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# **Kids Across the Spectrums**

## **Growing Up Autistic in the Digital Age**

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# APPENDIX: METHODS

In this appendix, I provide additional methodological background on the empirical research on which this book is based. I highlight several opportunities and challenges of conducting qualitative research with diverse youth on the autism spectrum and capturing the significance of media and technology in their lives. I further detail my positionality as a researcher and explain the participation criteria, recruitment methods, study design, and limitations of the study.

## QUALITATIVE RESEARCH WITH AUTISTIC CHILDREN

There is no single approach for maximizing the involvement of young people on the autism spectrum in research, as the methods need to be adapted to cater to their individual needs. Inclusive education scholar Carmel Conn details six general best practices for conducting qualitative research with this population, which I drew upon for this book.<sup>1</sup> First, researchers should aim for naturalistic inquiry. I did so by observing children engaging in routine activities with familiar people and by asking them concrete questions about their immediate surroundings. Second, research should be strengths-based. Parents took on a key role during our initial interviews by suggesting support strategies that would enable their child to participate, including how to pace interview questions.<sup>2</sup> Additionally, children were free to meet their sensory needs during interviews. I did not stop them from playing with stim toys and other objects or from scooting under tables if they preferred to answer my questions from there (as Caleb did for part of our interview). I also offered nonspeaking

children who used AAC (augmentative and alternative communication) the option to type question responses or use other preferred methods.

Third, Conn contends that the research ought to involve mixed methods. For this book, I employed a combination of interviews and observations with parents and autistic kids. I was also flexible with the child interview format in the moment,<sup>3</sup> such as making certain open-ended questions more structured if children were having difficulty responding.<sup>4</sup> Fourth, research with autistic young people should enable their participation. One strategy that I used toward the end of my interview with kids was telling them that they could ask me questions too. Rosalita, for instance, inquired whether I had any pets, which reflected her own interest in animals. Fifth, Conn writes that researchers should be reflexive and offer children on the spectrum opportunities to share their own interpretations. As I detail later in this chapter, several offered commentaries on the research process with me, which then informed my ongoing work. Lastly, research should be practice-oriented, as in geared toward producing actionable change. Throughout this book, I have made recommendations for parents and professionals.

## POSITIONALITY

As the primary ethnographer on this project, I was my own research instrument.<sup>5</sup> As such, it is important to reflect upon my positionality and the ways that I drew upon multiple visible and invisible aspects of my identity during the course of research,<sup>6</sup> including the ease with which I was socially accepted into homes and physically navigated fieldwork. It was both beneficial and detrimental in some cases that as an upper-middle class monolingual English-speaking White-appearing young woman, I looked and sounded like many of the health professionals that regularly provide in-home services to autistic children.<sup>7</sup> Upon my arrival at their house, for example, Emma's brother, Mikey, asked if I was there to teach his sister "how to talk," confusing me for a speech-language pathologist making a home visit.

But not all therapy providers are as warmly welcomed. Maya's father, Ismail, mentioned that his daughter had a traumatic experience with the applied behavior analysis (ABA) therapists who had worked with her at home. In discussing the timing of my return visit to observe Maya, Ismail said, "If you come to our house at 3 p.m., she'll start crying because that's when the ABA therapists came." We planned for me to arrive later in the afternoon next time, to avoid unnecessarily upsetting Maya.

During the period when I conducted field research, I did not yet have child-care responsibilities, so I could flexibly schedule my interviews and observations based on families' needs, including weeknight evenings and weekends. Additionally, an orientation to what I have elsewhere termed "inclusive sensory ethnography" shaped my fieldwork in homes.<sup>8</sup> I have no physical mobility constraints or chronic conditions such as chemical sensitivities or severe allergies. Studying how autistic children related sensorially to their built environment made me notice that I never had to think logistically about how I would enter homes or bother to ask parents if they had any pets before I came by. The "unsettled times" of the COVID-19 pandemic has limited in-person ethnography within personally intimate spaces, but such work was not so easily undertaken by many in the "settled times" prior to the pandemic either.<sup>9</sup> Reflexivity is not limited to a postscript discussion here or elsewhere in this book; rather, continuous reflection was central to the research process and the interpretation of data.<sup>10</sup>

