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DISABILITY, CHILDREN, AND THE INVENTION OF DIGITAL MEDIA

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Introduction

Much research, policy, and practice on digital media has struggled to move beyond the powerful dominant framing of children as humans in development, in need of protection, regulation, and guidance, especially in the face of the dystopian and threatening perceptions and realities of how social life is being recomposed via varieties of internet, mobile, and social media (Lahikainen et al., 2017). As Sonia Livingstone and Kirsten Drotner noted over a decade ago:

In many parts of the world, and for many decades, children have been early and avid adopters of new media. Indeed, they often challenge normative socio-cultural practices through the ways in which they use media. Yet, at the same time, many parents, educationalists and marketers consider that media permeate, even control, children’s lives to a degree that was unknown just a generation ago.

(Drotner & Livingstone, 2008, p. 1)

They make the telling and still relevant point that “debates over children and media throw into relief our basic understandings of childhood and, additionally, of media” (Drotner & Livingstone, 2008, p. 4). While much has changed in media, these propositions ring true – even more so – when it comes to children with disabilities and digital media.

Children with disabilities have tended to be overlooked in discussions of media. With the advent of digital media, and the various ways in which children have figured as key users, innovators, and sites of social anxiety and discussions of risk, attention has also been drawn to disability as an important dimension. There is now a notable sea change in children and media research (see, for instance, work by Meryl Alper, notably her key 2017 book Giving Voice; Golos, 2010; Hynan et al., 2015; Manhique & Giannoumis, 2019; Meredith et al., 2018; Smith & Abrams, 2019; Third et al., 2013, 2017; Tsaliki & Kontogianni, 2014). Various influential figures have acknowledged disability as a notable gap in research – and an important area to address for its potential contribution to the emerging agenda of intersectionality, diversity, equality for children, and digital media. As Meryl Alper, Vikki Katz, and Lynn Schofield Clark put it, “[g]iving full consideration to the identity, inequality, and marginality that affect children’s and adolescents’ experiences with media better enables researchers and other stakeholders to advance the rights of
young people across various forms of social distinctiveness” (Alper et al., 2016, p. 109). In their call for work on the “invisible children in media research” (Jordan & Prendella, 2019), Amy Jordan and Kate Prendella note that: “[a]nother significant part of the child population underrepresented in CAM [Children and Media] research is children with disabilities” (Jordan & Prendella, 2019, p. 236). They emphasise that “a lack of diversity within research can lead to a tilting of the questions we ask” (Jordan & Prendella, 2019, p. 237). Researchers on children’s rights have been pioneers in this regard, with Sonia Livingstone and Amanda Third, for instance, underscoring how:

the persistent exclusion of children living with disability illustrates a host of challenges associated with intersectionality online as offline. Such challenges are particularly acute online because of the hitherto lack of flexibility or contingency in the regulation of digital resources and infrastructure by comparison with the nuanced possibilities for shaping social norms and opportunity structures offline.

(Livingstone & Third, 2017, p. 665; see also Livingstone & Bulger, 2014)

If the scene is set for the late flourishing of research and children with disabilities and digital media, three questions need answering:

1. Do the frameworks, concepts, approaches, resources, and partnerships exist that are needed?
2. What might hold back work (or constrain the terms upon which it unfolds)?
3. What research, approaches, relationships, and engagement might/should emerge and be encouraged?

With this backdrop in mind, this chapter aims to put the topic of children with disabilities on the agenda for digital media research. The discussion is underpinned by two linked ideas, namely that: 1) children with disabilities are an important group to include when aiming to gain a comprehensive understanding of digital media and children; 2) beyond that, critical understandings of disability offer us important theoretical, policy, and practice insights into how to approach digital media, especially in relation to children.

