

1 Introduction

“For Children Who Cannot Speak, a True Voice via Technology,” the headline read. In 2012, the *New York Times* profiled one such child, nine-year-old Enrique Mendez. He was born with the developmental disability Down syndrome and speech apraxia, a motor disorder in which the brain cannot coordinate the body parts needed to produce oral speech.¹ Enrique has difficulty saying sounds, syllables, and words, but he can better ask his brother to play with wrestling figurines and greet his parents with “I love you” in the morning when using an Apple iPad along with an app named Proloquo2Go. The app converts the icons and text that Enrique selects on the tablet’s touch screen into synthetic speech output that his nearby conversation partners can hear.

Similar headlines about the iPad and Proloquo2Go, and the novel use of mobile technologies to generate voice, appear in newspapers like the *Boston Globe* and on television outlets such as CNN: “Technology Helps Autistic 12-Year-Old Find a Voice for His Bar Mitzvah” and “How Tablets Helped Unlock One Girl’s Voice.”² These contemporary reports are nearly indistinguishable from ones published decades earlier that also sang the praises of advancements in portable communication aids for individuals with communication disabilities. A 1977 *Wall Street Journal* article on a “hand-held device” known as the Phonic Mirror HandiVoice characterized it as “Offering an Electronic Voice to Vocally Impaired.”³ Two years later, a profile in the *Los Angeles Times* on a local area girl’s use of another technology, the Canon Communicator, led with the headline “Electronic Help for the Handicapped: The Voiceless Break Their Silence.”⁴

Today’s sleek mobile communication technologies are completely unrecognizable compared with their clunky predecessors from the late 1970s and early 1980s, yet the headlines have not changed much. Each article mentioned above speaks volumes about the rhetoric of revolution embraced by technophiles, paternalistic discourses of technology as an equalizer of

opportunity and access, and notions of voice as both symbolizing human speech and serving as a powerful metaphor for agency, authenticity, truth, and self-representation. All of the stories focus on objects, not people, when they frame mobile communication technologies as a medium for voice, tool for finding voice, and metaphoric key for freeing a caged voice. And none provide much insight into what does and does not get said through or about these speech-generating technologies in the long term after the journalists and users part ways.

This book is about what happens next. It centers on the social implications of communication technologies that purport to “give voice to the voiceless,” and explores the varied meanings of this phrase through the critical lens of disability. For its part, AssistiveWare, the Dutch technology company that produces Proloquo2Go, says that the app “provides a ‘voice’” to individuals with complex communication needs and also refers to the app *as* voice, with the tagline “A voice for those who cannot speak.”⁵

In a rapidly changing media ecology and political environment, the question is not only which voices get to speak, but also who is thought to have a voice to speak with in the first place. The values, desires, and ideals of dominant cultural groups are systematically privileged over others in societies, and these biases are built into the very structures of organizations, institutions, and networks. “Giving voice to the voiceless” regularly stands in for the idea that the historically disadvantaged, underrepresented, or vulnerable gain opportunities to organize, increase their visibility, and express themselves by leveraging the affordances of information, media, and communication technologies.⁶ Besides the iPad and Proloquo2Go, an endless list of technologies and platforms—including civic media, mobile Internet, Twitter, community radio, and open data—are all imbued with voice-giving qualities.⁷

These tools may selectively amplify voices within and across various publics and audiences, but their existence does not automatically call the status quo of structural inequality (i.e., racism, patriarchy, misogyny, and homophobia) into question. In particular, it is counterproductive when these same discourses about voice employ disability as a metaphor in the service of another’s cause. More often than not, media and communication studies scholars call on disability as emblematic of the human experience, such as in Marshall McLuhan’s “prosthesis” or Donna Haraway’s “cyborg.” When Nick Couldry writes that state actors can be “‘voice blind,’ that is, blind to the wider conditions needed to sustain new and effective forms of voice,” this language evokes both speech and visual impairment without

directly addressing the systemic violences that attempt to silence those with disabilities.⁸

Such instrumentalization underpins the message behind the slogan “Nothing about us without us,” which US disability activists first took up in the 1990s to describe their demands for active involvement in the planning of policies affecting their lives and their disdain for external sanctioning to speak up.⁹ One billion people, or 15 percent of the world’s population, experience some form of disability, making them one of the largest (though also most heterogeneous) groups facing discrimination worldwide.¹⁰ Efforts to better include individuals with disabilities within society through primarily technological interventions rarely take into account all the other ways in which culture, law, policy, and even technology itself can also marginalize and exclude.¹¹

These conditions overlap in ways that both enable and disable societal, cultural, and civic participation for those with disabilities, revealing contradictions in the modern human experience. Enrique and other disabled youth serve as cultural symbols onto which the able-bodied project their hopes and anxieties about health, well-being, and the future.¹² Mass media tend to depict youth with disabilities as beneficiaries of technology, while hailing well-intentioned engineers, scientists, and technologists (often white, male, and able-bodied) as their benefactors. Such portrayals distract us from seeing children, adolescents, and teenagers with disabilities as young people whose experiences with communication technology can be ordinary and even mundane. They preclude researchers from asking nuanced questions about the social and cultural contexts of their technology use and non-use. And perhaps most important, they mask how other dimensions of difference besides disability—such as class, race, ethnicity, gender, sexuality, and nationality—shape how youth with disabilities consume, create, and circulate media.

Beyond the hype and hyperbole, I argue in the following pages that technologies largely thought to universally empower the “voiceless” are still subject to disempowering structural inequalities. Over sixteen months, I engaged in qualitative fieldwork with the families of twenty young people in the greater Los Angeles area. For inclusion in the study, each child was required to be between the ages of three and thirteen at the start of research, have a developmental disability (such as autism and cerebral palsy), be either unable to produce oral speech or have significant difficulty doing so, and use the iPad and Proloquo2Go as their primary mode of communication (for a more in-depth discussion, see the chapter on methods).¹³ Parents came to obtain their child’s iPad and Proloquo2Go through a variety of

strategies, including direct purchase, charitable donation, temporary loan, and school provision.

Holding these participant parameters and communication system as constants, I observed children and their parents receiving at-home training on how to use the technology from two speech-language pathologists named Rachel and Caren, both of whom were under contract with a local disability resource center in Central Los Angeles.¹⁴ I conducted in-depth interviews with some of these parents and others throughout Southern California (in Los Angeles, Orange, and Ventura counties). I interviewed assistive technology specialists in local school districts who frequently interact with children who use the iPad and Proloquo2Go, interface with their families, and come into contact with other actors who directly and indirectly influence reception of the technology, including insurance company representatives and support staff in the assistive technology industry.

Throughout this fieldwork, my research questions centered on how parents managed their child's use of the iPad and Proloquo2Go as well as other communication technologies, and how they incorporated media into their family's daily life at home, on the go, and in the community. All of the parents I spoke with, regardless of their circumstances, stressed that they wanted the best for their child. Many believed wholeheartedly that mobile media could be powerful tools for their children to more effectively communicate their needs, preferences, and desires, and assert more control over their sometimes-chaotic lives. Each one was actively trying to maintain dignity in a world all too quick to strip them of it.

Against this shared background and these efforts for digital equity, clear distinctions emerged as these families adapted around a new set of routines. To borrow the phrasing of media scholars Leah Lievrouw and Sonia Livingstone, the social meanings that parents derived from these technologies along with the social consequences of them differed subtly and not so subtly across class, with additional considerations for gender, race, and ethnicity.¹⁵ Working-class and low-income parents talked about the iPad, Proloquo2Go, and other communication technologies in ways that were often out of sync with how middle- and upper-class school district staff, therapy providers, and the mass media characterized them. Whether intentionally or inadvertently, educational, medical, and media institutions preserved as well as reinforced the more privileged status of middle- and upper-class parents within this ecosystem, which directly and indirectly impacted less privileged lower-class families and the capacity to support their child.

Drawing on sociologist Pierre Bourdieu's theorization of capital and its application to research on education, parenting, and technology, I detail over the course of this book how parents' ability to mobilize social, economic, and cultural capital shaped the extent to which their children could not only speak but also be heard.¹⁶ In short, physically handing someone a tablet that talks does not in and of itself give that person "a true voice." Nor, contrary to a legion of pop psychologists, are handheld mobile devices single-handedly disabling people's empathy and capacity for face-to-face communication.¹⁷ Rather, voice is an overused and imprecise metaphor—one that abstracts, obscures, and oversimplifies the human experience of disability. Empirically investigating the use of mobile devices as synthetic speech aids provides a novel way of understanding voice and communication technologies. At its heart, this book supports the rights of all individuals in society to determine their own conceptual sense of voice, and to use those voices to feel known in the world.