## PARTICIPANTS

Table A.1 summarizes demographic information collected about all of the autistic children and caregivers who took part in my study from 2013 to 2020, while table A.2 offers more descriptive data on each child and family. All child participants were required to have an autism diagnosis as confirmed by their parents, which prior research has indicated to be a valid and reliable source.<sup>11</sup> Children had to be between the ages of 3 and 13 when I first met them and their parents. I selected this age range for several reasons. The global average age of an autism diagnosis is 3 years old.<sup>12</sup> Three is also the age at which children in the United States qualify under the US Individuals with Disabilities Education Act for an Individualized Education Program (or Plan) (IEP). Fourteen is the age by which students on the spectrum with an IEP must begin to receive services from public school districts to ease their transition to adulthood.<sup>13</sup> I also conceived of this population in terms of two age groups: 3–8 and 9–13. In the former age range, family members tend to be a child's primary social partners, and during the latter, nonfamilial relationships become more central to a child's life.<sup>14</sup>

Families participating in the research included those with employed, unemployed, or underemployed parents; mothers with graduate degrees and those with a high school education or less; caregivers who were software engineers and those who were Uber drivers (and Uber drivers with

Table A.1  
Demographics of Autistic Child Participants and Their Parents

Age (Median, years)	7
Gender <sup>a</sup>	
Boy	44
Girl	18
Parent-reported co-occurring conditions (in addition to autism) <sup>b</sup>	
Communication impairment <sup>c</sup>	26
Attention-deficit/hyperactivity disorder (ADHD)	6
Anxiety	3
Epilepsy	3
Other <sup>d</sup>	9
Race	
White	32
Nonwhite	30
Black <sup>e</sup>	11
Asian <sup>e,f</sup>	10
Latino/Latina <sup>e</sup>	9
Middle Eastern <sup>e</sup>	1
Other <sup>e,g</sup>	3
Yearly household income	
≥ \$100,000	29
\$99,999–\$50,000	12
\$49,999–\$25,000	11
< \$25,000	10
Parent/s born outside the United States	
Yes	17
Language other than English used at home	
Yes	16
Parent relationship status	
Married or unmarried/cohabitating	50
Other <sup>h</sup>	12
Mother's education	
College or advanced degree	47
Some college, high school, or less	15

Table A.1  
(continued)

State of residence	
Massachusetts	50
California	12

<sup>a</sup> Cisgender and transgender children.

<sup>b</sup> "Autism" includes parent-reported diagnoses of autism, autism spectrum disorder, Asperger's syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

<sup>c</sup> Parent reported that child used augmentative and alternative communication (AAC), had a communication disorder, had a speech delay, was "non-verbal," had childhood apraxia of speech, and/or had mixed expressive-receptive language disorder.

<sup>d</sup> Asthma, obsessive-compulsive disorder (OCD), dyslexia, intellectual disability, visual impairment, Fragile X syndrome, Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections syndrome (PANDAS), other genetic disorder.

<sup>e</sup> Children with at least one biological parent with that racial background.

<sup>f</sup> Bengali, Cambodian, Filipino, Indian, Japanese, Nepali, Pakistani, and Vietnamese.

<sup>g</sup> Cape Verdean, Armenian, and Azerbaijani.

<sup>h</sup> Divorced, separated, or single parent.

graduate degrees); and those who were married, divorced, remarried, separated, single, or polyamorous. Some parents and caregivers identified as neurodivergent or autistic, though most without a formal diagnosis. Parents had immigrated from countries such as Algeria, Bangladesh, Haiti, and Pakistan. The study required that at least one parent speak English. In the majority of households, only English was spoken, but in other homes, languages including Hebrew, Dutch, and Swahili were spoken as well. In addition to autism, several parents indicated that their children had additional diagnoses including attention-deficit/hyperactivity disorder (ADHD), anxiety, and epilepsy.

