

1 Introduction

This report synthesizes the existing scholarship, and suggests future areas for research on the various roles that media and technology play in the lives of school-age youth with disabilities (three to twenty-two years old) and their families in the United States, with a focus on media use at home and as part of household activities.¹ It has three main aims: to summarize how children with disabilities take up media for social and recreational purposes; to reframe common assumptions about the relationships (both positive and negative) between children with disabilities and information and communication technologies; and to identify areas for further inquiry into the role of new media in the lives of children with disabilities, parents, and caregivers. This book outlines the parameters of research on digital youth with disabilities, and calls for more investigation as well as better translation of research into practice.

Disability is central to the human experience. At one time or another, those of us who are “temporarily able-bodied” will become disabled, whether as part of the aging process or unexpectedly at any age. People with disabilities have the same human rights to live with dignity and self-worth as those without disabilities. Yet significant cultural, technological, political,

and economic barriers continue to limit the full societal participation of children and adults with disabilities in the digital age (Dobransky and Hargittai 2006; Ellcessor 2010). Only 54 percent of adults with disabilities in the United States report that they use the Internet, compared with 81 percent of adults without disabilities (Fox 2011). Fewer households headed by someone with a disability in the United States report owning a computer (53 percent) than do all US households (76 percent) (US Department of Commerce 2013). Lack of Internet connectivity impacts the extent to which individuals with disabilities can seek health information, find employment, learn about events in the world, and enjoy all the ordinary, mundane, and everyday activities that people do online. It is not just individuals with disabilities and their families who are impacted by this exclusion but also society writ large, which loses out on their contributions.

Contrary to popular claims, new media are not inherently “equalizers” for people with disabilities (Borchert 1998), just as the Internet is not innately liberating. The greater (though not fully realized) social and digital inclusion of people with disabilities in recent decades is largely due to a number of major social, cultural, and political shifts in the United States. The end of the twentieth century marked the hard-earned passage of landmark civil rights legislation, most notably the Rehabilitation Act of 1973, Education for All Handicapped Children Act in 1975 (amended in 1990 by the Individuals with Disabilities Education Act, or IDEA), Americans with Disabilities Act (ADA) in 1990, and Assistive Technology Act of 2004. The disability rights and independent living movements have fought—and continue to do so—for self-determination, self-respect, and self-representation for people with disabilities (Shapiro 1993).

For youth with disabilities, federal legislation ostensibly ensures their right to technology and related services as needed to access school curriculum (although the United States largely places the burden of protecting those often-violated rights on individual families) (Ong-Dean 2009; Trainor 2010). Since the passage of these laws, there has been significant research on the implementation and use of computers and assistive technologies in special education programs (Dell, Newton, and Petroff 2011). There is also a growing body of literature on the design and development of interactive technologies as well as robotics for rehabilitative and therapeutic use by children with disabilities (Alper, Hourcade, and Gilutz 2012). Some researchers, influenced by the participatory design movement, have also explored how young people with disabilities can benefit from being directly involved in the development of technology intended for their use, and in turn, how technology is improved by their participation (Guha, Druin, and Fails 2008).

Outside these curricular and experimental contexts, however, scholars have paid little attention to the day-to-day experiences of youth with disabilities when using new media and technology (Bouck, Okolo, and Courtad 2007), including their pleasures and frustrations. To borrow the terminology of Mizuko Ito and her colleagues (2009), youth with disabilities are “hanging out, messing around, [and] geeking out” with digital media too (Alper 2013). This omission reflects the ways in which the recreational activities of individuals with disabilities are primarily seen as an instrumental tool for diagnosis and therapy rather than as something with intrinsic value (Adkins et al. 2013; Goodley and Runswick-Cole 2010). In order to support participation in social, civic, and economic life for *all* young people, we need to know more about the kinds of opportunities that youth with various

disabilities regularly have and do not have with information and communication technologies.