Broken Records

Detailed below, Karun's experiences at opposite ends of the socioeconomic spectrum as a mother and immigrant to the United States offers a powerful entry point for understanding the complex role of privilege, social class, and capital in how US parents, including those of children with disabilities, support their children's communication skills and use of media and communication technologies.

"Back home, I used to play piano with him. Now I don't have piano," Karun said with a heavy heart. In the time and space between "back home" and "now," a civil war that broke out in Syria in spring 2011 had escalated, endangering her and her husband, Mihran, and their two sons, Pargev (age thirteen) and Joseph (age nine). At the time of writing this book, there are over four million Syrians refugees displaced globally due to the humanitarian crisis.¹⁸ Since I interviewed Karun in fall 2013, more than half of all US governors have announced that they oppose settling Syrian refugees in their states, stoking the fires of xenophobia and Islamophobia following the revelation that one of the suspects in the Paris terrorist attacks of November 2015 was granted entry to Europe among a wave of refugees by using documents falsely identifying him as Syrian.

Karun described a life of relative privilege in Syria prior to the war. Both she and Mihran attended private schools where they learned English. Mihran had studied abroad in England and became a radiologist in Syria. "I had *plenty* of time over there," Karun remarked, describing life in her home

country. "My housework was done by a nanny. I could afford there, a nanny. She used to help in cooking and cleaning the house." Karun also provided her children with various enrichment activities such as horseback riding, swimming lessons, and the aforementioned piano lessons.

"The war came very fast," Karun explained. She and her family sought asylum in California, where her relatives had settled years earlier, along with a large diasporic Armenian community. From 1980 to 2013, the Armenian population in Los Angeles County tripled to 170,000.¹⁹ When I met Karun, both she and her husband were unemployed, and the family was living on temporary refugee support from the US government. Not only did Karun not have her piano, but "right now, I don't have time," she said. "That's the bad thing here in the United States. Life is stressful. ... It's just run, run, run, run." The abandoned piano was a metaphor for the loss of a privileged life in Syria and adoption of a new, lower-class and marginalized identity in the United States.

The piano, however, also symbolized another kind of longing. When Karun remarked, "I used to play piano with him," she referred specifically to Pargev, who is autistic and has significant difficulty speaking. Karun thought that practicing the piano would be a more worthwhile leisure activity than how Pargev currently spent his free time at home. "Instead of playing with water or stimulatory behaviors, I want him to do something functional," Karun said. During each of the three 1.5-hour visits that I made to the family's Los Angeles apartment, Pargev engaged in self-stimulatory behavior, also known more colloquially as stimming. Many autistic people report that the repetition of physical movements or movement of objects helps them maintain emotional balance, regulates their senses, and provides pleasure.²⁰ Everyone stims to some degree, perhaps fiddling with a bookmark as you read this book. Suspending my own judgment of Pargev's behavior, he seemed calm and content to pour food and beverages, like chips and soda, back and forth into plastic bowls and cups of uniform sizes, taking periodic bites and sips.

Besides the piano, many of the other resources that Karun accrued had to be left behind in Syria. She explained how a few years earlier, "I was saving some money either to buy an iPad, because they are like \$1,000, or remodel my rooftop to make it a play area for Pargev." While she had heard that autistic children were benefiting from the iPad, she chose the play area as a longer-term investment. During the war, though, the rooftop became unsafe. She recalled, "All the time there's airplanes, the military airplanes. And plus lots of people were killed by just a bullet, just a running bullet, going through accidentally." Karun ultimately regretted her decision,

saying, "I didn't know it was going to be ruined, and we're going to leave and come here. I wish I'd bought from those days, the iPad."

After immigrating to California, Karun managed to acquire the device through a charitable donation. She was "really hoping to find something useful for [Pargev] on the iPad." In lieu of a physical piano, she downloaded "this little piano game" onto the device. Pargev, however, was not interested. "I wish he loves games," Karun remarked wistfully. Unlike the dominant cultural figure of the mother who sees no value in video gaming, Karun characterized the activity (as well as piano playing) as "something functional"—a category to which stimulating, according to her, did not belong. Along with the iPad, the charity provided Karun with a gift card to purchase the Proloquo2Go app. "Right now, he can say three-word sentences like, 'Give me please.' 'Move please,' 'I want juice.' Only three words, not more than three words," Karun said. She hoped that Proloquo2Go would expand Pargev's communication.

Karun wanted a better life for her son, but felt that she was getting little school support. Even though Karun had the donated iPad and Proloquo2Go, Pargev's school supplied its own copy of the hardware and software for him to use in the classroom with teacher and therapist supervision. While the school allowed Pargev to take its iPad back and forth between home and school, Karun had received little hands-on training on how best to use the technology to communicate with Pargev at home. "For this Proloquo, honestly, he needs [a] professional with me. I can do it, I can help him to use it constantly," she maintained, but the sporadic at-home training sessions she received from Rachel through California's Department of Developmental Services were "not enough." Insufficient family support from therapists and school staff as well as the lack of trained personnel are well-documented challenges for youth with disabilities and their families.²¹

"This is something that disappointed me in [the] United States," Karun commented. "They told me, 'Once you go to [the United States], you're going to be relieved and they take care of your child,' but it wasn't like that." In Syria, Karun had homeschooled Pargev. "Over there," she explained, "I'm in control. I can see what's going on." In the United States, she had less power over his learning, and felt that Pargev was regressing as a result. Karun noted that "Pargev knew the alphabet when he was four and a half. I used to contact with the teacher [in California] and tell her, 'Please teach him to write.' 'It's early,' she told me. 'It's early. It's early.' Always you get these answers." Karun had left her piano behind in Syria and tried her best to re-create it through a piano app on the iPad in the

United States; instead, she and Pargev wound up listening to a broken record of false hopes.

Cultural Capital

In her essay “Practicing at Home: Computers, Pianos, and Cultural Capital,” Ellen Seiter draws an extended analogy between pianos and computers.²² The piece relates to Karun’s story not only because it involves those same technologies but also because it offers a relevant theoretical framework through which to understand the role of social class in family media use. Seiter explains that baby grand pianos and personal computers have each historically served as an “instrument of modern education” in upper- and middle-class US homes.²³ Privileged children tend to gain more experience with these learning machines, and earlier in life, than do working-class children. They learn specific “codes” at home that less well-off children do not, be it computer keyboarding or playing the piano keys.²⁴ Educational institutions systematically reward students who can demonstrate the kinds of technological proclivities and literacies that upper- and middle-class children are more likely to have acquired outside school.²⁵ The higher status that schools associate with these seemingly “natural” competencies leads to the reproduction of social inequality, or what Seiter terms the “home technology divide.”²⁶

This gap persists not only due to household-level economic disparities but also parents’ unequal access to capital, including the social and cultural resources that they gain through their own education, careers, neighborhoods, friends, and extended family.²⁷ Bourdieu theorized that three main forms of capital—economic, social, and cultural—structure our world.²⁸ Economic capital is the way in which many of us initially think about capital: as monetary value. Social capital is the value of our human relationships and networks. Cultural capital encompasses modes and patterns of consumption and expression. Under certain conditions, social and cultural capital can be derived from economic capital through systems of value exchange. Context matters, though, as evidenced in Karun’s case, for capital is also sometimes irreparably lost in conversion and translation.

Having capital makes certain opportunities in life more possible, or what we might refer to as privilege. Conceptually, privilege describes advantages only available to certain individuals and groups. One need not have earned the power that flows from privilege, or even be aware of it, in order to accumulate privilege over time and benefit from it.²⁹ Social class plays an important role in understanding privilege. Class both structures privilege and is a

process through which privilege is produced as well as maintained. The structural view of class privilege defines social class through labels and hierarchical levels (e.g., working class, upper-middle class, or underclass), whereas the processual view defines it as an identity constantly shaped and reshaped by individual interpretations and shared experiences.³⁰ The descriptive categories under which privilege and inequality operate are themselves fluid and in perpetual motion. Distinctions between individuals and groups are both subjective and objective, with distinction being the capital that certain differences generate.

Bourdieu's conceptualization of cultural capital includes three forms as well: embodied, objectified, and institutionalized. Embodied cultural capital concerns learned ways of using one's mind and body, like the dialect or accent a person uses to speak. Objectified cultural capital involves the display of items and goods denoting status, such as a large collection of technological gadgets and obtaining the latest upgrades. Lastly, institutionalized cultural capital has to do with markers of official recognition and legitimation. This includes holding an advanced degree or set of credentials, and the use of any specialized terminology that only a degree holder might use. Bourdieu applied the theory of cultural capital to a range of "fields," or domains of life such as religion and law, but primarily focused on schools, arguing that institution plays the most significant role in reinforcing class relations.

