

# Emma Ben Ayoun

## Editor's Introduction

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It has been nearly 30 years since Martin Norden's *The Cinema of Isolation* famously argued that *isolation* was one of the defining characteristics of the experience of disability in the twentieth century, and that disability cinemas, however varied they might seem, returned time and again to the space of solitude, of an unwilling extraction from the social world. The kinds of separation written about by Norden are perhaps now best understood as figurative: disability, if it can be agreed to be anything at all, is a kind of *experience* of differentiation, filtered through myriad discourses: medical terminology, the institutional language of "accommodation," and most of all, the far more diffuse and unstable cultural language of bias and stigma, one that alternately conceives of and represents disability as pitiable, contagious, inspiring, terrifying, impotent, grotesque, duplicitous, alluring, mysterious, deserved—but always, always *other*, a population always asked to do two impossible things at once: to account for (and, often, advocate for) itself as human, and, as Sharon Snyder and David Mitchell, among many others, have written, to symbolize, to stand in for *something*: difference, the uneasy contours of the human, the unknowable, the "body," whatever that may be.

Much has changed in these 30 years, both for the state of disability media and its study. Scholars and activists have compellingly argued that interdependence and collaboration are just as central to the experience of disability as solitude, if not more. Disability, after all, can make many kinds of labor impossible and often requires active caretaking. A fight for autonomy and self-determination, disability activists remind us, is not the same thing as an adherence to the capitalist myth of the self-made man. Documentaries like the recent *Crip Camp* alert us to a long history of collective organizing both within disability justice communities and in tandem with other activist groups. Moreover, the advent of digital media has shifted the terms of image-making and access, both in terms of film production and distribution: for example, in her 2017 documentary *UnRest*, Jennifer Brea, who is grappling with the sudden

onset of Myalgic Encephalomyelitis (ME), more commonly known as Chronic Fatigue Syndrome, conducts digital interviews with other ME patients, patients who, like her, are often unable to leave their beds for more than short periods of time, which would have rendered conventional face-to-face interviews impossible.

YouTube, Vimeo, and other social media sites make it much easier for disabled filmmakers and artists to share their work widely and on their own terms; these shifts are at least partially responsible for the efflorescence of what might be called "new disability media" of the past decade, a set of media objects that not only value their creators' perspectives but engage with disability as a site for experimentation, play, potential. The work of Christine Sun Kim, Alison O'Daniel, Jordan Lord, Johanna Hedva, Reid Davenport, and so many others speaks to this shift. And media scholars have responded in kind, engaging with these artworks not, as Norden and his peers might have done (and in many ways *had* to do), as suspicious dispatches from some collective unconscious but, instead, as nuanced, creative expressions of life itself, in all its strangeness and diversity and endless change, in dialogue with one another, in dialogue with their cinematic predecessors. A cinema of isolation feels increasingly like a thing of the past.

Yet as I write this, in 2023, I am writing from three years into a global pandemic that is deeply marked by isolation: by lockdowns, by the reconfiguration of the workplace and the classroom, by the development of a new visual/virtual language of the everyday. For many disabled and immunocompromised people, there has not been a "return to normal," and public space remains fraught. Like all global crises, COVID-19 has already produced its own unique rhetorics, a key one of which is of collective isolation—the uncanny sensation produced by the fact that so many people have spent unprecedented amounts of time in their homes, that spending a maximum amount of time *alone* is necessary for the *public* good, and that access to isolation is, itself, a luxury for a very economically privileged few.

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And so we return, on very new terms, to isolation, one that is not Norden's subject "cut off" from the world but perhaps merely a new way of living in it. The global devastation wrought by the pandemic is inarguable, and I would be irresponsible, as a scholar of disability and cinema, to quickly transform it into a kind of teaching moment, to revive the medium's metaphoric imperative towards my own ends. But I am hopeful that, as it becomes increasingly impossible to keep up any pretense that the "normal" or "healthy" body is a stable or fixed entity, disability media studies, too, will take its rightful place in the field of media theory, no longer relegated to the academic margins. This issue is my humble contribution to that effort.

As I and many others have argued elsewhere, a disability studies approach to media allows us to think critically about not only the stakes of representation, but also the ways that cinema draws out the contours of the viewing subject, incites complex processes of identification and disidentification, and frames the body as a site of contact and signification. And the pieces included in this special issue each take very different approaches to their objects, from—in keeping with disability studies' history—a wide array of disciplinary backgrounds, but each with a commitment to facing, with openness and honesty, both the suffering that ableism has wrought and the radical possibilities that disability justice and disability theory can offer to our thinking, our art, and our work.