## RECRUITMENT

Research was conducted in two waves: first from 2013 to 2014, when I was a graduate student at the University of Southern California in Los Angeles, and then from 2016 to 2020, when I was an assistant professor at Northeastern University in Boston. Twelve children and their families were recruited in Wave 1, and fifty families were recruited in Wave 2. Wave 1 families included non-speaking and minimally speaking children on the autism spectrum recruited for the study on which my prior book, *Giving Voice*, is based. Ethnographic material included in this book but collected during Wave 1 did not appear in

Table A.2  
Descriptive Data of Autistic Child Participants

First Name	Age <sup>a</sup>	Gender	Race (Ethnicity)	Parent-reported diagnosis/ disability <sup>b</sup>	Yearly household income	Parents/caregivers name/s	Year(s) interviewed or observed
Aaliyah	3	Girl	Black	Autism	Less than \$25,000	Crystal & Mike	2019
Abbey	4	Girl	White	Autism	\$25,000–\$49,999	Molly & Steve	2017
Adhi <sup>c</sup>	9	Boy	Asian (Indian)	Autism	\$50,000–\$99,999	Meena & Arjun	2017
Adrian	13	Boy	White	Autism, Asperger's syndrome, dyslexia, anxiety	\$100,000 or more	Brianna & Stewart	2018
Alessandra	3	Girl	Latina	Autism, AAC user	\$25,000–\$49,999	Camila & Felipe	2017
Amaya	8	Girl	Black, Latina, and White	Autism, PDD-NOS, OCD, anxiety	Less than \$25,000	Kimberly	2019
Anthony	5	Boy	Black	Autism, asthma	Less than \$25,000	Danae & Darnell	2017
Bella	4	Girl	Other (Cape Verdean)	Autism	\$100,000 or more	Angelica & Dave	2019
Bennett	4	Boy	White	Autism, PDD-NOS, communication disorder	\$50,000–\$99,999	Shelby & Keith	2017
Brendan	12	Boy	White	Autism, PDD-NOS	\$50,000–\$99,999	Marcia	2018
Bryan <sup>c</sup>	7	Boy	White	Autism	\$25,000–\$49,999	Beca & Pedro	2019
Caleb	9	Boy	Black	Autism, ADHD	Less than \$25,000	Audrey	2019, 2020
Carter	3	Boy	Black and White	Autism, AAC user	\$25,000–\$49,999	Simone & Prince	2018
Casey	6	Girl	White	Autism, ADHD	Less than \$25,000	Jennifer	2019
Chike	7	Boy	Black	Autism, AAC user	\$100,000 or more	Esoa & Adamu	2014
Chris	4	Boy	Asian (Cambodian) and White	Autism, AAC user	\$100,000 or more	Chanda & Phil	2017

Cody	9	Boy	White	Autism, PDD-NOS	\$100,000 or more	Meg & Bobby	2018
Conor <sup>c</sup>	9	Boy	White	Autism	\$100,000 or more	Karrie & Adam	2019
Danny	6	Boy	White	Autism, epilepsy, AAC user	\$100,000 or more	Alice & Peter	2013
Diego	12	Boy	White	Autism, intellectual disability, epilepsy	\$100,000 or more	Francesca & Santos	2018
Eashan <sup>c</sup>	5	Boy	Asian (Indian)	Autism	\$50,000–\$99,999	Meena & Arjun	2017
Eli	4	Boy	White	Autism, AAC user	\$100,000 or more	Julie & Jason	2017
Emma	3	Girl	White	Autism	\$100,000 or more	Nikki & Seth	2017
Imay	5	Boy	Asian (Nepali)	Autism, AAC user	\$25,000–\$49,999	Geetu & Amir	2019
Isabella	5	Girl	White	Autism	\$100,000 or more	Amy & Brandon	2018
Isaac	8	Boy	White	Autism, AAC user	\$100,000 or more	Sara & Daniel	2013
Jackson	11	Boy	White	Autism, PDD-NOS, epilepsy, ADHD	\$25,000–\$49,999	Linda & Roger	2019
Jeremiah	8	Boy	White	Autism, Asperger's syndrome	\$100,000 or more	Natasha & Neil	2017
Joey	6	Boy	White	Autism, PDD-NOS	\$100,000 or more	Kerry & Doug	2016
Kahlil <sup>c</sup>	7	Boy	Black	Autism, speech delay, "non-verbal," AAC user	Less than \$25,000	Monisha	2019
Karim	8	Boy	Middle Eastern (Algerian)	Autism, PDD-NOS	\$25,000–\$49,999	Nour & Hakim	2016, 2019
Katie	6	Girl	White	Autism, ADHD, anxiety	\$50,000–\$99,999	Annemarie & Frank	2019
Kevin	13	Boy	Asian (Japanese) and White	Autism, speech delays, AAC user	\$25,000–\$49,999	Rebecca & Eric	2014
Levi	10	Boy	Latino and White	Autism, PDD-NOS	\$100,000 or more	Jamie & Jesse	2018
Lucas	5	Boy	Latino and White	Asperger's syndrome	\$100,000 or more	Melissa & Brady	2016–2017