Bourdieu's theorization of cultural capital is grounded in French schooling, status hierarchies, and signals of "high culture." It does not neatly map onto other cultural contexts and systems of legitimation.³¹ Returning to Karun, she was a more privileged parent than most in Syria, intensely involved in her child's education. In the United States, both Karun and her husband were unemployed, and she was only as involved in Pargev and Joseph's learning as she could be considering her constraints. Schooling in the United States is deeply tied to middle-class cultural values such as independence and individual potential, and is designed to prepare children to participate in middle-class life.³² In turn, educational reformers since the mid-twentieth century have blamed seemingly "uninvolved" working-class parents for declining schools. Cultural capital is widely used in the United States as grounds for social exclusion.³³

Annette Lareau reoriented Bourdieu's class culture perspective to the US public education system, demonstrating how the class-based ideology at its foundation impacts working- and middle-class families differently.³⁴ Lareau draws a direct connection between class background and parental involvement in schooling.³⁵ She finds that social class shapes the cultural resources

that parents have at their disposal to mobilize and influence their child's formal education. Beyond income, these resources include a network of college-educated individuals and professional work relationships. Child care centers, for example, introduce parents (and particularly mothers) to networks of opportunity. These benefits pay unexpected dividends in promoting child well-being for families across the socioeconomic spectrum.³⁶ Middle-class families have an easier time reliably activating these cultural resources, though, which enables them to build stronger connections between family and school. Challenging the misperception of uninvolved parents as unloving, Lareau finds that both working- and middle-class parents want their children to be successful.

Later research by Lareau has focused on variations in parenting styles.³⁷ She uncovered differing cultural ideas about child-rearing between working- and middle-class US families. These orientations are forms of what Bourdieu refers to as "habitus," or naturalized and internalized systems for structuring life. Middle-class families tend to follow a logic of "concerted cultivation," in that they value extracurricular activities and at-home learning experiences that nurture children's talents and interests. In addition to spending more energy meeting their children's basic needs, working-class families often orient their child-rearing practices around opportunities for "natural growth" such as unstructured play and time with neighbors. Public schools intentionally privilege middle-class approaches to parenting, and give middle-class children a "home advantage" at school. Lareau makes visible structural inequality in US public schools, and the complex dynamic between home and school life.

This work, however, centers primarily on mainstream classrooms. Socio-cultural factors influence power imbalances between parents of students with disabilities and school personnel.³⁸ Audrey Trainor writes that "because participation in special education requires specialized types of cultural and social capital and occurs in a field with unique rules of engagement (i.e., habitus) meaningful participation is challenging to establish."³⁹ The US Department of Education reports that as of 2013, 13 percent of children ages three to twenty-one in primary and secondary US public schools (approximately 6.4 million) were receiving special education programs; of these children, 21 percent had speech or language impairments.⁴⁰ Upper- and middle-class parents have an easier time speaking the very complex language of special education, which includes knowing the latest therapies and how to prepare for important Individualized Education Program (IEP) meetings with their child's teachers, therapists, and school administrators.

In the years following Lareau's research, Internet penetration into children's homes has increased via broadband and wireless connections, and home has become the primary site of disabled and nondisabled children's increasing time spent with new media.⁴¹ The iPads that children use as communication aids, and also as learning tools and fun toys, are but one technology among a constellation of other media that children and families use together. Parents borrow, purchase, and lease technology (e.g., books, computers, and Internet access) as a type of capital "investment" in their child's learning and down payment on future educational benefit.⁴² These decisions are influenced by parents' cultural values, personal goals, and perceptions of their child's maturity in handling the responsibility of technology.⁴³ Social class alone cannot fully explain patterns of family life, but it can serve as a lens through which we understand the resources, strategies, and ideologies that give shape to family media practices, meanings parents and children associate with personal communication technologies, and ideas about the proper role of new media in society.⁴⁴

Bourdieu wrote about "technical capital" as a subset of cultural capital (referring to manual workers' skilled use of machinery), but he did not discuss the networked and distributed skills needed to use information and communication technologies to one's advantage for improved opportunities in contemporary society.⁴⁵ Concurrently, technology can be thought of as a "strategic research site" for studying society and the organization of social practice.⁴⁶ It is not only technology but also the *culture of* technology that can reproduce social inequality.⁴⁷ In order to study how parents navigate their disabled children's iPad use, the technology must be understood within the system of social relations that shape and reshape its intended uses and cultural meanings.

Throughout this book, I empirically trace capital through technical and social domains, and make a theoretical contribution by linking understandings of capital and distinction across disparate work in education, disability, and technology. I concentrate in particular on the role of embodied, objectified, and institutionalized cultural capital in shaping how parents navigate their disabled children's use of mobile media and technology at home as well as the symbolic and material ways in which this use is tied to school and other institutions, such as health insurance companies and technology multinationals. In order to account for students with disabilities like Pargsev in the US education system and society writ large, the "home technology divide" must also be inclusive of assistive technologies and assistive uses of off-the-shelf computers, as described below.

Reconsidering Assistive Technology

Not only do iPads subsume both pianos and computers; they are also technologies known as augmentative and alternative communication (or AAC) devices. Many nonspeaking or minimally speaking individuals such as Pargev use AAC devices to *augment* other forms of communication they might already use (e.g., nonverbal gestures and sounds such as laughter) and serve as an *alternative* to oral speech. AAC covers a diverse range of manual practices (e.g., American Sign Language) and variety of materials. AAC tools range from low-tech (e.g., plastic communication boards) to mid-tech (e.g., electronics with disposable batteries) to high-tech versions that allow individuals to convert text into synthetic speech (e.g., the computer used by physicist Stephen Hawking). Just as all of us triangulate our modes of interpersonal communication beyond oral speech—for instance, waving to friend or sending them a text with the “waving hand sign” emoji besides speaking the word “hello”—high-tech AAC is often used in combination with the other forms of AAC.⁴⁸

It is difficult to get exact statistics on how many people communicate primarily through iPads and AAC apps. To provide a sense of scale, in one large school district in the Los Angeles area (with a K–12 enrollment of over 650,000), the district’s lead AAC coordinator relayed that there were “at least 150” students using “iPads with apps” for AAC. The American Speech-Language-Hearing Association estimates that at least 2 million people in the United States have an impairment—whether from birth, or acquired later in life through an injury, illness, or progressive condition—that limits their ability to talk in the traditional sense.⁴⁹ From 2004 to 2014, the total number of children receiving public benefits for speech and language impairment increased 171 percent (from 78,827 to 213,688 children).⁵⁰

AAC devices are traditionally categorized in the health and rehabilitation fields as a type of “assistive technology.” The US Assistive Technology Act defines assistive technology as “any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.”⁵¹ This definition encompasses an array of tools, from complex systems for accessing a personal computer through eye gaze input, to simple devices such as a magnifying glass for reading fine print. The US Individuals with Disabilities Education Act requires school districts to provide assistive technology to students with disabilities when it supports their acquisition of a free and appropriate public education, which is how Pargev ended up with a second, school-owned iPad with Proloquo2Go.⁵²

In practice, though, the definition of assistive technology is vague. The International Classification of Functioning, Disability, and Health states “that any product or technology can be assistive.”⁵³ This begs the question as to whether or not assistive technologies are exclusively for individuals with disabilities. Cultural theorists have understood artificial objects that mediate human subjectivity as “prosthetics,” “technologies of the self,” or things that enable the emergence of the human-machine “cyborg.”⁵⁴ With little exception, these theorists rarely interrogate the lived experiences of disability as grounds for theory building.⁵⁵ Instead, Katherine Ott challenges scholars of technology and society to “[keep] prosthesis attached to people,” and not ignore both the pains and pleasures that technology begets for those with disabilities.⁵⁶ Wheelchairs can provide comfort and ease of mobility, for instance, but prolonged sitting in one causes pressure sores.