The remainder of this introduction serves to unpack the title of this report. The term *digital youth with disabilities* is a loose, fluid category comprised of an incredibly heterogeneous population. It should be noted from the outset that all the research reviewed in this report is subject to children's individual and developmental differences. The insights on disability, children, and parenting presented here are limited to the degree that I do not identify as having a disability, and am not the child of someone with a disability, the parent or sibling of a child with a disability, or a parent at all. The published research discussed and commentary offered is drawn from a number of sources, including an extensive literature review across multiple disciplines, primary research from my dissertation, and participation in workshops and conferences related to individuals with disabilities' media and technology use.² In featuring children, adolescents, teenagers, and young adults with disabilities as digital youth, this report rejects the dominant characterizations of individuals with disabilities as deficient and other.

Defining Youth with Disabilities

As of 2009, youth with disabilities constituted approximately 13 percent of all students ages three to twenty-one, or nearly 6.5 million people (Snyder and Dillow 2012).³ Students with the following disabilities are eligible for special education and related services under IDEA: autism, deaf-blindness, deafness, developmental delay, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or

language impairment, traumatic brain injury, or visual impairment (including blindness).⁴ The conditions responsible for various impairments may or may not be immediately apparent to others. For example, while the use of crutches or a guide dog may visibly signal a disability, some disabilities (such as autism) are not necessarily easily identifiable through appearance. Some impairments are more permanent (e.g., paralysis), while others are temporary or fluctuate depending on the environment (e.g., chronic fatigue syndrome or multiple chemical sensitivities).

Various government agencies serving children in the United States provide different data about childhood disability. This complicates an understanding of the broader national trends in disability and effective provision of resources. While the numbers supplied by the US Department of Education define a *child with a disability* through the lens of educational performance (and the adverse effects of disability on education), the US Department of Health and Human Services surveys households to identify *children with special health care needs*, defined as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al. 1998, 138). Using this measure, there are an estimated 11.2 million children under the age of eighteen with special health care needs in the United States. Among all households, 23 percent include at least one child with special health care needs (US Department of Health and Human Services 2013).⁵

In addition to these institutional definitions, there are multiple other ways of conceptualizing youth with disabilities. Researchers studying the sociology of childhood contend that the category of youth has evolved over history, and the term

child is a social construction informed by perceptions of class, race, and disability (James and Prout 1997; Thorne 2009; Safford and Safford 2006). Factors including longer life expectancy, developments in medicine (e.g., vaccination), the introduction of compulsory education, and the enactment of child labor laws have all shaped understandings of children's intrinsic value to society as well as their parents (Zelizer 1994).

In a study of British child care manuals published between 1839 and 1924, Harriet Cooper (2013) traces a gradual shift in the West from concerns about illness and mortality in the nineteenth century to twentieth-century worries about children's abnormality. The idea of the "normal child" has only been in existence since the initial scientific study of child development during that era (Walkerdine 1993; Burman 2008). The normal child is a concept built on classical notions of the ideal body along with the invention of the bell curve, the field of statistics, and associated charts and diagnostic tools (Davis 1995). One "average" child is an amalgam of many—particularly measures of white, Western, male, middle-class children (Burman 2001). Individuals rarely simultaneously exhibit all social, emotional, intellectual, and physical behaviors and characteristics "typical" of that age.

Social constructions of normalcy create the "problem" of the child with a disability, whose chronological or biological age may not match up with their "developmental age." Children with disabilities have historically been subject to gross abuses of power by the able bodied. Many were victims of the eugenics movement in the early twentieth century in efforts to socially engineer "better babies" (Stern 2005). These attempts include institutionalization, sterilization, and physical and sexual abuse (Safford and Safford 2006). There has been no consistent way

to define youth with disabilities over the course of US history (Halfon, Houtrow, Larson, and Newacheck 2012). Youth is an evolving concept—one whose history is inherently interdependent with the regulation of children’s bodies.