(continued)



Table A.2  
(continued)

First Name	Age <sup>a</sup>	Gender	Race (Ethnicity)	Parent-reported diagnosis/ disability <sup>b</sup>	Yearly household income	Parents/caregivers name/s	Year(s) interviewed or observed
Luke	13	Boy	White	Autism, AAC user	\$100,000 or more	Debra & Rob	2013
Matt <sup>c</sup>	9	Boy	White	Autism	\$25,000–\$49,999	Beca & Pedro	2019
Max	5	Boy	Asian (Vietnamese) and White	Autism	\$100,000 or more	Norah & Mark	2017
Maya	8	Girl	Asian (Pakistani)	Autism, vision impairment, AAC user	\$100,000 or more	Nazanin & Ismail	2019
Moira	10	Girl	White	Autism, childhood apraxia of speech, AAC user	\$50,000–\$99,999	Vanessa	2014
Noah	3	Boy	White	Autism	\$25,000–\$49,999	Amanda	2017
Olivia	6	Girl	White	Autism	\$100,000 or more	Bailey	2017
Orion <sup>c</sup>	4	Boy	Black	Autism, speech delay	Less than \$25,000	Monisha	2019
Oscar	3	Boy	White	Autism	\$100,000 or more	Leslie & Abe	2017
Pargev	13	Boy	Other (Armenian)	Autism, AAC user	Less than \$25,000	Karun & Mihran	2013
Patrick	4	Boy	White	Autism, AAC user	\$50,000–\$99,999	Jessie	2017, 2019
Raul	5	Boy	Latino	Autism, AAC user	\$100,000 or more	Nina & Javier	2013, 2019
Robert	5	Boy	Black and Asian	Autism, ADHD	\$50,000–\$99,999	Gail	2017
Ronan <sup>c</sup>	10	Boy	White	Autism	\$100,000 or more	Karrie & Adam	2019
Rosalita	11	Girl	White	Autism, Asperger's syndrome	\$100,000 or more	Pamela & William	2019

Ryan	3	Boy	White	Autism, mixed developmental disorder, mixed receptive-expressive language disorder, AAC user	\$50,000–\$99,999	Tara & Craig	2017
Saaida	8	Girl	Asian (Bengali)	Autism, AAC user	Less than \$25,000	Tanvi & Hamsa	2017
Sam	8	Boy	White	Autism, intellectual disability, genetic disorder, AAC user	\$100,000 or more	Donna & Marc	2014
Saylor	12	Girl	White	Autism, PDD-NOS	\$100,000 or more	Maggie & Jon	2018, 2020
Sebastian	6	Boy	Latino and White	Autism, Fragile X syndrome	\$100,000 or more	Cathleen & Michael	2019
Skyler	6	Boy	White	Autism, ADHD	\$100,000 or more	Naomi & Jacob	2017
Sofia	5	Girl	Latina	Autism, AAC user	\$50,000–\$99,999	April & Seb	2019
Spencer	4	Boy	Black and White	Autism, PANDAS, AAC user	\$50,000–\$99,999	Rosie & John	2017
Stephanie	10	Girl	Latina	Autism, AAC user	\$25,000–\$49,999	Marisa & Nelson	2013
Talen	6	Boy	Black, Latino, and White	Autism, AAC user	\$50,000–\$99,999	Kameelah & Marcus	2013
Thomas	11	Boy	Asian (Filipino) and White	Autism, intellectual disability, AAC user	\$100,000 or more	Daisy & Joe	2013
Zahra	4	Girl	Other (Azerbaijani)	Autism	Less than \$25,000	Raina & Becky <sup>d</sup>	2017

<sup>a</sup> Child's age at the beginning of research.

<sup>b</sup> Parent selections of "autism" and "autism spectrum disorder" reported together.

<sup>c</sup> Autistic sibling.

<sup>d</sup> Domestic partnership.