The categorization of particular communication technologies as assistive and others as not is an inherently political choice.⁵⁷ While Apple’s voice-activated interactive assistant Siri might be an assistive technology when used by people with disabilities, she is otherwise considered a more or less helpful personal assistant when utilized by able-bodied individuals.⁵⁸ This relationship between *assistive* and *assistance* automatically varies for each of us over our life span due to human growth and bodily degeneration. We fluctuate between degrees of independence from and dependence on other technologies (such as canes) and services (such as personal home care aides or our relatives). In fact, some cultural anthropologists argue that all human communication is in some way aided by assistive technology in the form of conversation partners and socially learned techniques that none of us are born knowing.⁵⁹

Distinctions between mainstream and assistive technologies have material as well as symbolic consequences for people with disabilities. While their needs influenced the design of mass-market consumer goods and electronics in the late twentieth century through the philosophy of “universal design,” individuals with disabilities tend to remain outside industrial designers’ and engineers’ imagined user base and the public-facing image of these products’ promotion.⁶⁰ Assistive technologies have also historically been difficult for consumers to obtain and learn about because such knowledge tends to belong to specialized professional groups.⁶¹ They are culturally associated with dependency and victimhood (i.e., the phrase “confined to a wheelchair”), which can negatively impact the way in which people with disabilities see themselves as technology users and how others perceive them.⁶²

The immediate environment in which technology use is embedded, cultural factors impacting technology adoption, and dynamic qualities of both the technology and user all contribute to the social shaping of assistive technology.⁶³ With their exponential rise in ubiquity over the past two decades, mobile communication devices, as the next section details, are a significant site where the meanings of “mainstream” and “medical” technologies are being renegotiated.

Convergence of Mobile Media and AAC Devices

As a communication scholar, I was initially drawn to AAC devices because they are, by definition, mobile communication technologies (although they are not networked unless connected with Wi-Fi or cellular data). Clear plastic communication boards (also known as eye transfer boards or “e-tran”) with the letters of the alphabet visible from both sides of the board are portable tools for creating shared meanings between a nonspeaking individual who spells words through eye gaze and their conversation partner who holds the board.⁶⁴ High-tech AAC devices in particular, though, provide a unique lens for reflecting on the emerging complexities of mobile communication technologies as well as their political economy.

In reference to the exciting potential around iPads as AAC devices, Mark, the father of River (age seven), observed, “I can’t remember the guy’s name, but one of the very first TED conferences, he introduced the touch screen and it just seemed like it would be used for more than just cash registers.” The first-generation iPad debuted on April 3, 2010, a few months before I began my PhD program. In the days following the iPad’s release, parent-uploaded YouTube videos of toddlers navigating the tablet’s touch screen interface started to emerge online. This combination of nascent technology and nascent humans was a potent, user-generated marketing vehicle for the iPad. Noted one journalist of the newborn and new technology trend, “The litmus test for ‘user friendly’ until recently was ‘Can my mom use it?’ Increasingly it might become ‘Can my toddler use it?’”⁶⁵ Like emerging media from the telephone to the television set before it, the iPad was linked from its inception to notions of conception and innovation.⁶⁶

Mobile media are an increasingly integral part of many families’ everyday lives in developed nations. The growth in the 1960s of domestic mobile communication technologies, such as portable telephones and televisions, reflected a transformation from what Raymond Williams once termed “mobile privatization” to what Lynn Spigel calls “privatized mobility.”⁶⁷ While postwar telecommunications promised US suburban homes

connections to the outside world, portable devices marketed to families decades later allowed home to follow them wherever they went. Today's mobile technologies, including iPads, both shape communication patterns and are integrated into existing ones for older media—a process referred to as “domestication.”⁶⁸ There is no shortage of present-day ambivalence about mobile connectivity and family life, perhaps best illustrated by the 2011 book *Goodnight iPad* (a parody of the children's literature classic *Goodnight Moon*), which encourages children and their parents to power down as the sun sets.

Tablet devices running Apple, Android, or Windows operating systems can now be equipped with apps that mimic the software on “dedicated” AAC devices—dedicated in that their primary purpose is to aid oral speech. From a clinical standpoint, there are pros and cons to both dedicated and nondedicated AAC devices. Dedicated ones offer richer and more complex language software, but tablets are much lighter in weight. Many tablets have built-in cameras; one AAC specialist I spoke with called this feature a “game changer” because it allows users to customize the images that accompany vocabulary words within an AAC app (e.g., pairing a classmate's face with their name in the visual system), as opposed to taking a photo with a separate digital camera and uploading it to the dedicated AAC device via memory card or USB cord. Assistive technology companies such as Dynavox and Prentke Romich that produce dedicated devices have robust customer service divisions, but repairs to broken devices can take months; a busted iPad can be replaced with a quick trip to the nearest Apple Store.⁶⁹

While dedicated AAC devices have traditionally cost thousands of dollars, less expensive and commercially available tablets have unsettled the AAC market.⁷⁰ At a price tag of \$250 in 2016, however, Proloquo2Go is still one of the most expensive apps in the App Store—almost as costly as the least expensive new iPad, a 16GB Mini 2 going for \$269. AssistiveWare does not offer a free trial version of the app. So while the combination of the iPad and Proloquo2Go is less expensive than a dedicated device, even the app itself is cost prohibitive for many families, especially considering that the general out-of-pocket costs incurred by a family raising a child with a disability are already quite substantial.⁷¹

AssistiveWare was founded in Amsterdam in 2000, and has been intimately linked with Apple from its inception. The company exclusively develops products for Apple's mobile and desktop operating systems. It initially released Proloquo2Go in April 2009, prior to the debut of the iPad, at first for the iPhone and iPod Touch. In 2009, Apple named Proloquo2Go one of the top thirty apps of the year in its iTunes Rewind.⁷² AssistiveWare

made Proloquo2Go 1.3 available for the iPad in April 2010, shortly after the hardware's release, as a free upgrade for users of the app on iPhone and iPod Touch.⁷³ In May 2015, the app became integrated with the wearable Apple Watch for use across multiple mobile devices.

Youth with communication disabilities and their families represent a growing market for apps and tablet-based AAC devices in general, and iPads in particular. A 2014 market survey found that the Apple iPad was the number one brand among US children ages six to twelve, topping all other consumer products.⁷⁴ Just between 2011 and 2013, tablet computer ownership among families with children ages eight and under increased dramatically from 8 to 40 percent.⁷⁵ While overall ownership of tablets is on the rise among families, there are substantial divides by income. Among families with a combined household income of \$100,000 a year or more, two-thirds (65 percent) own a tablet computer, while among families earning less than \$25,000 a year, ownership is only at 19 percent.⁷⁶

Apple has a storied relationship with parents of disabled youth. In the early 1980s, Apple was one of the first computer companies to have an internal group dedicated to accessibility. In 1986, it partnered with the Disabled Children's Computer Group, a Bay Area organization comprised of well-resourced, tech-savvy parents of youth with disabilities advocating for their children's needs as computer users.⁷⁷ Apple, however, also had paternalistic motives in forging this alliance. The company did not target individuals with disabilities as a wider market but instead as beneficiaries of the company's charity and goodwill.

Apple has taken a similar approach to its association with Proloquo2Go and parents of children who use the app. A 2013 Apple marketing campaign featuring a Proloquo2Go user—Enrique Mendez, mentioned at the start of this chapter—and testimonials from his family claims that the company is "Making a Difference. One App at a Time"—that difference being an undoubtedly positive and constructive one.⁷⁸ Through the partnership, AssistiveWare receives major publicity and Apple gets to portray its brand in a flattering light. While Apple bills itself as representative of creativity, communication, and freedom, the company also heavily constrains what users can do to alter their hardware and software.⁷⁹

The short film also conveniently omits three important details, explained below: the time and labor-intensive process by which parents of children with communication disabilities attempt to obtain iPads as AAC devices, market-driven political economy of schools' selection of educational technology, and complexity of Proloquo2Go as a communication technology.⁸⁰

Traditionally, a child in the United States receives an AAC device (be it an iPad with Proloquo2Go or a different system) only after licensed specialists conduct clinical assessments, manage periods in which the device or multiple different devices are used on a trial basis, and write recommendations to schools (if the AAC system is deemed educationally necessary) and insurance agencies (if medically necessary) to ultimately fund an AAC device. In the United States, families usually play a significant role in this selection process, but there are significant barriers to participation.⁸¹ These include culturally and linguistically inaccessible forms of parent training, biases in funding processes, and technical difficulties in learning to operate the hardware and software.⁸²

Seeking financial support for obtaining a speech-generating device can also be an overwhelming, frustrating, and challenging process. The cost of AAC devices generally exceeds a user's ability to pay for it on their own. Each public and private funding agency sets its own terms for eligibility, requires particular formats and wording in their documentation (e.g., a letter of medical necessity written by a therapist or state-specific certificate of medical necessity), and demands multiple steps in application processes, all of which inevitably leads to missteps and request denials.