The discussion below structured as follows. First, this chapter brings into dialogue the state-of-the-art research and conceptualisations of children and digital media with accounts of children with disabilities, and considers how disability and digital media might be understood. Sketching this kind of theoretical synthesis leads us to draw attention to: the diversity of disabilities and impairments; the sense in which, if children figure as still-to-become full subjects and human, then children with disabilities are even further behind such a liminal position; the ways in which emergent, dynamic conceptions of children with disabilities are entangled with socio-technical arrangements of digital media. Second, the authors discuss the ways in which children with disabilities are imagined in relation to digital media. A central issue is that underpinning much discourse, ideas, and arrangements of digital media are problematic ‘disabling’ concepts about what ‘normal’ communication entails. As disability and technology scholars have suggested, this is a serious problem for understanding media and communication when people – such as children with disabilities – do not fit into the default concept of human (as able-bodied). The chapter then contrasts these often limited, particular, and misleading imaginaries with the materialities of affordances, use, innovation, and contexts of children with disabilities’ appropriation and enlistment in digital media. Here the authors offer an overview and discussion of key aspects of children with disabilities’ use of digital media. The chapter concludes with suggestions for the research agenda in relation to children with disabilities and digital media.
Children, Disabilities, and Digital Media: “Something Strange Happens”

The study of children with disabilities has been highly influenced by particular concerns, including the imperative of understanding the developmental, social, educational, and other challenges of children – by dint of their impairment, the power relations of disability, and the disparities in resources – that they themselves, their families, and communities experience in supporting them in the face of adverse, oppressive, or unequal situations. Across social life and research, the discourse and conceptualisation of children with disabilities has been profoundly shaped by ideologies and institutions of disabilities, in which narrow and partial ideas of disabled childhoods have predominated.

As disability studies has developed in recent years to challenge inadequate and problematic models of disability, there has also been an important movement to rethink research on children with disabilities. In 2014, Tillie Curran and Katherine Runswick-Cole proposed the need for a distinct domain of “disabled children’s childhood studies” founded on three key principles:

1. [Such research would] take a very different starting point from other studies of disabled children by moving beyond the discussion of impairment, inequality and abuse to enable disabled children to step out from under the shadows of normative expectations that have clouded their lives.
2. Disabled children’s childhood studies demands an ethical research design that seeks to position the voice and experiences of disabled children at the centre of the inquiry.
3. Disabled children’s childhood studies seeks to trouble these practices in their local, historical and global locations.

(Curran & Runswick-Cole, 2014)

The research gathered together under this banner (showcased in Curran & Runswick-Cole, 2013; Runswick-Cole et al., 2018) represents a major step forward, indicating from a contemporary disability-studies-inflected location the major dimensions of the lives of children with disabilities, the way their worlds are made, inhabited, and imagined, and exploring the ways that researchers might respond.

Armed with this new understanding, if the research landscapes and literatures that study children with disabilities and digital media are re-entered, readers are apt to be disoriented and disappointed. While a full discussion lies outside the scope of this chapter, it is fair to say that still, most surprisingly, the bulk of work focuses on particular issues, and from a limited range of frames. In addition, disciplines such as education, social work, medical and health sciences, rehabilitation engineering, and Human–Computer Interaction (HCI), have produced much of the research on children with disabilities and digital media. For their part, disciplines such as media, communication, and cultural studies, internet, mobile media and communication, games, social media studies, sociology, anthropology, science and technology studies, and other associated disciplines have rarely produced research. Overall, common foci of research relating to children with disabilities and digital media include: where digital technology fits into rehabilitation; accessible and inclusive design; use of digital media to extend children with disabilities’ participation in educational settings; the role of emerging digital media in enhancing augmentative and alternative communication for children; digital media’s potential to support social support and inclusion in families, friendships, and communities for children with disabilities.

Since the late 1990s, the body of work produced has increased dramatically and includes many important insights and advances in knowledge. To be sure, these are vital issues. However, the way that children with disabilities and their engagement with media are conceptualised, studied, and engaged leaves great swathes of their experiences relatively untouched, and lacking acknowledgement, exploration, and reflection as to what significance their ‘invention’ of digital
media holds. The frustration with these orthodox approaches is nicely expressed in a recent study of young people with disabilities and gaming:

But when researchers address a certain subcategory of young people — those living with disabilities — something strange happens. Now, digital arenas are defined in terms of potentialities to directly alleviate troubles linked to their disabilities, and users are defined in terms of treatment-receiving objects. Electronic games plus disability build up a striking case; research in this field tend to overlook how digital activities — also for gamers with disabilities — belong to young people’s construction of meaning and connectedness. Researchers now tend to define gaming as a sort of instrumental ‘disability-help’ and show little interest in young people’s gaming engagement as persons rather than clients.

