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Research Paper

## Crippling the new normal: Making disability count



### *Infirmier le nouveau « normal » et faire compter le handicap*

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#### ABSTRACT

We have been conducting research in New York City across a variety of sites where the presence of disability is dramatically increasing and transforming consciousness regarding this form of human variation in locations as diverse as schools, medical laboratories, film festivals, homes and religious institutions. We have learned how families form new kinship imaginaries around the fact of disability and how disability publics emerge through a variety of media forms and art activists. This article also addresses questions of demographics and futurity that we have encountered in our work. The number of disabled citizens, currently estimated at almost 20% of the USA population, is predicted to increase significantly over the next decade, both as an expanding portion of the population and a growing absolute number. Given the inevitable increase in disability across the life cycle, we highlight that what some disability scholars/activists call “accessible futures” will remain under constant negotiation. At the same time, the initiatives of people with disabilities and their supporters are changing the face of both public and private culture, and most importantly, the shape of future imaginaries in which disability is understood as a central aspect of the human condition. We conclude by asking how disability publics played a role in the 2016 American Presidential election.

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## R É S U M É

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Nous avons mené des recherches dans divers sites où la présence de personnes handicapées augmente de façon rapide en transformant la conscience publique concernant cette forme de variation humaine dans des endroits aussi divers que des écoles, des laboratoires médicaux, et des festivals de films. Nous avons appris sur le terrain comment les familles forment de nouveaux imaginaires de parenté autour du handicap et comment les publics handicapés émergent à travers une variété de formes de médias. Cet article traite également des questions démographiques et futuristes que nous avons rencontré dans notre travail. On prévoit que le nombre de citoyens handicapés, estimé à près de 20% de la population des États-Unis, augmentera de façon significative au cours de la prochaine décennie, à la fois en proportion croissante de la population et en nombre croissant. Ce que certains spécialistes des handicapés appellent des « futurs accessibles » restera donc en négociation constante. En même temps, les initiatives des personnes handicapées et de leurs alliés changent le visage de la culture publique et privée, et surtout la forme des imaginaires futurs dans lesquels le handicap est compris comme un aspect central de la condition humaine. Nous concluons en demandant comment les publics handicapés ont joué un rôle dans l'élection présidentielle américaine de 2016.

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... the disability civil rights movement is by no means over, and the status quo today is just as much in need of change as it was in decades past. (Ne'eman, 2012)

This article is based on longstanding advocacy as well as more formal anthropological research concerning cultural innovation around the experience of disability in New York City (and the USA context more generally) for our book-in-progress entitled *Disability Worlds: Crippling the "New Normal" in 21st Century America*. Over the last decade, we have been tracking the increasing awareness and inclusion of disability – and especially cognitive difference – since the 1990 passage of the Americans with Disabilities Act (ADA), which celebrated its 25th anniversary in July 2015.

In our fieldwork we are working with subjects of all sorts: activists, families, visionary educators, scientists, artists, technologists, and media makers. From them we have learned how kinship, care giving, and public culture are all being reorganized, as the fact of disability is reconfigured over the life course. When a family member is diagnosed with a disability, relationships and expectations are often revised, creating what we call the new kinship imaginary. As disabled kin move through the life cycle, their atypical experiences reverberate into the lives of their families in ways that reframe taken for granted assumptions. Family members find themselves recognizing and reorganizing tacit norms about familial relations and the temporality of the domestic cycle; in that process, the culturally ordered unfolding of a normative life course can no longer be assumed (Ginsburg & Rapp, 2011). Their innovations in intimate daily life worlds that we have been chronicling are often the basis for the accidental activism that results when loved ones “bring the disability rights movement into our home” as one parent phrased it.

The families with whom we are working hail from many different racial, ethnic, class and religious backgrounds; many are involved in cultural advocacy projects that offer us an ethnographic lens on a broader picture. They help us to see the everyday implications of demographic projections about the future of disability in the USA and elsewhere.

In this article, we tack back and forth between our ethnographic findings on the everyday life of disability in New York City, and some of the key constructs that help us to understand them in relation

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