US government provisions for therapeutic services and assistive technologies also differ greatly based on personal characteristics such as age (e.g., birth to three) and disability status (e.g., multiple disabilities) as well as by state and school district. Unlike adults, who do not have blanket entitlement to speech-language supports, school-age children in the United States are able at least in theory to claim educational necessity for their AAC devices under the Individuals with Disabilities Education Act when their communication limitations are so significant that they impact children's access to, participation in, and potential to demonstrate progress in the general curriculum, extracurricular activities, and other nonacademic activities.⁸³

Yet insurers have been resistant to fund tablet-based AAC devices. While Medicare considers speech-generating devices to be "durable medical equipment," this does not extend to personal computers used as AAC devices, only the speech-generating software that individuals download onto their computers.⁸⁴ Government and private insurers fear the fragility of the iPad when used for constant communication, liability risks, and potential for fraud and resale.⁸⁵ Medicare's stated explanation is that tablets "are useful in the absence of an illness or injury"—as are popular wearable health technologies such as fitness trackers produced by Fitbit—and thus cannot be classified as durable medical equipment.⁸⁶

Medicare coverage also stipulates that the technology must be “limited to use by a patient with a severe speech impairment.”⁸⁷ This reflects a cultural value of individualism that may not mirror the ways in which new forms of AAC devices are being used collectively in families. In a 2015 survey, 71 percent of families that own a mobile media device with an AAC app installed report that other family members had access to or used the device besides the person using AAC to communicate.⁸⁸ Along with apps for AAC, tablet-based devices provide a wide range of other apps for social media, communication, and entertainment.⁸⁹ A 2012 survey conducted by AssistiveWare indicated that 90 percent of people using iPads and iPods for AAC used the device for purposes besides speech output as well, such as Twitter, Facebook, and YouTube.⁹⁰

In the state of California, possible funding sources for a school-age child’s AAC device includes California Children Services, MediCal, private health insurance, general public school budgets for funding assistive technology, and philanthropic organizations. Children with a low-incidence disability (e.g., cerebral palsy) in California can have their iPads with Proloquo2Go funded by the school district through a special assistive technology fund, while children with a more frequently occurring disability (e.g., autism) tend to have their devices paid for by the child’s school. Though sales figures for Proloquo2Go are not publicly available, its impressive iTunes ranking (number forty on the list of top-grossing iPhone apps in the education category as of June 2016) is explained in part by bulk education sales. School districts get a sizable 50 percent discount on Proloquo2Go by purchasing twenty or more licenses of the app through Apple’s Volume Purchase Program for educational institutions.⁹¹ Districts nationally are uneven, though, in offering iPads for AAC as well as training speech-language pathologists, teachers, and staff on how to use them.⁹²

It is important to note that Proloquo2Go requires technical expertise, digital literacies, domain knowledge, and comprehension skills to understand and use. This explains the need for speech-language pathologists with additional education in assistive technology like Rachel and Caren to provide one-on-one at-home training to parents in how to support their children’s use of the app. While explaining the app’s full functionality, interface, and design is far beyond the scope of the book, figure 1.1 illustrates the main screen, or Grid View, of Proloquo2Go. It is one of three interface options for speaking with the app, including Recents View (which provides a shortcut to a set of messages recently spoken) and Typing View (which displays a text pad for speaking through words manually typed by the user). In Grid View, a home page contains a mix of buttons and folders.

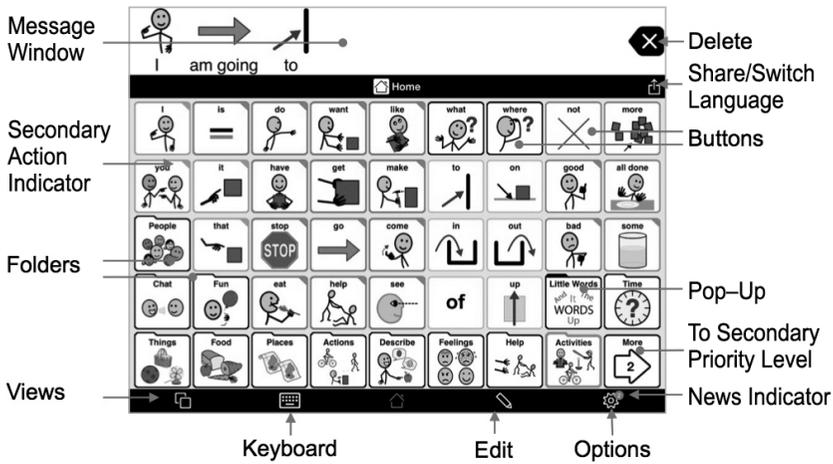


Figure 1.1

Proloquo2Go's Grid View, with explanatory labels as indicated in the Proloquo2Go user's manual. Image copyright AssistiveWare B.V. Used with permission.

Folders contain buttons grouped by categories, such as “Feelings” and “Places.” The Message Window serves as a sort of drafting board for users to string words and phrases together with buttons. Once the user is done drafting their phrase or sentence, they can press the white space of the Message Window for the message to be spoken through synthetic speech output.

At the beginning of my fieldwork, I was perpetually confused by Rachel and Caren's use of the phrase “programming the device” in reference to Proloquo2Go and the iPad. I wrongly assumed that it had something to do with coding in a computer programming language. “Programming the device” did involve computers and language, though; the term referred to the continual process of maintaining and making changes to which pre-loaded vocabulary was included in the AAC system (including adding, deleting, and modifying existing vocabulary words) as well as determining how best the vocabulary should be visually organized so that the AAC user could easily navigate the system independently.⁹³ Although Proloquo2Go comes with three preset vocabulary configurations (“Basic Communication,” “Intermediate Core,” and “Advanced Core”), these setups are endlessly customizable. One person's set and arrangement of vocabulary rarely exactly matches that of another user. The potential for disorganization and duplicate vocabulary entries in the system increases with more individuals going into the app and making programming

changes, including parents, therapists, and teachers that regularly communicate with the child.

The technological, economic, and cultural convergence of mobile media with other media forms, such as AAC devices and apps, creates opportunities for some families and exacerbates challenges for others.⁹⁴ When privileged parents buy iPads and Proloquo2Go with their own money, they circumvent public funding and school purchasing schemes. Considering the opportunities afforded by innovations in mobile communication and yet significant structural limitations, this book traces the extent to which the iPad and Proloquo2Go are actually “making a difference” in families’ lives, for better and worse, and what this difference looks like across the socioeconomic spectrum. Parents and children may learn to navigate Proloquo2Go’s Grid View with a helpful booklet, but there is no user manual for traversing the complex political and cultural conditions of raising young people with disabilities, or growing up with a disability, as the next section details.

Parenting Digital Youth with Disabilities

The contemporary role of media and technology in the lives of children with communication disabilities and their families must be understood within the context of particular US policies as well as historical conditions surrounding disability and parenting. Prior to the 1970s, US law actively suppressed disability in public spaces through the enforcement of “ugly laws” that barred “unsightly beggars” from city streets, eugenics laws that led to the institutionalization and forced sterilization of disabled adults and children, and laws prohibiting children with disabilities from entering public schools.⁹⁵ Psychologists thought parents caused their child’s disability, and promoted the removal of children from their families as cures.⁹⁶ By 2010, though, only 4 percent of those living in residential settings were age twenty-one and younger, compared with 36 percent in 1977—a shift accelerated by the passage of the Olmstead Act of 1999, which stated that the unjustified segregation of people with disabilities violated the Americans with Disabilities Act of 1990.⁹⁷

Discussions about parenting a child with a disability are also inexorably gendered.⁹⁸ Over the past decade, feminist disability studies scholarship has invited reexamination of the meaning of motherhood over history, and the ways in which media narratives reflect and shape the lives of families of children with disabilities.⁹⁹ One infamous example is the “refrigerator

mother theory," the largely discredited yet persistent Freudian-inspired concept developed by child psychiatrist Leo Kanner and popularized by psychoanalyst Bruno Bettelheim.¹⁰⁰ The theory alleges that "cold" mothering and women's career aspirations outside the home lead to childhood autism, and posits a causal link between the influx of domestic technologies (such as refrigerators) in the postwar US home and a perceived societal devaluing of mother-child relationships.¹⁰¹

While Kanner and Bettelheim's claims are widely considered suspect, mothers in the twenty-first century are still blamed in other ways for their child's disability.¹⁰² For instance, mothers of autistic children are admonished for having vaccinated their child, not being vigilant enough in noticing early signs of their child's autism, and insufficiently seeking out and administering the latest therapies and treatments.¹⁰³ The United States is in the midst of a cultural shift away from the refrigerator mother archetype toward an "intensive mothering" paradigm.¹⁰⁴ Amy Sousa writes that "warrior-hero mothers are now responsible for curing the disability, or at least accessing the intervention that will mitigate the disability's impact on their children."¹⁰⁵

Both the refrigerator mother and warrior-hero mother scenarios, however, define disability as something to be eradicated, and view children with disabilities as burdens to their parents. One alternative to the language of tragedy can be seen through resiliency theory in the field of social work. Resiliency theory puts forward the idea that families of children with disabilities generally develop accommodations, or "proactive efforts of a family to adapt, exploit, counterbalance, and react to the many competing and sometimes contradictory forces in their lives."¹⁰⁶ This might include preparing separate meals for the child with a disability, or making sure the doors of the home are always locked if the child has a tendency to wander.

