

# MAKING ACCESSIBLE FUTURES: FROM THE CAPITOL CRAWL TO #CRIPTHEVOTE

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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.”<sup>1</sup>

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## INTRODUCTION

This Article is based on long-standing advocacy as well as more formal anthropological research concerning cultural innovation around the experience of disability in New York City (and the U.S. 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

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<sup>1</sup> Ari Ne’eman, *What Do We Mean When We Say “Community?”*, YAI (May 29, 2012), <https://www.yai.org/blog/what-do-we-mean-when-we-say-community>.

twenty-fifth 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, caregiving, 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 expectations 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.”<sup>2</sup> Their innovations in intimate daily life, which 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 United States 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 to the history of the present as well as its future imaginary. In Part I, we focus on the demographic growth that has transformed the public presence of disability, including its increasing recognition in law and everyday life, what we (along with others) call “the new normal.” But normalization is an ongoing process; the inclusion of any range of disabilities is always incomplete. This social fact incites what has come to be known as “cripping,” which are acts of performative intervention that demand changes in exclusionary practices. This process and its potential for transformative “world making” is the subject of Part II, titled “Worlding.” In Part II, we address both the theory and practice of how subjects affect material and ideological changes in a range of cultural projects in alternative design, museum, and theater practices that we have encountered in our work as anthropologists. The next Part, “Screening Disabilities,” highlights the innovative and consequential role of screen media—from film festivals to YouTube platforms—made by, for, and about people with disabilities. These works, we argue, have been influential forms of visual activism, enabling their makers to

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<sup>2</sup> Rayna Rapp & Faye Ginsburg, *Reverberations: Disability and the New Kinship Imaginary*, 84 ANTHROPOLOGICAL Q. 379, 380 (2011).

represent themselves on their own terms. They also are screening to far more diverse audiences, thanks to adaptive technologies that enable heterogeneous participation on the part of those who were for too long excluded from such viewing experiences, including wheelchair users, blind, deaf, autistic, and other subjects. Our final Part, “#cripthevote and Beyond,” considers the dilemmas and potential of the so-called “slumbering giant” of an imagined, unified “disability vote,” through the lens of the 2016 American presidential race and its aftermath. We conclude where we begin by asking, “how do we make disability count?”

### I. DISABILITY, DEMOGRAPHY, AND POLITICAL ARITHMETIC

In America, disability is the fastest growing of any census category. Demographic facts may seem a remote abstraction from the lived realities of daily life and the need for political action. Yet, we found that “political arithmetic”—a phrase invented in the seventeenth century to describe the systematic collection of numbers pertaining to a nation’s population and economy—has enormous value in the present.<sup>3</sup> We turned to demography out of recognition that the percentage of those living with disabilities is rising in the United States and elsewhere, from its current estimate of around eighteen percent to an anticipated much larger proportion of the population by the end of the present century.<sup>4</sup> That increase is in large measure the consequence of improved medical care, enabling the survival of several categories of people: first, people born with disabilities and chronic illness who are now living far beyond the foreshortened life spans predicted in earlier periods. For example, when Samantha, daughter of co-author Faye Ginsburg, was born with the extremely rare degenerative genetic disorder, familial dysautonomia, we were told that her life expectancy was ten years. Sam is now twenty-eight years old, and her survival is no longer considered so exceptional as routine medicines—antibiotics and feeding tubes, for example—have changed the natural history of her condition from life-threatening to chronic, like that of many other disorders, such as cystic fibrosis and Down syndrome. Second, the category of disability is steadily propelled by the rapid expansion of the number of elderly living into extreme old age in the developed West—requiring an intensification of diverse

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<sup>3</sup> See Glenn T. Fujiura & Violet Rutkowski-Kmitta, *Counting Disability*, in *HANDBOOK OF DISABILITY STUDIES* 69–96 (Gary L. Albrecht, Katherine D. Seelman & Michael Bury eds., 2001); Julian Hoppit, *Political Arithmetic in Eighteenth-Century England*, in *THE ECONOMIC HISTORY REVIEW* 516–40 (Forrest Capie & John Hatcher eds., 1996).

<sup>4</sup> Faye Ginsburg & Rayna Rapp, *Making Disability Count: Demography, Futurity, and the Making of Disability Publics*, *SOMATOSPHERE* (May 11, 2015), <http://somatosphere.net/2015/05/making-disability-count-demography-futurity-and-the-making-of-disability-publics.html>.

forms of eldercare. This is reflected in a resulting spate of popular cultural works on topics that were taboo until recently. For example, surgeon and writer Atul Gawande's best-selling book, *Being Mortal*, examines the process of the decline and death of his own aged kin, as well as his older patients, and explores the limits of western medicine in assisting the infirm and dependent elderly.<sup>5</sup> Beyond the changing profile of childhood disability, chronic illness, and aging in the United States, we have huge numbers of veterans surviving the recent, longest war in American history with post-traumatic stress disorder and traumatic brain injury. And of course, this has all occurred in the context of the longstanding deinstitutionalization since the 1970s of people with a range of diagnoses, in particular those with the ever-increasing diagnoses linked to intellectual and emotional disabilities.