Disability—as a concept, culture, and identity—has changed as well (Nielsen 2012). In the United States, dominant cultural values such as self-reliance, individualism, and “fitting in” shape the ways in which people with disabilities are perceived (Longmore and Umansky 2001). Disability studies scholars contend that a “medical model” underpins prevailing Western views of disability and people with disabilities, meaning that disability is understood as an individualized case of biological burden or deficit. In response to the medical model, some disability activists and scholars emphasize a “social model” of disability, which shifts the focus from the individual to society. The social model makes distinctions between impairment (bodily difference) and disability (the social and built environment that disables as well as discriminates against different bodies) (Oliver 1990; Shakespeare 2013).

Some have critiqued both the medical and social models for overly simplistic notions of disability (Kafer 2013; McRuer 2006; Siebers 2008) as being similar to a false sex/gender binary (Butler 1990). Feminist disability scholars argue for a more fluid definition of “dis/ability” (Sobchack 2004). Rosemarie Garland Thomson (1996, 7) notes that all bodies—depending on the environment, situation, and interaction—have “varying degrees of disability or able-bodiedness, or extra-ordinariness.” This fluidity is difficult to express through standardized governmental measures of disability status.

What *is* clear is that each individual with a disability understands their own relationships to disability, their bodies, and

society in unique ways (Linton 1998). Language and terminology both reflects and shapes these relationships. The appropriateness of using “identity-first language” (e.g., someone who is deaf) or “person-first language” (e.g., someone with a learning disability) must be understood within the context of specific disabilities and their cultures, which this report aims to respect and value. For example, many within the community of autistic self-advocates (which includes both adults and children) prefer the term *autistic* to *people with autism*. They claim their autism as an inseparable part of their identity—more of a source of pride than an insult (see, for instance, Brown 2011; Fleishmann and Fleishmann 2012). Ultimately, all people should have the right to decide how they would like others to describe them.

Locating Disability among Digital Youth

Considering the myriad ways in which people with disabilities are often denied agency, it is helpful to draw on research more broadly on underrepresented youth. Many young people in the United States—with an array of racial, ethnic, cultural, and linguistic backgrounds—encounter a “participation gap” (Jenkins et al. 2006) that separates them in nuanced ways from those making the most of online and off-line opportunities and resources. Individuals and groups can leverage information and communication technologies to support greater social engagement, cultural contribution, and political involvement among youth challenging existing power dynamics (Cohen et al. 2012; Watkins 2009). While a complex mix of demographics, use, and expertise shape young people’s social and digital exclusion (Livingstone and Helsper 2007), disability tends to be an underrecognized component (Cole et al. 2011; Dobransky and Hargittai

2006). This not only dislocates children and adolescents with disabilities from important discussions of digital youth (Peppler and Warschauer 2012) but also masks the multifaceted ways in which disability and specific disabilities intersect with race, class, ethnicity, nationality, language, and gender in children's lives.

Feminist disability theorist Alison Kafer (2013, 32–33) writes of the figure of the child in US politics that “the always already white Child is also always already healthy and nondisabled; disabled children are not part of this privileged imaginary except as the abject other.” Addressing inequality among youth with disabilities necessitates confronting the ways in which class, gender, and race factor into broader conceptions of disability, particularly in the public education and penal systems in the United States (Morris and Morris 2006). For example, while there is no marked disproportion among racial and ethnic groups in low-incidence disability categories (e.g., deaf-blindness), black males are overrepresented in the high-incidence disability categories of intellectual disability, emotional disturbance, and learning disabilities (Aud et al. 2013; Ford 2012). While students with disabilities comprise 13 percent of all US students, they make up 25 percent of students receiving multiple out-of-school suspensions, 23 percent of all students getting a school-related arrest, and 19 percent of expelled students (Lhamon and Samuels 2014). While this report's focus is on home media use, it should be noted that not all youth with disabilities live at home, or do so on a full-time basis. Some are incarcerated, some live in residential facilities, and some spend part of their time in respite facilities.