This issue opens with Nancy Stern, Lilly Padía, and Jan Valle's article, "Stories of dual isolation and confinement: disability under occupation in Palestine," which takes as its focus a 2016 documentary by Ramzi Maqdisi that focuses on the lives of disabled Palestinians living in Gaza and the Occupied West Bank. Padía, Stern and Valle consider the impacts of life under occupation on disability: both on the experience of everyday life and the fragile horizons of its subjects' futures. Their intersectional approach takes isolation quite literally in a powerful way: how can we think about access and mobility in a space characterized by geographic and political confinement? The essay that follows, Jacob Eli Goldman's "Not Isolation, But a Fragment," approaches the concept of isolation from an utterly different angle. Goldman's essay takes a careful look back at the nonverbal, deafblind, or merely noncommunicative subjects

of Jean-Pierre Gorin's *Poto and Cabengo*, Werner Herzog's *Land of Silence and Darkness*, and Primo Levi's *The Reawakening*: three vastly different case studies of isolation and its apparent effects on language. Goldman considers the paradox at the heart of any representation of isolation: if isolation, in its fullest form, can never receive a witness, then to make any attempt to reveal it reveals, in the end, only the desires that haunt that making. From that haunting, then, we move to Billie Anderson's "The Monstrous Disability and the Disabled Monster: Jeffrey Jerome Cohen's Seven Monster Theses and Disability Creationism," which also takes a historical turn. Anderson's essay methodically revises Jeffrey Jerome Cohen's classic, *Monster Theory*, in light of recent developments in disability scholarship as well as horror studies. Anderson argues that the monster's inherent marginality *and* its cultural ubiquity make it a particularly salient artifact for thinking disability. Maddy DeWelles' essay "Anything But Sorry: An inquiry into the cultural production of sorrow and the construction of childhood, dreams, and parenthood" also takes a cultural/sociological approach; DeWelles thoughtfully explores the rhetoric of sorrow surrounding Down syndrome through an analysis of the Canadian Down Syndrome Society's "Anything But Sorry" campaign, arguing that the discourses that would either view disability as sorrowful *or* resist sorrow entirely both fail to capture the complex web of feelings, dreams, and expectations that media representations of disability reflect and produce.

The next portion of this special issue contains two very different kinds of collaborations. First, Jose Miguel Esteban, Elaine Cagulada, Phil Kim, and Dedra McDermott's "Troubling Dance Film: A Documentation of *Panalangin seeks us...*" offers both a collective documentation of and reflection on the group's film, *Panalangin seeks us...*, a piece that its makers describe as "a dance film and more than a dance film." In considering the film's status as dance work and disability art, the collaborative and isolated components of its production, alongside a poetic transcript and collection of stills, the filmmakers allow their work to take on new and extended life, enacting precisely the kind of translation and boundary-blurring so vital to so many kinds of disability art and theory. Margrit Shildrick has famously taken up Donna Haraway's question—*why should our bodies end*

*at the skin?*—as a way to conceptualize disability and embodiment; these filmmakers ask, perhaps, why our films should end at the screen. Following their work is a roundtable discussion with Pooja Rangan, Tanya Titchkosky, and Neta Alexander, three interdisciplinary scholars—Rangan and Alexander hailing, broadly, from the world of media studies, and Titchkosky from sociology and education—whose significance to disability media theory cannot be overstated. In their dialogue, these critics—each of whom has written extensively and across disciplines—take stock of the current state of disability media, of the relation between disability, culture, technology, and image, and together, they speculate about a disability media landscape to come.

Finally, the issue closes with reviews of two recent works in disability theory: Sami Schalk's

*Black Disability Politics*, reviewed by Dineo Maine, and *Health Communism*, by Beatrice Adler-Bolton and Artie Vierkant, reviewed by Lewis Brown. These are not disability media texts, per se, though both do consider the stakes of representation in various ways. Rather, they are vital tools, I think, for any budding scholar of disability media: rich in history and provocation, these books extend far beyond any one discipline or imagined readership. If isolation itself, as I suggested at the start of this introduction, is subject to historical contingency, then so may be community: and I hope that the many diverse pieces in this issue come to form a kind of community unto themselves, full of dialogue, full of questions, full of listening, and always amenable to change.

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