It is important to remember that undergirding these demographic expansions is the expectation that caregiving frequently falls to the family, especially women, or to underpaid (often immigrant) sectors of the labor market.<sup>6</sup> This circumstance characterizes nearly one in five Americans and many more people who are allies, caregivers, and intimate supporters. We place our work in the context of all these transformations, part of what we see as the new normal—a phrase that has emerged in response to this increasingly widespread presence of disability in everyday life, although the term has been used in many other relevant contexts as well.<sup>7</sup> As the *New York Times* noted in a 2013 article aptly entitled, *Disability Studies: A New Normal*, those raised after the passage of the ADA in 1990 are now in college or entering the work force. The article states that “[t]hey are educated, perhaps without even realizing it, in the politics and realities of disability, having sat in the same classrooms in a more accessible society.”<sup>8</sup>

But our title goes beyond the new normal: we added the word “cripping” in keeping with the language of disability studies and activism, where the once pejorative noun “crip”—used to stigmatize those with atypical gait or “cripples”—is resignified as a verb. Now, instead, crip indicates an effort to adopt this once negative discourse to positively embrace the concerns of disabled subjects, much as the word queer has been similarly rehabilitated. In the United States, the term crip has helped refresh the thinking of disability scholars and advocates,

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<sup>5</sup> ATUL GAWANDE, *BEING MORTAL: MEDICINE AND WHAT MATTERS IN THE END* (1st ed. 2014).

<sup>6</sup> AI-JEN POO, *THE AGE OF DIGNITY: PREPARING FOR THE ELDER BOOM IN A CHANGING AMERICA* (2015).

<sup>7</sup> *Origin of 'the New Normal' as a Freestanding Phrase*, ENG. LANGUAGE & USAGE, <https://english.stackexchange.com/questions/215012/origin-of-the-new-normal-as-a-freestanding-phrase> (last visited Oct. 1, 2017).

<sup>8</sup> Cecilia Capuzzi Simon, *Disability Studies: A New Normal*, N.Y. TIMES (Nov. 1, 2013), <http://www.nytimes.com/2013/11/03/education/edlife/disability-studies-a-new-normal.html>.

as Carrie Sandahl underscored over a decade ago, pointing out the fluidity of the use of the term.<sup>9</sup> A decade later, the American disability and queer studies scholar Robert McRuer called attention to

the defiant reclaiming and reinvention of crip . . . linked to the critical reinvention—by activists, artists, and scholars—of queer. Most important, queer and crip activism share a will to remake the world, given the ways in which injustice, oppression, and hierarchy are built (sometimes quite literally) into the structures of contemporary society.<sup>10</sup>

More recently, disability scholar Alison Kafer pointed out that crip is “a term that has much currency in disability activism and culture but still might seem harsh to those outside those communities.”<sup>11</sup> Yet, the term has generated critique in the disability studies community as well, as anthropologist Don Kulick and gender studies scholar Jens Rydstrom point out in their 2015 book on disability and sexuality in Scandinavia.<sup>12</sup> They underscore the minimal recognition in crip studies of those with severe disabilities who cannot join the ranks of activists or serve as exemplars, a concern we take extremely seriously. Nonetheless, we retain the concept of crippling as any intentional performative intervention that dramatically reveals the taken-for-granted inequities and exclusions that shape the experience of disability. A foundational instance of such potent political theater was emblazoned across American television screens over a quarter century ago when sixty activists abandoned their wheelchairs in 1990, performing the “Capitol Crawl” to ascend the steps of the United States Capitol, successfully publicizing the need for the ADA.<sup>13</sup>

That act of crippling helped to forge what became the new normal, when the ADA required barrier-free access so that people using wheelchairs could cross streets and enter public buildings like all other citizens. Yet, as anyone who currently navigates public space using wheels knows too well, the recognition of and material support for this new normal is imperfect at best.

Viewed thus, the new normal is always a work-in-progress and

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<sup>9</sup> Carrie Sandahl, *Queering the Crip or Crippling the Queer?: Intersections of Queer and Crip Identities in Solo Autobiographical Performance*, 9 GLQ: J. LESBIAN & GAY STUD. 25, 27 (2003).

<sup>10</sup> Robert McRuer, *Crippling Queer Politics, or the Dangers of Neoliberalism*, SCHOLAR & FEMINIST ONLINE (2012), <http://sfonline.barnard.edu/a-new-queer-agenda/cripping-queer-politics-or-the-dangers-of-neoliberalism>.

<sup>11</sup> ALISON KAFER, FEMINIST QUEER CRIP 15, 15 (2013).

<sup>12</sup> DON KULICK & JENS RYDSTRÖM, LONELINESS AND ITS OPPOSITE: SEX, DISABILITY, AND THE ETHICS OF ENGAGEMENT 13–17 (2015).

