

Bregt Lameris and Lesley Verbeek

## Introduction: Disability Media Histories

We call for a disability media studies that advances the field by integrating disability and able-bodiedness as a category of analysis for film and media scholars.<sup>1</sup>

In 2017, ‘Disability Media Studies’ (DMS) was coined by Elizabeth Ellcessor and Bill Kirkpatrick as the title of their anthology in which they discuss and present academic work combining disability and media studies.<sup>2</sup> Since then, DMS has grown as a new research field, covering the wide range of topics that media studies is known for and the large variety of technologies it researches, i.e. film, television, sound, prosthetics, and transmedial cultural objects. However, the disability studies perspective opens up new research questions about the functionalities of media technologies and representations of deviant bodies and behaviours.

Indeed, in media studies, special interest groups were started on disability and media (e.g. SCMS, GfM, NECS), discussing the intersections of media and disability. In teaching, disability is also increasingly included in media studies curricula, not necessarily in separate courses, but as a topic to discuss.

With this special issue of TMG (Journal for Media History), we wish to contribute to this new field with articles that approach the topic from a media historical perspective.

### Historical overview

Alongside global activism for emancipation led by marginalised peoples, several new fields of study emerged in academia during the early 1970s, including women’s and then gender studies, postcolonial studies, and queer studies. These fields have a 10-year head start on disability studies, established in the early 1980s, even though disability activists had already been fighting for emancipation alongside other movements since the 1950s. The first large-scale improvements in quality of life on a legal, governmental level did not occur until the 1970s, starting in the United States. Only in 2006 did the United Nations draft the Convention on the Rights of Persons with Disabilities, which most nations have signed but is only upheld by a few; the Netherlands, for instance, received firm criticism from the United Nations in August 2024 for neglecting disability rights.

Disability studies, although not yet as incorporated into academia as other such fields, continue the work by deconstructing disability and disabled people's position in society. It reflects on the dependence of the definition of 'disability' on how it is perceived in a socio-cultural and political context. We can see this in the emergence of the social model of disability in the 1980s, which challenges the medical model of disability that had been dominant until that moment. In short, the medical model understands disability as located solely within the impairment of an individual 'body-mind' and sees this as something in need of prevention or cure. The social model considers disability as the result of inaccessible and discriminating environments, such as ableist institutions and physical barriers in public spaces.

There are currently many more models of disability to account for the complicated myriad of factors contributing to a 'disabled identity' and the socio-historical and political context of disability, among which, for instance, a cultural model, a political/relational model, and a complex embodiment model.<sup>3</sup> Such models respond, among other things, to the binary opposition between the medical and social models, as the social model has been criticised for overlooking the materiality of disability. As Liz Crow explains: 'Most of us cannot just pretend that impairment is irrelevant because it affects every aspect of our lives.'<sup>4</sup> In other words, an impairment itself can still be considered disabling, as certain impairments are still embodied and experienced regardless of, or together with, external societal barriers (e.g. chronic pain or fatigue).

In their article *Performing Plurality* in this special issue, Hoek et al. unravel the complexity of how a 'disabled identity' is constituted by highlighting embodiment and aspects from the dominant culture and online counternarratives as dialectic constituents. For instance, the authors emphasise the influence of historically stigmatising labels, psychiatric language and media portrayals on the generally negative public perception of dissociative identity disorder (DID) and discuss the destigmatising potential of online self-representation and the need for community-driven neologisms denoting specifics of the disabled experience and its embodiment that are not captured in the psychiatric/medical paradigm.

In the early 21<sup>st</sup> century, critical disability studies (CDS) emerged to position disability in academic and activist conversations and practices regarding intersectionality. Nirmala Erevelles, for instance, has argued that 'the ideology of disability has been used to justify the racial and gendered division of labour based on heteronormative notions of the family and, in doing so, organises class relations in a capitalist society.'<sup>5</sup> CDS brings disability and ableism into conversations with other

oppressive structures, such as patriarchy, capitalism, colonialism, and racism, and understands marginalised and oppressed identities and communities as having historically been co-constituted through these structures. Further, CDS aims to bring attention to disability studies and activism in the global south, as this has traditionally been largely overlooked in the Eurocentric disability studies of the global north, including in the medical and social models of disability.<sup>6</sup>

From the late 1980s, studies were published on media representation of disability and mental illness.<sup>7</sup> In 1999, The Cinema and Disability Group (CDG) organised a conference called SCREENING DISABILITY at the University of Iowa. The aim was to organise an event to establish film and disability scholarship as a new field. The CDG considered studying disability and cinema as a separate field of research, combining disability and cinema studies into something new. Christopher Smit, the organiser of the event, writes: ‘The combination of both fields added to the independent construction of theories, methodologies, and aesthetic principles that fuse several concerns in one, allows cinema and disability studies to gain the status it requires to remain a contribution in the humanities.’<sup>8</sup> However, this attempt to bring disability and film studies together was not yet sustainable. This might be because of the timing of this project, which had a strong focus on film and cinema at a time when film and cinema started to be increasingly understood as one among many media. As we all know now, during the late 1990s and the first decade of the 21<sup>st</sup> century, new media technologies would shake up the field of film and cinema studies in academia, resulting in a merger of digital media, television and cinema into larger media studies departments.