(Wästerfors & Hansson, 2017, pp. 1143–4)

Wästerfors and Hansson are among a growing group of researchers who make a persuasive case that the current research is simply not good enough, first and foremost because it leaves us lacking fundamental and vitally important insights and knowledge into the lives of children with disabilities. All in all, there is as yet little work that explicitly responds to or brings together the dual imperatives represented by disabled children’s childhood studies, as set out by Runswick-Cole and collaborators, and various other scholars, and the new trajectories and approaches for work sketched by key researchers in children and media that would take international, intersectional disabilities as a cutting-edge future topic. There is every reason to think digital media is more than ever central to the lives of very many children with disabilities — as often remarked in relation to digital media and social life generally; but researchers do not know as yet in what ways, and with what significance. So, it is a priority to consider how to transform research in this area, and secure its integral and generative contribution to research and conversations on children and media generally.

**Imagining Digital Media and Children with Disabilities**

To understand the layers of deep conceptual and attitudinal bedrock that needs dismantling, some basic understanding about how disabilities are still imagined in relation to digital media is required. A good place to start is at the heart of things, by identifying and interrogating problematic ‘disabling’ concepts about so-called ‘normal’ communication (Alper et al., 2015). These concepts underpin much discourse, ideas, and arrangements of digital media and, as disability and technology scholars have suggested, are a serious problem for understanding media and communication when people — such as children with disabilities — do not fit into the default concept of human (as able-bodied) (Alper, 2017b; Ellcessor, 2016; Ellis & Kent, 2011; Roulstone, 2016). Following this, the chapter explores three key approaches to the study of children and digital media and their relationship to deficit approaches to both disability and childhood.

From the time they are born, children are subject to a series of tests and assessments to ensure they are developing along a ‘normal’ continuum. There are many online checklists parents can consult about their child’s development, particularly with reference to communication. Communication is both a key site of assessment and a mechanism through which to assess. For example, the Victorian State government in Australia offers this list of problems that should prompt parents to seek help:

- You think your baby or child has difficulty hearing;
- Your toddler isn’t speaking at all by two years of age;
Your child doesn’t understand what you say by two years of age;
Your child stutters or has some other form of speech difficulty;
You have problems communicating with your child.

(Better Health Channel, 2018).

The role of digital communications in assessing these milestones is suggested by work on pivotal elements of emerging digital media, such as algorithms. Consider, for instance, Michele Willson’s interrogation of the intersection between algorithms that “surveil, interrogate, manipulate and anticipate activities and outcomes”, on the one hand, and the “social, cultural and political discourses that imagine the ‘ideal’ child” (Willson, 2018, p. 1), on the other hand. While Willson does not focus on the disabled child in this paper, her account is helpful because it underscores the way in which families, businesses, and governments all make use of algorithms within a health framework (amongst others) to recognise normal development and facilitative diagnosis and intervention. This is a potential new front opening up in the profoundly normative ways that communication is conceived and operationalised for children with disabilities – where disability meets health in the new landscapes of digital media and consumption, raising many questions about their digital citizenship (Goggin, 2016; Third & Collin, 2016).

