child on the autism spectrum. This aligns with calls for pediatricians and other health care specialists to, during the COVID-19 pandemic, change their screen time messaging to one that is more positive and avoids stigmatization.⁵⁹

Lastly, industry players like Google should better implement technological guard rails for autistic kids, even if it hurts their bottom line. Outside of self-regulation, government intervention in the United States is needed to push the technology industry toward greater transparency and accountability. Though some parents may curate limited playlists for their children in YouTube Kids, there is no option to do so on regular YouTube, even with a supervised account (which Google promotes for families of children ages 9 and up).⁶⁰ This is likely because algorithmic recommendation and targeted advertising generates significant profit for Alphabet, Google's parent company.⁶¹ Considering the number of families with whom I spoke whose autistic children under 9 flatly rejected the YouTube Kids app, their needs are not being served by the website, despite its inescapable presence in their lives. For example, besides playing Whac-A-Mole with the "Report" button, there was no way for April to prevent Sofia from discovering scary videos of her favorite children's cartoon character, Clifford the Big Red dog, especially because videos like these are often preceded by pre-roll advertisements of children's toys.

Better supporting autistic kids in society requires strengthening social support for their families without overemphasizing parents as the only active choice makers in the family system, especially when it comes to technology. Media can be more central to the functioning of families of autistic children, requiring greater reorganization of family life around securing access (i.e., resources, schedules). Siblings may play an outsized role in how children on the autism spectrum learn to navigate the digital world, and more research is needed on this topic. On an even larger scale, it is important

to think about not just what is best for individual families of children on the spectrum, but also the greater good of families of autistic kids in society, considering their socioeconomic, ethnic, and racial diversity. It would be a mistake to assume that all families of children on the spectrum are similarly resourced to help their child derive the most benefit from technology and media and to avoid the greatest risks. I turn next to children's social partners outside the familial structure—peers and friends—and the associated opportunities and challenges for connection posed by new media.

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