“Digital divide” rhetoric tends to naturalize underrepresented youth as outsiders to technological progress and masks structural inequalities (Everett 2008a). The irony is that the technological

world as we know it has actually been fundamentally shaped by youth with disabilities who found their way around complex systems. In the 1950s, for instance, blind youth were among the first to discover that they could “hack” the telephone system using perfect pitch to trigger automated switches—a phenomenon known as “phone phreaking” (Rosenbaum 1971). They became central figures in the history of hacking, and have been directly cited by Apple founders Steve Jobs and Steve Wozniak as highly influential (Lapsley 2013).

Youth with disabilities in the United States tend to be made visible for the political purposes of others. When culturally depicted as “poster children,” they are defined exclusively by their medical needs (Longmore 2013). Each child with a disability also has abilities, hobbies, and personal preferences. Considering the slogan of the disability rights movement, “Nothing about Us without Us” (Charlton 2000), there is a pressing need to invite youth with disabilities and the important people in their lives into the dialogue about new media and participatory culture, where they have much to contribute when it comes to reshaping and bettering society.

The Role of Families

The promises and pitfalls of children’s media use, and specifically among those with disabilities, are also bundled up with policies impacting families, such as affordable health care and access to health insurance, the living wage, and the increasing costs of child care in the United States. For example, Sue Lin, Stella Yu, and Robin Harwood (2012) found that autistic children and those with other developmental disabilities from immigrant families are more than twice as likely as nonimmigrant

families to lack consistent care, and three times as likely to lack any type of US health care coverage. Family income below the federal poverty level is also associated with a higher prevalence of parent-reported developmental disabilities (Boyle et al. 2011). Families of children with disabilities reflect this country's racial, ethnic, socioeconomic, cultural, and linguistic diversity, and may have little else in common with one another.

Caring for youth with disabilities in the United States also has a number of gendered dimensions, as highlighted by various feminist disability studies scholars (Adams 2013; Jack 2014; Landsman 2009). In earlier generations, US children with disabilities and complex medical issues were more likely to be institutionalized than live at home with their parents and in their communities (Metzel and Walker 2001). In the mid-twentieth century, the “refrigerator mother theory,” popularized by psychologist Bruno Bettelheim, naturalized the placing of blame for children’s autism on their supposedly “cold” and emotionally distant mothers. This era was also marked by the relocation of many young families from the cities to the suburbs, displacing mothers from their existing networks of friends and family who might have otherwise assisted with child care. Some argue that the United States is currently in the midst of a cultural shift away from the refrigerator mother archetype toward a neoliberal “intensive mothering” paradigm (Hays 1996). Instead of being recipients of misplaced blame, today’s ideal “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” (Sousa 2011, 221).

The scenarios of the refrigerator mother and warrior-hero mother both define disability as something to be eradicated, or that should be prevented. Difficulties in obtaining health

insurance and government support as well as a lack of reliable, culturally appropriate, and community-based resources often result in family members (mostly mothers) foregoing employment to fill caretaking roles in households with people with disabilities (Scott 2010). Though families of children with disabilities frequently experience concrete difficulties such as financial hardship, they are unfairly stigmatized and viewed through a lens of tragedy in US society, as if in a state of perpetual crisis and in need of charity (Green 2003). For many families, disability can be a source of pride as well as a positive aspect of their and their child's identity (Rapp and Ginsburg 2011). Many parents of children with disabilities, working alongside adults with disabilities, have been important advocates and members of the US disability rights movement (Shapiro 1993).⁶

Starting in the 1960s, human development and family relations researchers began to question these preconceived assumptions about families of children with disabilities and test them empirically (Barsch 1961). Resiliency theory (Patterson 2002) suggests that families of children with disabilities 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” (Bernheimer, Galimore, and Weisner 1990, 223). Rather than equating disability with adversity, “a child ought not to be routinely described as a stressor or a nonnormative demand on families who may perceive them otherwise” (Maul and Singer 2009, 157). Families of children with disabilities face significant challenges but also have unique strengths (Solomon 2012).