The underlying structural dynamic in communication flows from the way in which both the ideal and the norm are defined in opposition to disability (Davis, 1995; Garland-Thomson, 1997; Goggin et al., 2017; Kumari Campbell, 2009; McRuer, 2006). Davis argues that because no one human can meet the ideal, people strive for the norm or rely on other bodies deemed less like the norm than their own to feel better about not achieving the ideal (Davis, 1995, p. 25). Similarly Rosemarie Garland-Thomson delineates between the normate and extraordinary bodies. While the normate is defined as “the corporeal incarnation of culture’s collective, unmarked, normative characteristics” (Garland-Thomson, 1997, p. 8), extraordinary bodies, such as the disabled body in its various forms, act as a metaphor for society’s concerns, preoccupations, and anxiety. The fundamental issue, explored by many disability studies scholars, is the unsettling ways in which incidence and experience of impairment upturns accepted concepts of humanness (Garland-Thomson, 2019; Goggin & Newell, 2005; Kumari Campbell, 2009; Taylor, 2017). Consideration of children’s use of digital media reveals the ways childhood functions as a repository for ideologies of disability (Alper & Goggin, 2017). For example, children with disabilities are framed in popular discourse as beneficiaries of digital media (Alper, 2014). Affordable and portable tablet computers present new opportunities for children with disabilities to communicate. While this is a real phenomenon, it is often only heard about through uncritical celebratory popular news media narratives in which these children are presented as a homogeneous group with little recognition of differences related to class, cultural capital, and other forms of privilege (for a critique of this phenomenon see Alper, 2017a).

Within current discussions of digital media it is common for a normative approach to be taken, excluding people along age, race, ability, nationality, and generational lines (Livingstone & Third, 2017). Indeed, the preferred user of digital media typically upholds an able-bodied norm (Ellcessor, 2016; Johnson, 2019; White, 2006). Thus, the debate surrounding children and digital media has been imagined and framed in particular ways – typically proceeding from a medical model framework and focussing on particular, narrow notions of risk. Again, the discussion excludes children with disability and assumes the child potentially accessing digital media possesses a normative body and mind – with the result that important specific issues for children with disabilities can be overlooked (for example, see the discussion of information ethics and privacy issues for children with communication disability in Meredith et al., 2018).
A common example lies in often-expressed concerns for the impacts of ‘screen time’ on children’s brains, a frequent source of moral panic. Children’s use of digital media is an interdisciplinary concern; scholars within cultural and media studies, education, health, psychology, and medicine all focus attention on this topic. Deficit approaches cataloguing the negative or antisocial consequences of media usage popularised during the early twentieth century continue to dominate many of these disciplines. As Meryl Alper reflects:

[Instead of the lopsided concern with the internet ‘changing’ children’s brains, we need to take a step back and identify societal biases in how we think about minds and bodies, reflect on how these assumptions inform research questions (and research funding), and ultimately shift understandings of the ‘normal’ brain in order to more fully account for the neurodiversity of all children and their uses of new media.]

(Alper, 2016)

The broader issue is highlighted in the criticism levelled by scholars that childhood media studies remains characterised by a skewed focus on so-called ‘WEIRD’ families (Western, Educated, Industrialised, Rich, and Democratic) at the expense of other groups, including children with disability (Alper et al., 2016).

What we find is that the disabled child is both absent and hyper-visible in the discussion of society, individuals, and digital media – a peculiar resonance of a long-observed overarching dynamic in the economies of visibility in disability (Ellis & Goggin, 2015; Hirschmann, 2015). For example, in a study of digital media usage by children and adolescents published in Paediatrics, digital media, following in the wake of traditional media before it, is seen to have negative consequences on children and adolescents who are framed in normative ways (Reid Chassiakos et al., 2016). Disability enters the discussion only when the researchers turn to a consideration of health and recognise the benefits of community belonging in social media spaces dedicated to particular illnesses, disability, and other marginalised identifications (Reid Chassiakos et al., 2016, p. 6).

Use of digital media by children with Autism Spectrum Disorder (ASD) is of concern within both medical and educational fields (Desch & Gaebler-Spira, 2008; Odom et al., 2015). In a review of literature published between 1990 and 2013 (Odom et al., 2015) regarding use of technology at school, home, and in the community by adolescents with ASD, Odom et al. acknowledge the efficacy of technological support including digital technologies but call for continual reassessment and systematic revaluation. However, some researchers still foreground the primacy of risk in arguments for limiting screen time for youth with disability, even when digital media is used to augment communication (Reid Chassiakos et al., 2016, p. 6). Such work neglects the rich research and alternative theorisations of autism that have emerged in research and disability activism (see, for instance, Alper, 2017b; Jack, 2014). In addition to this medicalised deficit discourse, digital media use by children with disability is explored within a narrowly conceptualised educational context. On the one hand the benefits of the use of digital technology is considered ‘self-evident’, yet, on the other hand, questions remain regarding quality for children with disabilities in educational contexts, especially if we have in mind the full range of international settings (Larsen, 1995; Musengi & Nyangairi, 2019).