<sup>13</sup> *A Magna Carta and the Ides of March to the ADA*, MINN. GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES (Mar. 1, 2015), <http://mn.gov/mnddc/ada-legacy/ada-legacy-moment27.html>.

cripping is often essential to mobilizing its forward motion. In our research, we find frequent evidence of such projects, what we call “cripping the new normal,” across many cultural spheres from museums, to film festivals, to everyday design.<sup>14</sup> Yet, we were struck by the remarkable absence, until quite recently, of almost any discussion of disability’s increasing presence in the United States in the electoral political sphere. Where is the rigorous debate about how we, as a society, are going to successfully support and creatively incorporate a heterogeneous population that includes growing numbers of vulnerable citizens across the life span? This question haunts our increasingly neoliberal public sphere in which state support for those with disabilities is shrinking. We were temporarily heartened when, during the turbulent presidential electoral cycle for our 2016 elections, disability activist voices emerged via social media through a Twitter campaign called “#cripthevote,” urging the fifty-six million Americans who identify as disabled to exercise their bipartisan power as citizens representing the nation’s largest minority, a point to which we return at the end of this Article.<sup>15</sup>

Despite American legislation that mandates inclusion of people with disabilities in civic life, their uneven recognition is not only a reality in the present that demands our concern, but also shapes future imaginaries. This point is underscored by disability scholar Alison Kafer in her important book, *Feminist Queer Crip*. She argues persuasively that disability as a social category is continually rendered invisible and undesirable. As Kafer writes:

the value of a future that includes disabled people goes unrecognized, while the value of a disability-free future is seen as self-evident . . . casting disability as a monolithic fact of the body, as beyond the realm of the political and therefore beyond the realm of debate or dissent . . . [despite the fact] that decisions about the future of disability and disabled people are political decisions and should be recognized and treated as such. Rather than assume that a “good” future naturally and obviously depends upon the eradication of disability, we must recognize this perspective as colored by histories of ableism and disability oppression.<sup>16</sup>

Using another rhetorical register, but coming to the same conclusion, a study of *The Future of Disability in America*, by the Institute of Medicine, makes a similar point about the new normal. The

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<sup>14</sup> Faye Ginsburg & Rayna Rapp, *Cripping the New Normal: Making Disability Count*, ALTER: EUR. J. DISABILITY RES. (July 15, 2017), <http://www.em-consulte.com/article/1132964/article/cripping-the-new-normal-making-disability-count>.

<sup>15</sup> #CripTheVote: *Our Voices, Our Vote*, DISABILITY VISIBILITY PROJECT (Jan. 27, 2016) [hereinafter #CripTheVote], <https://disabilityvisibilityproject.com/tag/crip-the-vote>.

<sup>16</sup> KAFER, *supra* note 11, at 3.

authors write:

The future of disability in America is not a minority issue. If one considers people who now have disabilities, people who are likely to develop disabilities in the future, and people who are or who will be affected by the disabilities of those close to them, then disability affects today or will affect tomorrow the lives of most Americans.<sup>17</sup>

The introduction to *The Future of Disability in America*<sup>18</sup> makes the case for the significance of attention to interventions in the material conditions of daily life that can have a profound effect on whether disability is experienced as exclusionary or participatory. For example, what has come to be known as inclusive or universal design incorporates everything from the spatial layout of the home to the infrastructure of public space that we routinely encounter at its most basic level of mobility access through ramps and the wheelchair logo. We now have many accommodations that were unimaginable even two decades ago. Consider these relatively recent innovations: closed captioning on television as a legal requirement; service dogs permitted on buses, in courtrooms, department stores, and places of worship; programs for those with autism and Alzheimer's now routine in many museums; and adaptive technologies built into digital tablets, to mention only a few. This extraordinary progress in the public life of disability should not be underestimated. More broadly, how do we construct a world that embraces inclusion and the necessary supports for people with disabilities to live as fully as possible in their communities? These are difficult questions given the current zeitgeist where public expenditures are constantly at risk of cutbacks in America and elsewhere. Nonetheless, with or without state support, the initiatives of people with disabilities and their supporters are changing the face of public culture, creating what we call "disability worlds."

## II. WORLDING

The question remains open: how do disability worlds come into being, even in the face of continuing discrimination? We have come to think of this process as "worlding." New York City, where our research takes place, is both the worst of worlds and the best of worlds. Beyond the continuous legal challenges to the many ways in which the city remains inaccessible, it is also home to many nascent, innovative

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<sup>17</sup> COMM. ON DISABILITY IN AM. & INST. OF MED., *THE FUTURE OF DISABILITY IN AMERICA* 16 (Marilyn J. Field & Alan M. Jette eds., 2007), <http://www.nap.edu/catalog/11898/the-future-of-disability-in-america>.