Another type of accommodation that families of children with disabilities make is altering their media and technology use.¹⁰⁷ Some accommodate for behavioral difficulties on car rides by providing backseat DVD players. Others make changes in their home television viewing habits, including having separate screens for different family members, watching child-oriented programming together, or not watching television at all.¹⁰⁸ Due to sensory, hormonal, and neurological issues, some children have difficulty sleeping; children who cannot fall back to sleep may turn to media for comfort. For many of these families, and those with disabilities themselves, disability can be a source of pride as well as a positive aspect of individual and collective identity.¹⁰⁹

Digital Media and Disability

The approach to parenting, media, and technology in this book bears the influence of critical disability studies as well as work from media, communication, and science and technology studies that incorporate disability perspectives.¹¹⁰ Disability studies scholarship in the United States is rooted in civil rights activism of the late twentieth century, following in the tradition of critical race, gender, and sexuality studies while building on this work as well.¹¹¹ Much disability studies scholarship pushes back against the “medical model” of disability, which is grounded in the assumption that disability is an individual biological burden or deficit.¹¹² In response to the medical model, some disability activists and scholars emphasize a “social model” of disability. This model holds society accountable for shaping the lived experience of disability and its potential to enhance or detract from an individual’s life as well as our collective culture.¹¹³ The social model generally makes distinctions between impairment (bodily difference) and disability (the social and built environment that disables different bodies).

A number of scholars drawing on feminist and poststructuralist theory critique the social model, though, for drawing clear differences between impairment and disability, akin to a false sex/gender binary.¹¹⁴ Rosemarie Garland-Thomson notes that all bodies, depending on the environment, situation, and interaction, have “varying degrees of disability or able-bodiedness, or extra-ordinariness.”¹¹⁵ Alison Kafer further complicates this view with work from the environmental justice movement, writing that “disability is more fundamental, more inevitable, for some than others: the work that one does and the places one lives have a huge impact on whether one becomes disabled sooner or later, as do one’s race and class position.” Drawing on queer and feminist theory, Kafer instead offers a “political/relational model of disability,” in which disability is a set of political practices and social associations—“a site of questions rather than firm definitions.”¹¹⁶ Feminist disability theory stresses that disability is experienced in and through relationships, is bound up with the lives of people with and without disabilities, and that fighting back against discrimination requires coalition building.

In the digital age, a variety of technological, political, and economic barriers limit the agency of individuals with disabilities and their families.¹¹⁷ Various platforms, applications, and websites strongly discourage individuals with disabilities from cultural as well as societal participation. This includes files and websites that cannot be properly read by the screen read-

ers of blind and visually impaired individuals, and YouTube videos sans captioning or with poor auto captioning viewed by Deaf audiences.¹¹⁸ Inaccessible technology helps very little and, in fact, creates new forms of exclusion where none existed before.

At their core, these incomplete remedies are based on a seductive belief in the easy technological fix as well as a view of individuals with disabilities as most in need of fixing—whereby technology repairs or eliminates impairment.¹¹⁹ In a technologically determinist version of this relationship, technology alone enables disabled individuals to overcome disability and serve as inspirations for nondisabled people; in a socially determinist form, visionary technologists liberate individuals with disabilities from the constraints of their minds and bodies. These narratives take on new meanings among parents, teachers, and therapists. As one AAC specialist I spoke with noted, “Sometimes parents hold on to. . . . They want a thing. They want a device to help, to fix their child. Which, it’s not. It’s a tool, and all tools are human dependent.” Dismantling determinist views of the relationship between technology and disability requires examining up close the range of mediated encounters had by disabled individuals across the socioeconomic spectrum, including youth with disabilities and their families. This reflects Williams’s call to reject both “technological determinism” and “determined technology.”¹²⁰

Empirical research on the well-documented social and cultural “participation gap” among youth has been quite limited with respect to disability.¹²¹ Outside classroom and therapy settings, we know very little about the experiences that disabled youth, their siblings, and their parents have with media and technology at home and as part of domestic activities.¹²² While research on how class, gender, sexuality, and race shape new media use among young people is growing, Gerard Goggin writes, “There has been even less work on disability, youth, and mobiles, with the research literature focusing still on issues of accessible design, or hamstrung by outmoded accounts of impairment and disability.”¹²³ This book takes up Goggin’s call, identifying intersecting issues of privilege and oppression that affect the lives of youth with disabilities in their engagement with media and technology.

Intersectionality and Distinguishing Parents

The caregivers of youth with disabilities tend to be grouped together under the umbrella of “special needs parents.” In her ethnographic work with US mothers of children with disabilities, Gail Landsman saw no significant

difference by socioeconomic class or education level in terms of how these women constructed their identities. She found that mothers instead believed they were “in a class by themselves” compared to mothers of non-disabled children, due to their distinct child-rearing experiences. Moreover, Landsman suggested that “discrimination against persons with disabilities extends broadly across class lines in U.S. culture.”¹²⁴

Children with disabilities and their families also represent this country’s racial, ethnic, socioeconomic, cultural, and linguistic diversity, and as such, may have relatively little in common with one another. Over the past decade, parent-reported childhood disability in the United States has steadily increased to nearly six million children under age seventeen, growing by 15.6 percent between 2001–2002 and 2010–2011.¹²⁵ Family incomes below the US federal poverty level are associated with a higher prevalence of parent-reported developmental disabilities.¹²⁶ Under the specter of extreme income inequality in the United States, policies impacting health insurance, housing, food insecurity, minimum wage, and costs of child care profoundly impact these families. For instance, autistic children and those with other developmental disabilities from immigrant families were more than twice as likely as nonimmigrant families as of 2012 to lack consistent health care, and three times as likely to lack any type of health coverage at all.¹²⁷

Studying the experience of disability in the digital age and especially among families requires an intersectional approach.¹²⁸ Intersectionality, as a concept, emerged in the late 1980s and early 1990s as a way to critique academic work that focused either on race or gender in isolation, and pushed black women away from centers of power.¹²⁹ While a sweeping discussion of the benefits and drawbacks to intersectional analyses along with its grounding in work by feminists of color is beyond the scope here, it is important to acknowledge the far-reaching applications of intersectionality theory to the study of intergroup and intragroup relations.¹³⁰ The advantages and disadvantages of different types of privilege are not simply additive or subtractive.¹³¹

Patricia Collins instead emphasizes the significance of dynamic centering and relational thinking, which consists of placing two or more systems of power at the middle of an analysis, and asking how they shape one another.¹³² For my purposes here, I focus more squarely on the dual distinctions of disability and class, while also attending to how individual identities and institutional factors interact with age, gender, race, ethnicity, immigration status, and linguistic background. For example, the cultures that immigrant parents like Karun come from frame how they view their

children and understand disability. I forefront the simultaneity of these identities and their fluidity, with parental privilege relative to the context of the greater Los Angeles area.

With that, I identified four characteristics of more and less privileged parents in my study, centering on mothers’ education level, household income, English-language fluency, and ownership of the iPad that the child used for AAC. Table 1.1 provides a list of the names of children and parents observed or interviewed in each group.¹³³ Of the twenty families I studied, ten were more privileged and ten were less so (for further discussion, see the chapter on methods).