This also explains why the books and studies related to Disability Media Studies focused mainly on the cultural aspects of representation and less on the foundational elements that make up media studies. Still, we might want to consider them as a starting point and announcement of the new field Disability Media Studies that we are currently trying to establish.

## **How does Disability Media Studies transform research?**

Interestingly, similar to Smit’s observations about new theories and methodologies emerging from combining disability and film studies, Disability Media Studies also offers space for such new perspectives and approaches in both fields. For example, it allows for an intersectional and multi/interdisciplinary focus on the multiple perspectives of media studies, e.g., the study of representations, media technologies, media industries and the in- or exclusion of disabled makers, or

intersectional and postcolonial perspectives on media and disability. All this is reflected in the diversity of topics the authors in this edition have brought to this journal. As such, it:

[...] bridges two fields that each have something to gain from being put into conversation. Disability studies, which has tended to focus on textual analysis, stands to benefit from a more expansive and precise understanding of the technologies and industries that produce and have been shaped by modern conceptions of disability. And media studies is enhanced by a better understanding of how different types of embodiment have informed and been formed by technology, as well as greater attention to the way physical experience structures the form and content of media.<sup>9</sup>

Works in DMS can ‘reveal the unexpected insights and alliances that merge when media narratives are examined through the lens of disability’<sup>10</sup> and vice versa. In Florin Persson’s “Biblioscope: The construction and configuration of a Swedish reading apparatus for people with physical impairments, 1954–1966,” for instance, the media archaeology that is performed not only critically reviews the process of a technology being designed for patients but also offers an insight into the efforts that have historically – and for many of us possibly unexpectedly – been made to accommodate people with disability/illness. This allows us to rethink our relationship both to disability/illness and to everyday technologies and how we embody these technologies.

Furthermore, DMS is necessarily intersectional and multi/interdisciplinary as, arguably, the (non-teleological) road towards DMS consists of ventures by disability and media scholars into psychoanalytic film theory - which aims to study the psyche / psychological condition of both film characters and audience - and theories on reception and representation from fields such as feminist film theory. Taking an intersectional and interdisciplinary approach to film analysis, for instance, Debinski’s “‘A Part of Some Other’s Experience’: *Dark Victory*, Interdependence, and the Limits of ‘Normalcy’ in the 1930s” reveals a new perspective on an approach to disability in the 1930s by shedding light on the film *Dark Victory* and the interbellum society in a way that highlights signs of interdependency and co-habitation of abled and disabled bodies. This is exemplified in the female relationship’s interdependency in the film and in the interdependency depicted in historical images of two highly public and influential disabled figures at the time, President Franklin D. Roosevelt and Hellen Keller.

Another fascinating new perspective is the role of the disabled body in creating art. Looking at the history of media and culture through the lens of disabilities can bring a new understanding of the history of various cultural media practices. As Mills and Sterne noticed in 2017, this new approach can help us understand how disability has for example, shaped music. A deeper understanding of composers' disabilities can help us understand how their impairments (e.g. deafness, blindness) have shaped their creative agency and, thus, their art.<sup>11</sup> For this special issue, Gilker's "(Sounding) Silence: Dysfluency Mediated Otherwise" precisely studies how the disabled body/mind should be considered if we want to understand the music of specific composers in relation to their situated identities and social positions.

## **Towards epistemic justice**

Disability activists aim to challenge the status quo for people with disabilities as a marginalised group, using the now famous slogan 'nothing about us without us.' In the Netherlands, among other countries (e.g. Ireland, Australia), we see a shift towards doing inclusive research with people with intellectual/learning disabilities (ID) and neurodiversity in (academic) research.<sup>12</sup> This is essential in adhering to the 'nothing about us without us' credo, as inclusive research with people with ID challenges the dominance of logocentric propositional knowledge within knowledge production in academia and contributes to epistemic agency and justice.<sup>13</sup> Several authors contributing to this journal are experts by experience themselves.