Media can play a significant role in family accommodations. A number of researchers have found that families often alter their technology and media use in order to adapt to their child

with a disability, and make family life more harmonious (see, for example, Maul and Singer 2009; Shane and Albert 2008; Nally, Houton, and Ralph 2000). Some accommodate for behavior difficulties by providing DVD players when their children ride in the car. Others take proactive efforts to make changes in their television-viewing habits at home, including having separate screens for different family members, watching child-oriented programming together, reducing background television, or not watching any television at all (Keilty and Galvin 2006). Parents might use media as a reward for painful treatments or long hospital stays (Mattingly 2003).

Accordingly, this report does not presume that children with disabilities are a stressor on family life or family media use. Research on parenting decisions about children's media use indicates that these choices are not made independent of other caregiving behaviors (see, for example, Clark 2013; Katz 2014; Seiter 1999). Parents and other primary caregivers of young people with disabilities (i.e., foster parents or grandparents) make decisions about media consistent with their beliefs about successful family functioning—beliefs that are in part shaped by their racial, ethnic, cultural, and class backgrounds.

Summary

Insights from the fields of feminist disability studies, the sociology of childhood, and human development and family relations are helpful for understanding the broader issues shaping what it means to raise digital youth with disabilities in the United States today. Supporting the societal participation of young people with disabilities calls for critical and purposeful inquiry into the overlapping intersections of youth and disability, disability and

digital media, and disability and child rearing. The relationships between these various elements are always evolving, bound up with broader historical, social, cultural, economic, and political shifts in the United States that impact how families thrive.

While this report is written primarily for fellow researchers and scholars, my aim is that it is accessible and comprehensible for a general audience beyond academia, technology, and policy circles. Parents of children with disabilities often feel uncertain about the appropriateness of media and technology in their children's lives (Durkin and Conti-Ramsden 2014). The professionals who work in educational and therapeutic contexts with youth with disabilities rarely have a background in children's media use, are frequently ignorant about new media, and are in need of professional development in the classroom to support their own understanding of digital media and integrating technology into curriculum. Parents also express feeling that professionals lack an understanding of their own family media habits (Nally, Houlton, and Ralph 2000).

The following chapters place disability in the center of our understanding of children's recreational experiences and informal learning with new media. Chapter 2 focuses on the notion of *screen time*, a phrase coined by the American Academy of Pediatrics (AAP) and readily adopted by the mainstream press that refers to children's time spent with screen-based media. Screen time is generally employed in a pejorative manner—for example, through public service campaigns aimed at parents to reduce children's screen time. While other scholars have pointed out how this terminology is particularly problematic, new angles to these arguments emerge when considering children with disabilities along with their and their families' varied use of media (e.g., students who use augmentative and assistive

communication devices in the form of iPads as their primary mode of communication, or autistic children who use media to make connections to others).

Chapter 3 delves deeper into how young people with various disabilities use media to socialize with their caregivers, siblings, and friends. Youth with disabilities are frequently stereotyped as being socially isolated, and new media have historically been imagined as both being the cause and cure for this segregation. The existing research, however, suggests a much more complex story than the one presented by these technologically and socially determinist discourses. Chapter 4 explores issues that parents of youth with certain disabilities (e.g., attention deficit hyperactivity disorder [ADHD] or autism) specifically encounter in selecting, managing, and purchasing media for their child. Beyond considering children's individual preferences and needs, this chapter also raises critical awareness of external factors shaping the media and technology available to youth with disabilities—namely, the limits of existing platforms, content, and age standards. In chapter 5, I conclude with a discussion of future research directions.

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