<sup>18</sup> *Id.* at 16–34.

cultural experiments that inform our research and writing. These offer utopian glimpses into what happens when people with disabilities are really included in civic space, sometimes through mundane but necessary accommodations, as well as through imaginative interventions. The significance of these projects described below, we argue, does not necessarily reside in their size (some are small) or even longevity (some are ephemeral while others have endured). Rather, their value lies in their contributions to “world making,” a concept we borrow, along with other anthropologists, from two different philosophical lineages. One derives from philosopher Nelson Goodman’s 1978 book, *Ways of Worldmaking*, which addresses the role of both representational and material structures in building and reshaping the realities in which we live.<sup>19</sup> As we continue to encounter new formations, we often feel we are witnessing a kind of active world making: the post-ADA landscape that imagines an inclusive and creative cultural future for the broad range of humanity hailed by the language of disability rights. But language and law can only go so far without the claims to recognition through concrete world making projects. For example, the groundbreaking work of wheelchair activists who organized Americans Disabled for Accessible Public Transit in the 1970s in Denver, Colorado, gathered on the city’s streets under the banner, “We Will Ride!”<sup>20</sup> They surrounded and immobilized two inaccessible busses until the city “eventually agreed to 100 percent access in all future bus purchases.”<sup>21</sup> Their world making model quickly spread to disability activists in other American cities.<sup>22</sup>

Worlding has another discursive philosophical lineage that we draw on as well. This neologism was first introduced by Martin Heidegger in 1927 in his influential book *Being and Time* that explores the experience of “being” in the world.<sup>23</sup> Since then, the idea of worlding has been taken up across many disciplines. As media scholar David Trend describes in his website, *Worlding*:

Many of us think about a better world. But opinions may vary over how to get there, and especially about what “there” we want . . . . Historically critiqued as a colonializing device, the term worlding now also is regarded as a utopian strategy . . . [t]he desire for

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<sup>19</sup> See NELSON GOODMAN, *WAYS OF WORLDMAKING* (1978).

<sup>20</sup> FRED PELKA, *WHAT WE HAVE DONE: AN ORAL HISTORY OF THE DISABILITY RIGHTS MOVEMENT* 378 (2012).

<sup>21</sup> *Id.*

<sup>22</sup> See GOODMAN, *supra* note 19; PELKA, *supra* note 20.

<sup>23</sup> MARTIN HEIDEGGER, *BEING AND TIME* (John Macquarrie & Edward Robinson trans., 2008).



something not-yet-achieved . . . .<sup>24</sup>

Among anthropologists, the concept of worlding has been used in science studies, medical anthropology, critical urbanism, and beyond. Recently the term has been deployed by anthropologists Michele Friedner and Emily Cohen. In their introduction to a series of essays exploring disability for the online journal *Somatosphere*, they explain their title “Inhabitable Worlds: Troubling Disability, Debility, and Ability Narratives” as follows: “[w]e see ‘inhabitable worlds’ as both analytic and material worlds, worlds that have existed, that do exist, and that will exist . . . . [P]eople . . . transform these discourses through political advocacy and personal tactics they develop to navigate the material realities of bodily differences and built environments.”<sup>25</sup>

They remind us that making inhabitable disability worlds requires attention to the material conditions of daily life that have a profound effect on how disability is experienced. Worlding includes the spatial design of the home, the infrastructures of public space, aspects of universal design that are familiar to most Americans through curb cuts, and the wheelchair logo.

We want to underscore that inclusive design is foundational to human rights for people with disabilities. For example, the Swedish design firm Veryday embraced this concept beginning in the late 1960s when they were called Ergonomidesign. Now, as its website asserts, “human diversity is part of our very DNA and founding values.”<sup>26</sup> Its philosophy is straightforward: “[i]nclusive design is about making sure that as many people as possible are included and can equally use products, services and spaces.”<sup>27</sup> Denmark can claim the now-familiar original design for the International Symbol of Access, with a white seated profile stick figure in a wheelchair against a bright blue background, created by Danish art student Susanne Koefoed in 1968 for Rehabilitation International.<sup>28</sup> It was recently updated by the American designer-activist co-founders of the Accessible Icon Project, Sara Hendren and Brian Glenney, who “crippled” the original Danish icon by making the figure lean forward, so that it appears dynamic and pushing

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<sup>24</sup> David Trend, *Worlding.org*, DAVID TREND, [http://davidtrend.com/?page\\_id=142](http://davidtrend.com/?page_id=142) (last visited Oct. 23, 2017).

<sup>25</sup> Michelle Friedner & Emily Cohen, *Inhabitable Worlds: Troubling Disability, Debility, and Ability Narratives*, SOMATOSPHERE (Apr. 20, 2015), <http://somatosphere.net/2015/04/inhabitable-worlds-troubling-disability-debility-and-ability-narratives.html>.

<sup>26</sup> *Inclusive Design – Innovation for ALL People*, VERYDAY, <http://veryday.com/aspect/innovation-for-all> (last visited Oct. 23, 2017).