Currently, we are trying to make DMS more inclusive, for example, with a workshop on doing inclusive research at the NECS conference in Izmir this past summer and by working together with a co-researcher / expert by experience on a PhD research project on eugenics and the media representation of intellectual disability. We intend to push this further in various forms, e.g. applying for grants to hire further experts by experience when studying topics in disability media studies.

Finally, questions of the (media) archive are pivotal. Since disability and neurodiversity are marginalised in our society, they are understudied in archival and heritage studies. As a result, their voices need to be more present in the (media) archives. Recently, there seems to be an emerging effort to 'crip the archives' by scholars and activists with disabilities, similarly, for instance, to the decolonisation efforts of the FIAF cataloguing committee.<sup>14</sup> For instance, the website DisPLACE, run

by Manon Parry, Paul van Trigt and Corrie Tijsseling, aims to collect information on Dutch disability history.<sup>15</sup>

Additionally, the Koninklijke Bibliotheek, the Institute for Sound and Vision, and other partners are developing research projects aimed at finding ways to make Dutch archives more accessible for people with disabilities. Internationally, crippling the archives is done through the lens of intersectionality and accessibility.<sup>16</sup> This includes new independent initiatives to create (accurate) disability archives (Disability Archives Lab; Disability Visibility Project) with the understanding that past and present media representations determine ‘crip futures’.<sup>17</sup>

The historical and historiographical perspective on the representation of disability and neurodiversity is understudied. Rachel Adams illustrates the richness of such an approach in her brief intervention on Matthias Buchinger and the intersections of media and disability in the past.<sup>18</sup> Finally, in Disability Media Studies, the Eurocentric and Anglo-Saxon focus is a problem to address (and as such, perhaps it is already time for a Critical Disability Media Studies).

In all, bringing media and disability studies together into Disability Media Studies will bring new perspectives through dialogue and expected synergy.

## Structure of this issue

The articles special issue opens with Anna Debinski’s “‘A Part of Some Other’s Experience’: Dark Victory, Interdependence, and the Limits of ‘Normalcy’ in the 1930s”, which discusses the topic of care and interdependence in the 1930s, with the film *Dark Victory* (1939) as a starting point. In this film, Academy Award-winning actress Bette Davis plays Judith Traherne, a woman facing blindness and death from a brain tumour. At first sight, the film seems to reinforce stereotypes of disabled individuals as pitiable, dependent on others, and no longer able to live an everyday life. However, Debinski argues that a deeper historical perspective suggests otherwise. She shows that the film can also be interpreted as emphasising the value of *interdependence* and care. As such, the film countered the era’s dominant ableist and eugenics ideologies that isolated disabled people by stigmatising their dependency. To substantiate her argument, Debinski elaborates on historical figures of the time, such as Helen Keller and Franklin D. Roosevelt, as well as activist groups such as the League of the Physically Handicapped. These historical figures and groups promoted interdependence as a value of humanity. As a result, the film reflects a counter-discourse of the 1930s that went against the eugenicist myth of absolute independence and promoted the value of shared human reliance.

From disability representation in film, we pivot to subversive disability artistry in music: in “(Sounding) Silence: Dysfluency Mediated Otherwise,” Andi Gilker establishes the works of dysfluent artists Alvin Lucier and JJJJerome Ellis as building on John Cage’s legacy and as contributing to an anti-ableist media ecology. In Cage’s 4’33” (1952), a 4 minute and 33 second ‘silent’ piano piece, during which attention is drawn to the precise *lack* of silence in the environment, the avant-garde composer challenged normative expectations of music and the binary of silence and sound. Lucier and Ellis’ work, in turn, challenge the normativity and supremacy of fluency in speech, silence/sound and temporal unfolding, creating ‘crip time’, by incorporating dysfluency as a central component in their art. Additionally, attention is given to other aspects of these artists’ identities, creating an intersectional understanding of their (subversive) social positions within music history.

As an insightful contribution to new media history, Liorah Hoek, Louis van den Hengel, Inge van Nistelrooij and Alice Schippers, explore the affordances of YouTube in “Performing plurality Meet the Alters vlogs on YouTube as breeding grounds for epistemic justice.” Throughout its history and ever-growing popularity, YouTube (founded in 2005) allows people to tell their own stories without the types of gatekeeping that occur in traditional media and with direct interactions with their audiences. Vlogs (video logs) are a way for people with Dissociative Identity Disorder (DID) to challenge the societal stigmas they face and to challenge the medical paradigms that only understand DID as a psychiatric disorder rather than as an identity. These videos can provide viewers with epistemic and hermeneutic resources for understanding (their own) plural identities and offer an alternative to the stereotypical and harmful ways DID has historically been represented in traditional media.