Abbreviations: AAC = augmentative and alternative communication; ADHD = attention-deficit/hyperactivity disorder; OCD = obsessive-compulsive disorder; PANDAS = Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections syndrome; PDD-NOS = Pervasive Developmental Disorder-Not Otherwise Specified.

that earlier publication. In each wave, recruitment began after approval from the university's institutional review board (IRB). The recruitment strategy and study design for Wave 1 has been detailed elsewhere, so the discussion here will focus on Wave 2.<sup>15</sup> Families in Wave 2 were recruited via professional referrals, electronic communication, print flyers, and community meetings. Parents were screened via phone, email, or text message to confirm their eligibility, and they signed a consent form prior to participating.

Families received a USD \$30–\$50 gift card after completion of the study. Parents' primary motivations to participate, however, were not financial in nature. Most wanted to help researchers such as myself learn more about autism and ultimately better support their child and children like them. Some parents provided specific insights, like Nour, who thought of my interview with her son, Karim, as a kind of therapeutic intervention. She explained that not many people visited her home because no relatives lived nearby, let alone in the country. Due to the novelty of visitors, Karim was "very interested [in] people who come to [their] house." My visit was an opportunity to capitalize on that interest and have Karim work on social communication skills like introducing himself and "presenting one's relatives to another person."

## STUDY DESIGN

This study employed three primary qualitative methods: semi-structured interviews (with parents and autistic children), semi-naturalistic observation (with autistic children and their families), and participant observation. During Wave 2, I was aided in conducting observations and interviews by three undergraduate and graduate student research assistants on eleven different occasions. Collectively, they had professional experience at an autistic self-advocacy nonprofit organization, personal experience as the sibling of an autistic person, and graduate training in public health and qualitative research on youth mental health.

## PARENT INTERVIEWS

Parent interviews were primarily, though not exclusively, conducted with mothers. Fathers sometimes joined in or were the primary interviewee, especially if mothers were not proficient in English. As noted in chapter 1, I conducted follow up interviews (as well as child observations) with several

families (one from Wave 1 and four from Wave 2). Interviews with parents in Wave 2 lasted from one to two and a half hours and were conducted by using a semi-structured interview guide. Interviews began with warm up questions about the family and child's background (i.e., autism diagnosis process, child's average weekday and weekend schedule). The interview then covered eight main topics regarding their child's media and technology use: overall media preferences and experiences, specific types of media use and media environments, cognitive and behavioral development, sleep and physiological development, social and emotional development, communication and self-expression, fun and learning, and social norms and values. The interviews concluded with an opportunity for parents to talk about any topic not discussed or point that they wanted to clarify.

Nearly all parent interviews took place at their homes to gain richer insights into the family milieu. One parent requested that we meet at a coffee shop near her child's preschool, and two wanted to be interviewed in their office spaces at work. For interviews conducted at homes, other family members (e.g., grandparents) and the autistic child were sometimes present and took part peripherally as a subject of discussion (i.e., the parent commenting on the child using media in the background) or as an active member of the conversation. For instance, when Meg mentioned that Cody went through phases of being interested in certain video games, like *War Robots*, he interjected from the other room, "I don't play that anymore!" to which Meg responded with a laugh, "Yeah, I know you don't play that anymore, but you did for a while."

Following the interview, parents filled out a family background form to provide demographic information about their household (e.g., average yearly household income). Before leaving, parents and I discussed plans for my follow-up visit with their child, which would entail either a media use observation or a combined interview and observation. I asked parents whether or not their autistic child was capable of being interviewed, and if so, what communication support they might require (e.g., having the parent also be present). Return visits were scheduled around optimal times for the child to be engaged. For instance, Melissa said that any time would be fine for her son, Lucas, "as long as it's not right after school because that's when he needs his alone time." Fieldwork with each family was spread out over one to three weeks, depending on availability.

### FAMILY OBSERVATIONS

Some children were not able to be interviewed, so I instead observed them at home engaging in a routine media activity that was typically undertaken with another family member (i.e., parent, sibling). Field notes focused on social interactions between autistic children and their social partners, the child's media consumption practices, and any parent commentary on the activity. Parents sometimes helped to interpret their child's nonspoken behavior. For example, at one point during my initial observation with Karim, Nour turned to me and said of her son, "He's getting more comfortable with you because he's singing." Family observations lasted thirty to ninety minutes. The specific media activity and social configuration was left purposefully open for families to choose. Observations primarily occurred in communal areas of the home (e.g., living room), but sometimes in a child's bedroom if it was the regular site for a particular media ritual (e.g., Skyler and Naomi's afterschool parent-child "book reading" on YouTube).