<sup>27</sup> *Id.*

<sup>28</sup> Elizabeth Guffey, *The Scandinavian Roots of the International Symbol of Access*, 7 DESIGN & CULTURE 357, 358 (Jan. 29, 2016), <http://www.tandfonline.com/doi/abs/10.1080/17547075.2015.1105527>.

its own chair.<sup>29</sup> Using this design, they organized a grassroots guerilla sticker project in Boston, placing their new image over the classic static wheelchair image, in order to catalyze dialogue about the way society views disability.<sup>30</sup> Their modified version was exhibited in the Museum of Modern Art's 2014 show entitled *Collection of Ideas* and is now part of the museum's permanent collection.<sup>31</sup> It then became the official icon of New York State in 2014.<sup>32</sup> Soon, there emerged other iconography signifying diverse forms of embodied difference requiring varied forms of infrastructural support. In addition to the wheelchair access logo, icons have expanded to include telephone typewriter (TTY) service, assistive listening systems, sign language interpretation, closed captioning, Braille, low-vision access, and volume control telephone.<sup>33</sup> All of these icons use the classic royal blue background with simple white figures; they are now incorporated into public institutions in New York City not simply for their design. Additionally, the icons signal an awareness of the human and material infrastructure necessary to welcome diverse audiences into public spaces such as museums, locations for our shared cultural heritage that historically have excluded people with disabilities.<sup>34</sup>

The Museum Access (MAC) movement arose to creatively address the issue of inclusion in museums more than twenty-five years ago in New York City.<sup>35</sup> Currently MAC encompasses over 100 institutions. Since the turn of the twenty-first century, these cultural centers have been serving a million or more people with disabilities in the city ranging from those with mobility issues to the deaf and hard of hearing.<sup>36</sup> Increasingly, there are also programs for people with dementia and Alzheimer's, individuals with learning and developmental differences, and those who are blind and partially sighted.<sup>37</sup> Crippling an exhibition may only require attention to small details such as Braille

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<sup>29</sup> Sara Hendren, *An Icon Is a Verb: About the Project*, ACCESSIBLE ICON PROJECT (Feb. 2016), <http://accessibleicon.org> (last visited Oct. 23, 2017).

<sup>30</sup> *Id.*

<sup>31</sup> Sara Hendren, MUSEUM MOD. ART, <https://www.moma.org/artists/44525?locale=en> (last visited Oct. 24, 2017).

<sup>32</sup> Niraj Chokshi, *The Handicap Symbol Gets an Update—at Least in New York State*, WASH. POST (July 29, 2014), [https://www.washingtonpost.com/blogs/govbeat/wp/2014/07/29/the-handicap-symbol-gets-an-update-at-least-in-new-york-state/?utm\\_term=.0cce822539aa](https://www.washingtonpost.com/blogs/govbeat/wp/2014/07/29/the-handicap-symbol-gets-an-update-at-least-in-new-york-state/?utm_term=.0cce822539aa).

<sup>33</sup> *Disability Access Sign Symbols for Download*, SIGNS & SYMBOLS (Mar. 6, 2011) [hereinafter *Disability Access*], <https://signsanddisplays.wordpress.com/2011/03/06/disability-access-sign-symbols-for-download>.

<sup>34</sup> See ART BEYOND SIGHT, <http://www.artbeyondsight.org?dic/module-6-museum-access-inclusive-practices-by-museum-teams> (last visited Oct. 24, 2017).

<sup>35</sup> Museum Access Consortium, *About MAC: Professional Development Workshops*, MUSEUM ACCESS CONSORTIUM, <http://museumaccessconsortium.org/about> (last visited Oct. 24, 2017).

<sup>36</sup> *Disability Access*, *supra* note 33.

<sup>37</sup> Museum Access Consortium, *supra* note 35.

signage or audio description, yet these are too rarely present.<sup>38</sup> When we find it strange that Braille signage or audio description—and equivalent affordances accounting for other modes of embodiment—are missing at an exhibition, movie theater, or school, we will have succeeded in crippling/creating a revised understanding of the new normal.

As yet another example of disability worlding, in 2011, the MAC movement extended its reach to the National Autism Theatre Initiative (ATI), a group that modifies performances of Broadway plays in order to welcome audiences on the autism spectrum and their supporters.<sup>39</sup> In this fieldwork site, we have worked as volunteers at a Broadway production of Norwegian Welsh author Roald Dahl's children's classic *Matilda*.<sup>40</sup> For ATI performances, audiences are encouraged to familiarize themselves ahead of time with different aspects of their visit, from getting to the theater to the staging of the performance via "social narratives."<sup>41</sup> The interior of the theater is modified to account for different modalities. Lighting and sound are diminished to accommodate sensory issues for audience members; actors and staff are trained to tolerate noisy participants, and special quiet lounges are created for audience members who need a break from the nonstop input of musical theater. Among the affordances provided are small hand-held fidget toys that have a calming effect. Additionally, ATI creates and distributes maps of the neighborhood showing restaurants that are hospitable to people on the autism spectrum, since so many families had encountered hostility to atypical behavior such as "stimming" or flapping.<sup>42</sup> Providing such accommodations is no small matter. The value of such projects is considerable. The National Organization on Disability finds that in New York City forty percent of people with significant disabilities, including autism, are not at all involved in their communities due to the lack of adaptive programming.<sup>43</sup>