First, in more privileged families, mothers tended to be college educated, while those in less privileged families had more often completed high school at most or had taken some college classes. Second, more privileged families tended to have a combined yearly household income of \$100,000 or more, whereas less privileged families generally indicated earning \$50,000 per year or less—below the median income in all three counties under study in the Los Angeles area.¹³⁴ This is not to say that income is a fixed variable. Some parents, like Karun, experienced fluctuations in their economic stability due to factors such as divorce or illness. Nelson explained that before the 2008 economic recession in the United States, “I used to make more money,” but with his wife’s cancer and his daughter’s autism diagnosis, the job could not accommodate his family’s needs. He found a

Table 1.1
Members of Less and More Privileged Families

Less privileged families		More privileged families	
Child	Parent/s	Child	Parent/s
Paul Michael	Garine and Levon	Nash	Taylor and Todd
Beatriz	Pilar and David	Thomas	Daisy
James	Cathy	Raul	Nina
Madeline	Teresa	Luke	Debra and Rob
Stephanie	Marisa and Nelson	Danny	Alice and Peter
Pargev	Karun	Isaac	Sara
Talen	Kameelah	Eric	Anne
Kevin	Rebecca	Chike	Esosa
River	Mark*	Cory	Perri
Moira	Vanessa*	Sam	Donna

*Single parent

job that while paying less, allowed for more flexible hours. "I'm only here," he explained, "because this job gives me the freedom to be with my family whenever I have to be."

Third, both more and less privileged parents tended to be fluent in English, although this commonality is exclusively due to my own sampling bias. One requirement for participation in the study as well as a limitation was that at least one parent needed to be fluent in English. This was owed to my lack of non-English-language skills and limited funds for a translator during my dissertation research. In a couple of families (Beatriz and Stephanie's), though, one parent (all fathers) translated for the other one.

Fourth, greater numbers of more privileged families (six out of ten) owned the iPad that their child used with Proloquo2Go (as opposed to it being school owned) than did less privileged families (two out of ten). Of those two families, one had saved up money to buy the least expensive iPad Mini for their child (River), and the other had received the iPad and Proloquo2Go from a charity (Pargev). As more privileged parents had greater amounts of discretionary income, they also tended to have other Apple devices at home onto which Proloquo2Go could be installed as a backup. The AAC coordinator for one district explained, "Sometimes I have families that will have an iPad with Proloquo2Go loaded at home, and we have the school one. They don't want the school one to be sent home. What we will do is create a common Dropbox account so that they'll have the same vocabulary on both iPads."

More privileged parents also tended to view iPads as easily replaceable should the technology break. For instance, Peter, father of Danny (age six), remarked, "Quite frankly, if Danny destroys this tomorrow, I can go buy an iPad 2 for 400 bucks that runs." Rob and Debra mentioned how a few months ago, their house had been broken into and someone stole the iPad that their thirteen-year-old son, Luke, was using on loan from school. Rob said, "I suppose, technically, [the school] would have to supply it," but instead he went out and immediately bought another iPad. "There was no way I was going to wait for [the school]," explained Rob. "I had to quick order one, get it down here, and get it, that kind of thing."

In contrast, less privileged parents were more often fearful of something happening to the iPad, and being on the hook for replacing or repairing the broken technology out of their own pockets, per their loan agreement with schools and regional centers.¹³⁵ One assistive technology specialist in a predominantly low-income and Hispanic-Latino neighborhood in Los Angeles mentioned that the parents they worked with tended to hesitate about bringing home the iPad that their child used to communicate in school:

“We said, ‘Don’t worry, please take it, use it.’ And they said, ‘Oh, OK, because we don’t want anything to happen.’” That specialist’s apprentice concurred, noting, “We’ve had parents nervous that their kid would be taking it on the bus to go home, and they’re worried that another kid would steal it on the way home. They wanted to put a lock on their backpack.” Their remarks as well as the others above make it clear that we cannot refer to parents of disabled youth as being in “a class by themselves” without unpacking the class distinctions and other forms of difference among them.

Giving Voice

As I mentioned at the start of this chapter, reports about the use of tablets and smartphones as speech-generating devices explicitly call on the phrase “giving voice” to highlight narratives of personal liberation via technology. Such accounts have been widespread in the North American news media since the launch of the Apple iPhone in 2007 and resulting market for AAC apps.¹³⁶ These news stories portray technology as allowing individuals to “overcome” their disability as an individual limitation, and are intended to be uplifting and inspirational for able-bodied audiences—both common themes in the mass media historically.¹³⁷ Consider Microsoft’s Super Bowl ad in 2014, which features former NFL player Steve Gleason, who lost the ability to produce oral speech due to ALS. The commercial claims that the Microsoft Surface Pro tablet computer “has given voice to the voiceless,” exemplified by Gleason providing the ad’s voice-over, with the implication that he was once voiceless but now has voice thanks to Microsoft’s innovations (figure 1.2).¹³⁸

Mass as well as social media are implicated in the valuing and devaluing of voice. Spokespeople, celebrities, elected officials, and public figures serve as mouthpieces by speaking on behalf of others. The *Code of Ethics* of the Society of Professional Journalists explicitly states that a key journalistic duty is to “be vigilant and courageous about holding those with power accountable. Give voice to the voiceless.”¹³⁹ Yet mass media give more lip service than voice by perpetuating the essentialist notion that being “voiceless” is a stable and natural category. Social media differ from the press by giving voice en masse, but this collective sounding board can be both productive and destructive when speech is used for peaceful or violent means, such as with online harassment and networked misogyny.¹⁴⁰

A “sociology of voice” interrogates the structural conditions that strip humans of their humanity as well as their right to communicate.¹⁴¹ This book offers a new angle on established critiques of how communication



Figure 1.2

Screen grab from a YouTube video of Microsoft’s 2014 Super Bowl commercial. Former NFL player Steve Gleason, who lost the ability to produce oral speech due to ALS, narrates that Microsoft’s technology “has given voice to the voiceless.”

technologies give or limit voice through the case of individuals with communication disabilities who rely on mobile devices for speech. Jo Tacchi notes that the consequences of digital media for voice are not bestowed on the technology itself but instead enacted in contexts.¹⁴² In turn, what if we *accounted for* and were *accountable to* those unable to produce, or who have significant difficulty producing, embodied oral speech, or what one might traditionally call “talking”? How useful is this figure of speech if we are to be fully inclusive of all citizens? What kind of discursive work does “giving voice” do? Does this converge or diverge from the meanings and practices that AAC users along with their conversation partners associate with the iPad—a tool that converts physical actions like button pressing into audible voice?

Mobile communication technologies can exacerbate rather than reduce inequalities. This is particularly true among “underconnected” children and their parents, who get by with intermittent mobile-only Internet access through one or a few smartphones, but face difficulty in accomplishing complex tasks for work and school that are better suited for a computer.¹⁴³ While mobile media are widely hailed as the most accessible tools to give voice to marginalized populations—due to their pervasiveness, low cost, and ease of use—I found that far from being equalizers or amplifiers, such tools unintentionally contributed to naturalized disempowered states and

exclusionary positions, such as being “voiceless,” “speechless,” and “silent.” The notion that mobile media “give voice” masks assumptions about ability, embodiment, and difference in the design, construction, and study of sociotechnical systems.

Though “voice” is problematic in its own right, it is also important to highlight how the terms “verbal” and “speech” tend to imply normative associations with the body and orality. It is common clinical practice to refer to users of speech-generating devices as “nonverbal.” But that phrase does not reflect all the ways in which individuals with communication disabilities engage with the world of words through various media and technology. In a discussion of people who communicate primarily by typing on a keyboard, feminist scholar Lisa Cartwright explains, “Here we have an obvious double mediation: the computer and the human hand mediate speech in the place of the normative technology of speech, embodied oral voice.”¹⁴⁴ I draw on Cartwright and employ the term “embodied oral speech” (i.e., people who have difficulty producing embodied oral speech) instead of “nonverbal.”

I also focus deliberately on the experiences of parents in managing their non- and minimally speaking children’s media and technology use. Kathy L. Look Howery writes that “unlike a child who has learned to speak naturally and therefore in a true sense ‘have’ their words, ... a child who uses [a speech-generating device] is given their words. Parents, therapists, or teachers put vocabulary (words) into the devices, when children are learning to use their [devices] they must find the vocabulary that others have given to them.”¹⁴⁵ While parents do not put words into their nonspeaking children’s mouths, they do have a unique relationship to the linguistic equipment that their children use to communicate. I embrace a child-centric approach that takes context seriously and does not overemphasize the individual. By concentrating primarily on parents, and secondarily on therapists and teachers, I complicate the idea that children’s voices, both disabled and nondisabled, somehow exist in a state free from adult influence (including researchers), and push beyond a simple dichotomy of adulthood versus childhood.¹⁴⁶ The metaphor of voice more often reproduces than repairs imbalances of power and knowledge.

Overview of the Chapters

It is worth noting that this is the first book-length study of iPad use and adoption, not just among people with disabilities and their families but in general. Anyone interested in smartphones, tablets, and mobile

communication will be interested in the chapters that follow due to the close attention paid to the unfolding developments of this technology, its influence across the business, health, and education sectors, and how individuals use, domesticate, negotiate, and shape their media tools. As opposed to lengthy industry-focused white papers on new technologies, which tend to paint broad strokes with a positive spin, I take an expressly critical and social scientific approach that situates the device in specific everyday contexts.