### CHILD INTERVIEWS AND OBSERVATIONS

Prior to each child interview, assent was obtained by reading a printed document aloud to the child that explained the purpose of the study. Based on best practices,<sup>16</sup> autistic children were told that they did not have to answer all of my questions, could skip any, and were able to stop or take a break. Interviews were mostly conducted on the living room sofa, sitting side-by-side without forcing the child on the spectrum to make eye contact. Children could instead look at the page of interview questions that I had printed out on paper and see the interview's progression.<sup>17</sup> I used a semi-structured interview guide designed to aid in children's comprehension. Each question was typed in large print and was accompanied with a small graphic that symbolized the question (e.g., the YouTube logo next to a question about YouTube). Either I or the child checked a box in a column next to the question after it was answered or skipped. Sample questions included, "Who is your favorite character from a TV show, movie, book, or video game? What do you like about them?" and "What do you not like about media or technology?" Interviews lasted approximately thirty minutes, after which I asked children to show me their favorite media or technology activity, which I then observed and discussed with them for an additional thirty minutes.

During the child interviews, parents of older children with more cognitive and verbal capacity mostly left the child and me alone to talk in a

nearby room. Other caregivers provided more direct and indirect support by scaffolding their child's conversation and helping me gain an understanding of their child's "sociocommunicative lifeworld."<sup>18</sup> For example, at one point during my interview with Conor, he turned to his dad, Adam, who sat a few feet away at the kitchen table, and asked, "Daddy, daddy! You help her answer questions. Which YouTube, which videos I was banned from?" In reporting children's responses in this book, I also tried to keep their language patterns intact; for example, Diego's word repetition when discussing his digital bookmarking in chapter 3.

### CHILD FEEDBACK

As noted earlier, young people on the spectrum could be reflective about their research participation. For example, Adrian noted, regarding his loquaciousness, "I always talk as if I'm doing a TED Talk." Some expressed annoyance at my presence. I ended up conducting Levi's interview in between him watching videos on YouTube, which was less than ideal due to the distraction of the screen. I periodically asked him to pause so that I could pose another question. "You know this is like school," he said during our interview. "What's like school? Me asking you questions?" I replied. "Yep. And I get to earn screens," he said, perhaps reflecting on the reward structure within his household that was noted in chapter 4. With an awkward laugh, I responded, "Hopefully it's a little more fun," to which Levi declared, "Yeah, it isn't."

My passable knowledge of popular culture helped in rapport building, something which could go a long way for other adults working with autistic kids. I know next to nothing about the Pokémon franchise, except for the fact that there is one character with essentially the same name as me—Marill, a cute blue mouse-like creature. I shared my single Pokémon fact with Adrian after he expressed his love for the series, to which he responded, "So you're not just *studying* studying. You're not just here to study autism. You're here because you're a geek." Adrian then added how it put him at ease when the clinicians with whom he regularly interacted took the time to engage him in discussions about such things: "I'll just happen to wear a Pokémon sweatshirt or like some geeky shirt [to the doctor's office]—because I seriously don't run out of those at all—and I'm so excited anytime a doctor says, 'Oh hey, that's Sandslash [another Pokémon character]. Are you into that?' I can start the conversation and they'll be like, 'Oh, we're going to put this needle in your arm,' and I'm like, 'What? Oh, sure.'"

Other kids offered metacommentary on interviewing as a methodology. During my interview with Casey, she started scribbling with pencil on a piece of scrap paper. I noticed that she had drawn a question mark and I asked her what it was. “You,” she responded. Seeing as I do not look particularly question mark-shaped, I asked her if she drew me that way because I was asking a lot of questions. Without directly answering me, she added, “I’m the exclamation mark,” drawing one on the page as well. Maybe, I thought, Casey considered herself the exclamation mark because of the focused attention that I was giving her. Playing along, I asked what her mom, Jennifer, was. Casey declared that she was a period, which she drew in between the question mark and the exclamation mark. Jennifer was in a way playing the role of a “period” during our conversation: an emotionally neutral authority figure with final say, mediating the space between myself and Casey. She had directly conveyed her interpretation of our social roles through punctuation—? . !—and the symbolic meanings she assigned to them. With more than words alone, Casey not only playfully and creatively communicated to me who she was, but also who I might be to the children I was observing.