In addition to the question of infrastructure that enables diverse audiences to be included in public culture such as theaters and museums, some curators focus on works created by artists with

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<sup>38</sup> See Barry Ginley, *Museums: A Whole New World for Visually Impaired People*, 33 *DISABILITY STUD. Q.* (2013), <http://dsq-sds.org/article/view/3761>; RE-PRESENTING DISABILITY: ACTIVISM AND AGENCY IN THE MUSEUM 3 (Richard Sandell et al. eds., 2010).

<sup>39</sup> Theatre Development Fund, *National Autism Theatre Initiative*, THEATRE DEV. FUND, <https://www.tdf.org/nyc/131/National-Autism-Theatre-Initiative> (last visited Oct. 24, 2017).

<sup>40</sup> ROALD DAHL, *MATILDA* (Puffin Books, 2007).

<sup>41</sup> Museum Access Consortium, *Examples of Social Narratives for Visitors*, MUSEUM ACCESS CONSORTIUM, <http://museumaccessconsortium.org/resource/social-narratives> (last updated Apr. 3, 2015).

<sup>42</sup> Vidya Viswanathan, *Making Theater Autism-Friendly*, ATLANTIC (Apr. 6, 2015), <https://www.theatlantic.com/health/archive/2015/04/making-theater-autism-friendly/388348>.

<sup>43</sup> GuideStar, *City Access New York*, GUIDESTAR, <http://www.guidestar.org/PartnerReport.aspx?ein=20-3786663&Partner=Demo> (last visited Oct. 24, 2017).

disabilities. A prominent example is the California-based Australian disability activist and art historian Amanda Cachia, a short-statured person. In exhibitions she has organized, such as *Medusa's Mirror*, she has featured remarkable works, including a series of “anti-portraits” by short-statured artist Laura Swanson.<sup>44</sup> By doing this, Cachia asks us to consider: “What does it mean to inscribe a contemporary work of art with the experiences of disability?”<sup>45</sup>

### III. SCREENING DISABILITIES

Clearly, since the turn of the twenty-first century, the available cultural scripts regarding the public face of life with a difference are being powerfully revised in multiple sites that we are tracking in our work, especially in screen media, from documentaries to popular culture to digital media. A powerful and influential example is provided by the neurodiversity activist Mel Baggs, previously known as Amanda Baggs. Her first YouTube video, which dramatically brought her to public attention, offers a particularly compelling instance in which we see how the infrastructure of the Internet offers alternative modes of communication that have opened pathways of recognition entirely unavailable until recently.<sup>46</sup>

In 2007, Ms. Baggs launched *In My Language* (IML), on YouTube.<sup>47</sup> She shot and edited the nine-minute work in her apartment in Vermont, a powerful example of the do-it-yourself style typical of many user-generated video works shared on that platform.<sup>48</sup> Ms. Baggs's video offers a riveting glimpse into her life, immersing the audience virtually into how she experiences the world differently from “neurotypicals.”<sup>49</sup> The first part shows us Ms. Baggs engaged in a variety of repetitive gestures around her apartment—playing with a necklace, typing at her keyboard, sitting on her couch, moving her hand back and forth in front of a window—to the sound of a wordless tune she hums off camera, creating a meditative, almost mesmerizing effect.<sup>50</sup> Ms. Baggs, who stopped speaking verbally altogether in her early twenties,

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<sup>44</sup> LAURA SWANSON, <http://www.lauraswanson.com> (last visited Oct. 24, 2017).

<sup>45</sup> *What Can a Body Do?: Curated by Amanda Cachia*, HAVERFORD C., <http://exhibits.haverford.edu/whatcanabodydo> (last visited Oct. 24, 2017).

<sup>46</sup> Mel Baggs, *About*, WORDPRESS: BALLASTEXISTENZ BLOG, <https://ballastexistenz.wordpress.com/about-2> (last visited Oct. 24, 2017).

<sup>47</sup> Mel Baggs, *In My Language*, WORDPRESS: BALLASTEXISTENZ BLOG (Jan. 15, 2007), <https://ballastexistenz.wordpress.com/2007/01/15/in-my-language>.

<sup>48</sup> See David Wolman, *The Truth About Autism: Scientists Reconsider What They Think They Know*, WIRED (Feb. 25, 2008), <https://www.wired.com/2008/02/ff-autism>.

<sup>49</sup> Baggs, *supra* note 47; see also Andrew Solomon, *The Autism Rights Movement*, N.Y. MAG. (May 25, 2008), <http://nymag.com/news/features/47225>; Wolman, *supra* note 48.