Erik Florin Persson’s “Biblioscope: The Construction and Configuration of a Swedish Reading Apparatus for People with Physical Impairments, 1954–1966” is a fascinating work of media archaeology that delves into a niche historical development with far-reaching implications. In the mid-1950s, Gothenburg-based photographer Andrej Gavrusjov developed the Biblioscope, a microfilm reading device specifically designed for hospital patients with physical impairments. Over the next decade, these devices and microfilmed books were distributed to hospital libraries across Sweden. However, by the mid-1960s, the Biblioscope was discontinued and largely forgotten. This article revisits this overlooked technology. While primarily intended for patients with physical impairments, the Biblioscope anticipated the modern use of digital books on portable devices. By examining the Biblioscope, Persson contributes to disability media studies and highlights how many media technologies we now take for granted were initially conceived to address the needs of people with disabilities.



We close the special issue with an interesting article by Jan Müggenberg and Andreas Wagenknecht, who analyse the AAC from a historical-biographical perspective. As a result, they successfully show the importance of an interdisciplinary approach in Disability Media Studies. They propose a perspective on media technology as an assistive entity, creating an interdependence of technology and body/mind that produces new possibilities and opens up new ways of considering and working with media. As a result, they convincingly show how the interplay between technological possibilities and individual practices shapes diverse ways of living. Finally, by examining the interactions between technological advancements and reconstructions of user experiences, they aim to develop a comprehensive, empirically grounded understanding of assistance and assistive communication media technology.

**Disclaimer:** As guest editors, we would have wanted to experiment with AI to create accessible versions of the articles, read-aloud versions, simplify texts, and use colours and fonts to make articles better readable. Unfortunately, due to technological limitations, this was not yet possible. We hope to bring awareness to academic publishing that accessibility is also a form of openness, and we apologise that this special-issue does not yet fulfil those needs.

## Notes

1. Elizabeth Ellcessor and Bill Kirkpatrick, "Studying Disability for a Better Cinema and Media Studies," *Journal of Cinema and Media Studies* 58, no. 4 (2019): 139.
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9. Rachel Adams, "Afterword I: Disability in Disability Media Studies," in *Disability Media Studies*, eds. Elizabeth Ellcessor and Bill Kirkpatrick (New York University Press, 2017), 358.
10. Adams, "Afterword I," 360.
11. Mara Mills and Jonathan Sterne, "Afterword II. Dismediation-Three Proposals, Six Tactics," in *Disability Media Studies*, eds. Elizabeth Ellcessor and Bill Kirkpatrick (New York University Press, 2017), 375.
12. Jeroen Knevel et al., "Experiences of Inclusive Action and Social Design Research with Social Workers and People with Intellectual Disabilities," *Social Sciences*, 11, no. 3, (March 2022): 121; S. Sergeant, H. Sandvoort et al., "On the Road Together: Issues Observed in the Process of a Research Duo Working Together in a Long-Term and Intense Collaboration in an Inclusive Research Project," *Social Sciences*, 11: no. 185 (2022); Miriam Zaagsma et al., "A Closer Look at the Quest for an Inclusive Research Project. 'I Had No Experience with Scientific Research, and Then the Ball of Cooperation Started Rolling'," *Social Sciences*, 11, no. 186 (2022); Lesley Verbeek et al., "Understanding Epistemic Justice through Inclusive Research about Intellectual Disability and Sexuality," *Social Sciences*, 13, no. 8 (Aug. 2024): 408.

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18. Adams, “Afterword I”.

## Biographies

**Dr. Bregt Lameris** is working as a senior lecturer in media studies at the Open University in the Netherlands. In 2023, she successfully finished her habilitation in Film and Media Studies at the University of Zurich. Her research interests include colour in media, media archaeology, film archiving, film historiography, affect, emotions and subjectivity, media and mental health, and disability media studies. In 2017 she published her first monograph, *Film Museum Practice and Film Historiography. The Case of the Nederlands Filmmuseum (1946-2000)*, which is available in Open Access through Amsterdam University Press. Her second monograph, *Feeling Colour. Chromatic Embodiment in Film Culture (1950s-1960s)* is currently in production and will be published by Open Book Publishers.

**Lesley Verbeek** is a PhD researcher at the Open University in the Netherlands, where she studies audiovisual media representation of people with intellectual/learning disabilities, and its interaction

with (de-)stigmatization in society. She works together on this research with Daniëlle Amelsbeek (Amerpoort), a co-researcher and expert by experience with intellectual disability. Before this PhD she received a research master's degree in Arts, Media & Literary Studies at the University of Groningen. As a researcher she engages with the fields of film and media studies, critical disability studies, feminist posthumanism, critical future studies and indigenous studies.

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