#### PARTICIPANT OBSERVATIONS

In addition to these interviews and observations, I attended a dozen public gatherings for children on the autism spectrum and their families, as well as some targeted toward parents exclusively. These observations added context to my knowledge about the availability of local autism resources. Sites included sensory-friendly film screenings at suburban movie theaters and in-person parent support group meetings in underresourced neighborhoods. Observations lasted one to two and a half hours each.

#### ANALYSIS

All interviews and semi-naturalistic observations were audio recorded and later transcribed by research assistants and the transcription service Rev.com. In addition, field notes or “jottings” were taken by members of the research team during each encounter.<sup>19</sup> Transcripts and notes were supplemented with reflective memos written by researchers immediately following site visits, supported by written field notes. Digital photographs of relevant activities, environments, and materials were also taken, both to aid in interpreting written material and to supplement the eventual interpretations shared publicly. All typed memos, notes, and transcripts were entered

into the qualitative data analysis software program MAXQDA to create a customized searchable database of documents.

In developing grounded theory, open and selective coding and recoding of the data were employed to identify key concepts and categories.<sup>20</sup> I also applied a constant comparative method approach to analyzing the data by coding throughout the course of fieldwork and being attentive to patterns that I noticed emerging, such as parent language regarding the use of media rewards and restrictions as a behavior modification tool for autistic children.<sup>21</sup> Although I served as the sole coder, I discussed data exclusions and interpretations with participants and research assistants during fieldwork and data analysis to validate findings, a practice known as “member checking.”<sup>22</sup> I used a combination of inductive and deductive approaches to coding the data;<sup>23</sup> for example, theoretical work on autistic sociality informed coding for parents’ discussions of how their child might be described as “social,” particularly in the context of their media use. I also benefited immensely from feedback on early drafts of the manuscript by autistic scholars who encouraged me to avoid centering the neurotypical experience as necessarily preferable to or entirely separate from that of neurodivergent people, and they also urged me to reconsider sections of writing that drew on the rather unstable epistemic authority of biological autism science.

## RESEARCH LIMITATIONS

Though this book adds to understanding of autistic children’s everyday media and technology practices and of theories of social technologies, there are a number of limitations to address. The first is that I was not able to recruit a significant number of nonspeaking and minimally speaking autistic children who were also able to be interviewed. Access to communication is not a right that all young people on the autism spectrum have realized, especially those additionally marginalized on the basis of their race, ethnicity, or class. Though the recruitment material for parents of autistic children ages 9–13 explicitly stated their child did not need to “be verbal” or speak, that the interview format could be adapted, and that parents could provide communication support for their child, few parents of adolescent autistic AAC users responded. Inclusion of more of these young people may have added complexity to the themes discussed in this book. To fill in some gaps, I have woven relevant quotes into the text from nonspeaking autistic



memoirists who were adolescents at the time of their writing, such as Ido Kedar and Naoki Higashida.

Second, due to time constraints and the coronavirus pandemic, I was unable to interview non-English-speaking parents and observe their autistic children. Right before the pandemic struck, I had been planning to conduct research with primarily Spanish-speaking parents. All of the recruitment materials had been translated into Spanish with additional IRB approval, I had a Spanish-speaking research assistant join my team, and we had already recruited one parent. Unfortunately, those plans had to be canceled once much of Boston went into lockdown. Future work on autistic children's media use should incorporate the perspectives of non-English-speaking parents from the outset.

Next, one critique that some may make is that I did not separate out my findings by autism severity or use any formal quantitative autism assessments (e.g., the Autism Diagnostic Observation Schedule). This is partly related to the fact that I did not recruit families through established research databases and programs. Not being a clinician myself, I followed the lead of autistic self-advocates who have pointed out there is often much in common between autistic people with high support needs and those with low support needs.<sup>24</sup>

Lastly, though this book delves into issues surrounding friendship, including both parents' and autistic children's discussions of the topic, I had few chances to directly observe kids on the spectrum playing with their peers around and through media. This is largely due to my focus on the home environment. For example, in another version of this book, I could have recruited whole classrooms of children on the spectrum, mapped out their social networks, and studied the role of media and communication technology in mediating their online and offline relationships and interactions. This is yet another opportunity for future researchers to extend the work described in this book.

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