<sup>50</sup> Baggs, *supra* note 47.

provides the “translated portion” of the piece.<sup>51</sup> Her spoken voice is rendered via an augmentative communication device, a DynaVox VMax computer (a technology currently being replaced by iPads). Her typed words emerge as a synthetic female voice—as well as in yellow subtitles.<sup>52</sup> The video ends with an impressive message:

In the end, I want you to know that this has not been intended as a voyeuristic freak show where you get to look at the bizarre workings of the autistic mind. It is meant as a strong statement on the existence and value of many different kinds of thinking and interaction in a world where how close you can appear to a specific one of them determines whether you are seen as a real person or an adult or an intelligent person. And in a world in which those determine whether you have any rights there are people being tortured, people dying because they are considered nonpersons because their kind of thought is so unusual as to not be considered thought at all. Only when the many shapes of personhood are recognized will justice and human rights be possible.<sup>53</sup>

IML makes stunningly clear how social media technologies can provide unanticipated and powerful platforms for those with disabilities to communicate to a broad range of publics. This is particularly important given findings documenting the number of characters with disabilities on American television are virtually invisible, comprising “less than 1 percent of all scripted series regular characters,” despite recent interventions in this bleak landscape with television comedies such as *Speechless*.<sup>54</sup> Online media offer entirely different opportunities for inclusion and participation. Blogs and YouTube for example, enable first-person presentation of people with disabilities to assert an alternative sense of personhood—as does Ms. Baggs—without requiring others to mediate for them. Moreover, the accessibility of social media forms has dramatically enhanced the possibilities for forming community for those who have difficulty speaking or sustaining face-to-face conversation. As Mel Baggs explains it, “[a] lot of us have trouble with spoken language, and so a lot of us find it easier to write on the Internet than to talk in person.”<sup>55</sup> The battles that were fought for

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<sup>51</sup> *Id.*

<sup>52</sup> *Id.*

<sup>53</sup> *Id.*

<sup>54</sup> *Study Reveals Continued Lack of Characters with Disabilities on Television*, SAG-AFTRA (Sept. 28, 2011, 4:08 AM), <https://www.sagaftra.org/study-reveals-continued-lack-characters-disabilities-television>; *Speechless* (ABC Television Broadcast 2017), <http://abc.go.com/shows/speechless> (last visited Nov. 24, 2017).

<sup>55</sup> Joseph Shapiro, *Autism Movement Seeks Acceptance, Not Cures*, NPR: ALL THINGS CONSIDERED (June 26, 2006, 2:41 PM), <http://www.npr.org/templates/story/story.php?storyId=5488463>.

ramps, elevators, Braille signage, and visual signals for the hearing impaired have been extended to and transformed the digital media world into a more heterogeneously inclusive space.

Several other cases from our research illustrate how, in the twenty-first century, people with disabilities are finding new avenues for inclusion and participation that expand our collective sense of personhood and social life. The *Loud Hands* project includes a collection of essays written by and for autistic people chronicling their experience from the dawn of the neurodiversity movement to contemporary blog posts of today.<sup>56</sup> The title *Loud Hands* embraces the stigmatized hand flapping common to people on the spectrum, who are constantly told by families, therapists, and teachers to have “quiet hands.”<sup>57</sup> Self-advocates assert that whether or not they speak orally, their “obviously autistic communication and thoughts have intrinsic worth,” an idea they claim as inherently revolutionary.<sup>58</sup> Their work shows how activist demands for inclusion require recognition for their distinctive forms of communication as legitimate, an argument they claim as foundational to their human rights.

Mel Baggs and *Loud Hands* are instances of what disability scholar Rosemarie Garland-Thomson calls “visual activism,” a term she deploys to describe how people with disabilities increasingly are putting themselves in the public eye on their own terms.<sup>59</sup> She argues that these representations can “[stretch] our shared understanding of the human variations we value and appreciate and invite us to accommodate them,” while literally reversing the stigmatizing stare that so many people with disabilities experience.<sup>60</sup>

Visual activism is evident in disability film festivals that build inclusion and participation across diverse minds and bodies. For example, New York City’s ReelAbilities Film Festival, one of our field sites, is part of this process. Founded in 2007, this event offers an international showcase for outstanding films by, for, and about people with disabilities.<sup>61</sup> We have been following the festival’s remarkable growth; it has tripled its attendance since its inaugural years. Screenings are well-attended and are followed by audience discussions with filmmakers, as well as representatives of the disability worlds portrayed in the films. Intensive planning for festival success requires off-screen

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<sup>56</sup> LOUD HANDS: AUTISTIC PEOPLE, SPEAKING 7–8 (Julia Bascom ed., 2012).

<sup>57</sup> *Id.*

<sup>58</sup> Faye Ginsburg & Rayna Rapp, *Crippling the Future: Making Disability Count*, in ANTHROPOLOGIES AND FUTURES: RESEARCHING EMERGING AND UNCERTAIN WORLDS 43, 56 (Juan Francisco et al. eds., 2017).