I found that parents' understandings of their child's iPad use aligned with or differed from popular, professional, and institutional definitions. Moreover, the function of economic, social, and cultural capital in parents' meaning-making processes varied. Using grounded theory, I identified five key areas (one for each main chapter) of difference in parents' understanding of their child's use of the iPad for AAC. Each chapter details how more and less privileged parents articulate what the iPad means to them, how these meanings shape management of their child's media and technology use, and how these conceptions both conflict with and complement dominant discourse about technology "giving voice."

Meaning making is an ongoing practice of turning *things* into *things that matter to people* through social and psychological transformation.¹⁴⁷ I make use of an expressly social definition of media, per Lisa Gitelman, who refers to media as "socially realized structures of communication," encompassing cultural forms, learned techniques and protocols, and shared practices.¹⁴⁸ In addition, I employ Don Norman's notion of the "conceptual model," or a mental simulation of a given piece of technology that designers and users each develop.¹⁴⁹ The conceptual model serves as a reference point for how users think media and communication technologies should be interacted with, or what they are designed to do. While this cognitive representation is in part due to a technology's physical properties, a person's conceptual models for a device such as an iPad also emerge from their life experiences, understandings of social norms, and cultural context.¹⁵⁰

Each chapter thus poses a basic question about how parents interpreted one aspect of their child's iPad, framed at the beginning of each chapter with a provocative quote or two from parents directly. Chapter 2 explicitly poses the question, "What is voice?" As noted above, voice reoccurs as a rhetorical trope over history in popular discourse about nonspeaking individuals as well as AAC devices. This reduction of voice obscures the ways that privilege is built into sociotechnical systems—both programmed into the software itself and embedded into social practice. More and less privileged parents each constructed different meanings of voice in relation to

the iPad, their child, and the perceived possibilities and limitations of the speaking world.

Chapter 3 asks, “What is a mobile communication device?” and responds with an unexpected answer. While it has been well documented by communication scholars that mobile devices have symbolic meanings beyond the messages they transport, I illustrate in this chapter how the protective case *around* a mobile device, an otherwise-unremarkable and forgettable object, is itself a key visual and material signifier of the sociotechnical world. I discuss how the choice of an iPad case became a major source of frustration and site of negotiation between school districts and parents. The iPad case reflected various tensions in how children with disabilities are perceived: between normalization and the child’s “special” status as well as whether the goal of the case was to protect the computer or empower the child over the long run. Working-class youth were the most vulnerable to mercurial school district policies that valued their investment in the technology over a sustained buy-in toward students’ futures.

In chapter 4, the question is, “What is an iPad for?” Regardless of their socioeconomic status, most families in my study somehow ended up with two iPads in their household. All families distinguished between the two in some manner. More and less privileged parents differed, however, in where they drew these boundaries—one iPad for “fun” and one for “communication” (among more privileged parents), and one iPad for “education” and one for “entertainment” (among less privileged parents). Their conceptual models and social understandings emerged and diverged partly due to how the iPad is designed and manufactured, but also due to class differences in the regulation of children’s technology use in public and private spaces.

In chapter 5, I inquire, “What does it mean to communicate with an iPad?” Clinicians promoted Proloquo2Go as the “proper” way to communicate using an iPad; yet many parents interpreted their nonspeaking child’s recreational use of iPad apps and other media as expressing socioemotional, cognitive, and verbal skills—complicating the fun/communication binary explored in the prior chapter. I look at the need to shift perceptions of both disability and children’s popular culture away from having to do with deficit and deficiencies (i.e., disability as a lack of ability and kids’ media culture as lacking educational value), and instead toward more asset-oriented models. It is nevertheless important to note that less privileged parents faced greater difficulty than more privileged parents in parlaying their children’s expressive media use at home into recognition of value among teachers and therapists.

Chapter 6 examines the question, “How do media shape understandings of the iPad?” This chapter analyzes parents’ interpretations of cultural representations of the iPad, Proloquo2Go, and AAC as well as their participation in the consumption, circulation, and creation of media about disability, parenting, and assistive technology. More and less privileged parents engaged in some similar but also strikingly different media practices. While the “disability media world” may be expanding, it also remains largely dominated by those parents with access to more distinctive forms of social, economic, and cultural capital.¹⁵¹

Lastly, in chapter 7, I summarize the ways in which more and less privileged parents’ lives converged and diverged—not only in terms of their approaches to the iPad, but also in how they conceived of themselves and their children as representative or unrepresentative of the other families participating in the study. Researching kids’ and families’ media and technology use through the lens of intersectionality, I argue, allows for more effective coalition building among families pushed to the margins and otherwise silenced.

Conclusion

During a coffee break at a small, local, assistive technology conference in Southern California, I chatted with a more privileged parent named Donna, the mom of Sam (age seven), a nonspeaking boy with multiple disabilities, including autism and spina bifida. Sam had used Proloquo2Go on the iPad for about a year, but then switched to a type of dedicated high-tech AAC device known as a Vantage Lite. Donna told me how Sam used his Vantage Lite to speak to his grandmother remotely. “Each and every night,” Donna shared, Sam “uses FaceTime through the iPhone. We place the phone through the handle [of the Vantage Lite] so it stands up, and he talks to his grandma and tells [her] about his day.” The video chat does not bridge a long distance; in fact, Sam’s grandma “lives five miles away,” said Donna. “They converse and it’s all for practice. ... It’s a nightly ritual that we do.”

Karun described how her extended family had participated in a similar ritual back in Syria. As part of Pargev’ homeschooling, Karun taught him “communication by mobiles.” She started out by having Pargev memorize phone numbers that she had written for him in a little address book. “We would put mommy’s number, daddy’s number, grandmother, grandfather’s number, all the numbers,” Karun recounted. After Pargev had memorized them, Karun wrote each phone number down on a little scroll of paper.

Each day, as part of his lesson, Pargev had to select one scroll and call the number.

Like Donna, Karun enlisted both her social network and the telecommunications network in order to distribute support for her son's learning. She tasked each family member with asking Pargev questions like "How are you? What did you do? Did you do math? Where are you going today? What day is today? What time is it?" Things like that, just to make him get used to talk[ing] on the phone." Whereas Donna currently found it easy to implement daily chats between Sam and his grandmother, Karun spoke of their family's routine strictly in the past tense. "I used to do things like these things a lot over there," she told of life in Syria. Now, the family had to live within a much more constrained set of economic, social, and cultural resources. "For my husband, he left his own clinic. We left our parents. Everything else we left there," said Karun.

While smartphone owners increasingly use these tools for much more than telephone calls, their association with vocalization persists. A cadre of contemporary critics, most notably MIT professor Sherry Turkle, frequently pen articles and give interviews contending that (to use Karun's words) "communication by mobiles" is replacing interpersonal communication in everyday life.¹⁵² They say that too often, technology is a communication replacement, not an enhancement. Clinical psychologist Catherine Steiner-Adair argues that our handheld devices get in the way of authentic connections and erode "the art of talking."¹⁵³ Turkle warns of phones at the dinner table being a distraction as well as diluting conversation even if they are turned off.¹⁵⁴

This binary between face-to-face and mediated communication is patently false and further complicated by individuals who primarily "talk" using mobile media and employ communication technologies that both augment and provide alternatives to their oral speech production.¹⁵⁵ The mobile device on the kitchen table, in the form of an iPad propped up with the Proloquo2Go app open, does not degrade an empathic bond between family members so much as potentially enable it in the first place. How Sam, Pargev, and their families experience connection and disconnection on a societal as well as interpersonal level cannot be reduced to the technology, or their disabilities, alone.

In the chapters that follow, I argue that the sociocultural, political, and economic institutions within which families of children with disabilities are embedded shape the role of new media in their lives. I investigate how boundaries are maintained between the home and outside world, between public and private spaces, and between the iPad screen and screens of other

technologies that families regularly use. Parents' class background influences how they understand the value and purpose of the iPad as well as their relationships with the social entities shaping the use and deployment of the technology at home. Tablet-based AAC devices have incredible potential to support agency, independence, and personhood, but they do not enter into a vacuum devoid of other injustices. They become part of a system reproducing structural inequalities; nonspeaking children whose parents are best able to leverage social, cultural, and economic capital to navigate the bureaucracy tend to benefit the most. Essentially, when individuals adopt and use communication technologies that are expected to "give voice," they frequently get much more than they bargained for.