A major challenge to the continuing primacy of legacy ‘deficit’ approaches – such as the medicalised approaches to disability we have discussed, or the evolution of concepts and canonical topics associated with disability developed in only partially decolonised fields such as ‘special education’ (now often renamed as ‘inclusive education’) – has come from the rise of disability human rights – and the central place it accords digital technology in the present conjuncture. The United Nations Convention on the Rights of Persons with Disabilities
(CRPD) defines people with disability as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2006). This recognition of the disabling impacts of both the body (impairment) and society therefore proceeds from the so-called social model of disability. The social model is one of a number of approaches that have developed since the 1970s that offer a direct contrast, and challenges, to the more pervasive biomedical and charity models of disability. Digital media features prominently throughout the CRPD (Alper & Goggin, 2017; Ellis, 2019) — with the result that governments, civil society, and technology providers alike have been paying greater attention to questions of disability and digital technology. What is especially promising are the ways that the CRPD builds on, combines with, and indeed goes beyond the Convention on the Rights of the Child (CRC) (Alper & Goggin, 2017; Livingstone & Third, 2017). As Ralph Sandland suggests

the way the CRPD restructures orthodox understandings of rights and their limits, rejects tests of capacity as disempowering and discriminatory, and does so on the philosophical basis of a ‘social model’ of disability, raises far-reaching and awkward questions regarding the continued viability of an essentialist, status-based and non-socialised construction of children and their rights.

(Sandland, 2017, p. 126)

The prominence of rights as a frame in contemporary disability research, practice, policy, and politics makes it the most readily available approach for breaking the lock held on research on children with disabilities and digital media by the disabling paradigms of previous traditions (see, for example, Bosman et al., 2015). However, rights too have their shortcomings and exclusions — as an often critically unexamined lens that overlooks many aspects of the topic. Rights approaches to children with disabilities, then, can be complemented and extended by many other productive approaches, including work that seeks to rethink citizenship (Goggin, 2016; Third & Collin, 2016), social inclusion, ethnographic work (including the new area of digital ethnography), and research on the complex intersectional cultural and social dimensions at play (e.g., Atkin & Hussain, 2003; Bachen, 2015; Banaji, 2017).

**Conclusion and Future Agenda**

An archaic adage holds that children should be seen but not heard. For children with disability it is often the case that they are also not expected to be seen, particularly in the case of digital media (cf. Renwick, 2016). Children and their impairments can disappear on the other side of the screen, rendering their disability invisible along with the unspoken demands for universal design and digital inclusion that disability visibility and advocacy champion.

Future directions in research for this group need to start by acknowledging and exploring from the perspectives of children with disabilities regarding what their digital media concerns are, and not assuming that they directly map onto other children’s or adults’ issues. There needs to be a greater understanding of how children with disabilities fit and reconfigure the full range of existing and emerging digital media and platforms. What are their preferred and specific formats, media, social and digital practices, meanings, and platforms? A fuller understanding of the ‘invention’ of digital media by children with disabilities across all settings is essential. In keeping with a general imperative in media studies, this includes more international work (Sakr & Steemers, 2017; Watermeyer & Goggin, 2018) and theorisation and research on non-traditional issues of pleasure, fun, play in/with digital media for children with disabilities.
To make this transformative project possible, there needs to be greater engagement with policymakers, children with disabilities and their families, partners, allies, and supporters around rights for children with disabilities in the digital age and a greater level of engagement and ownership of co-research with this diverse group to extend the disability activists’ dictum of “nothing about us without us” (Liddiard et al., 2019). Scholars must develop intersectional children’s media research that is transformed by embracing the perspectives of children with disabilities and champion the ensuing innovative approaches, concepts, methods, and, above all, relationships.

Happily, such an overdue shift will help researchers and society more broadly rethink children and digital media via the insights provided through this sharpened, deepened, and enriching focus on disability.

References