<sup>59</sup> ROSEMARIE GARLAND-THOMSON, STARING: HOW WE LOOK 195 (2009).

<sup>60</sup> *Id.*

<sup>61</sup> *Our Story: ReelAbilities NY Disabilities Film Festival*, REELABILITIES FILM FESTIVAL, <http://reelabilities.org/about-us#ourstory> (last visited Oct. 24, 2017).

recognition of the accommodations needed for diverse audiences, including the creation of audio description tracks on films for those with visual impairments, closed captioning and signing for deaf audience members, seating that allows for many power chairs, along with room for guide dogs, a large percentage of people on the autism spectrum using assistive communication devices, and a high tolerance for audience unruliness. This infrastructural welcome offers a stark critique of the unaccommodating and ableist arrangements of most viewing spaces.

The 2014 New York premiere of *Invitation to Dance*, the autobiographical documentary by disability activist Simi Linton and filmmaker Christian von Tippelskirch, was sitting and standing-room only. The film tells the story of Linton's post-automobile accident transformation into a wheelchair-riding activist and her life as part of the avant-garde of disabled artists and radical thinkers, all unstoppable in their quest for "equality, justice, and a place on the dance floor."<sup>62</sup> As we joined the crowd walking, rolling, and limping into the theater for the film's debut, the sense of celebration was palpable, produced by the audience's recursive recognition of disability activist accomplishments reflected in Linton's story. People stayed on for lively post-screening conversation, followed by a party with wheelchair dancers featured in the film taking the lead. This kind of material and cultural inclusion enables existential repositioning not only because of what is on the screen, but also due to the experience of the event itself.

The feature-length documentary *Wretches and Jabberers* closed the festival in 2012. The film had the requisite off-screen adaptations for crippling the viewing space that, in this case, interpellated audience members with autism. The documentary, made by Gerardine Wurzburg, features Tracy Thresher and Larry Bissonnette, two middle-aged men with autism who have limited oral speech.<sup>63</sup> "As young people, both faced lives of isolation . . . It was not until adulthood when each learned to communicate by typing" with the help of assistive technology that their lives changed dramatically, finally providing them with a way to express their wide-ranging thoughts, needs, and feelings.<sup>64</sup> "After more than ten years of advocating for people with autism, they felt it was time to take their message global—to help people with autism in other countries around the world break through the isolation they both knew so well."<sup>65</sup> The film has mobilized a global campaign through

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<sup>62</sup> See *INVITATION TO DANCE* (Christian von Tippelskirch & Simi Linton 2014).

<sup>63</sup> *WRETCHES & JABBERERS* (State of the Art Inc. 2012), <http://www.wretchesandjabberers.org/about/synopsis>.

<sup>64</sup> *Id.*

<sup>65</sup> *Id.*

the densely connected autism network. Since its inception, ReelAbilities—which began at a single location in Manhattan—has now proliferated, with thirty venues in the New York metropolitan area and festival partnership in fifteen American cities, demonstrating the growth of what we call disability publics.<sup>66</sup> Clearly, representation of disability on media screens is a crucial form of self, community, and wider public recognition. Yet, representation in the political sphere raises additional challenges.

#### IV. #CRIPTHEVOTE AND BEYOND

In conclusion, we want to reflect on the future of disability publics in the United States, more than a quarter century after the passage of the ADA. This groundbreaking legislation was necessary, but not sufficient, to undergird the actual transformations required for people with disabilities to be fully recognized as citizens, whether in movie theaters, on the Internet, or in the voting booth. We see these, along with the emergence of small, but significant, initiatives such as #cripthevote, as prefiguring the potential history of disability futures. In a 2016 essay inaugurating *Disability*, a series of weekly essays in the *New York Times* written by and about people living with disabilities, scholar-activist Rosemarie Garland-Thomson wrote about the expansion in numbers and recognition of people with disabilities:

[D]isability is everywhere once you start noticing it . . . The National Organization on Disability says there are 56 million disabled people. Indeed, people with disabilities are the largest minority group in the United States, and as new disability categories such as neurodiversity, psychiatric disabilities, disabilities of aging and learning disabilities emerge and grow, so does that percentage.<sup>67</sup>

Given these numbers, we were excited when disability activists launched two remarkable nonpartisan efforts to get the 2016 presidential candidates to talk about issues relevant to this community for the first time in American history. Using the reach of social media, the Twitter campaign #cripthevote engaged voters and encouraged politicians to have a national conversation about disability rights.<sup>68</sup> Additionally, Washington, D.C. based disability activists launched

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<sup>66</sup> See REELABILITIES FILM FESTIVAL, <http://www.reelabilities.org> (last visited Oct. 24, 2017); *A Guide to ReelAbilities*, REELABILITIES FILM FESTIVAL, <http://newyork.reelabilities.org/guide2017> (last visited Oct. 24, 2017); *Our Story: ReelAbilities NY Disabilities Film Festival*, REELABILITIES FILM FESTIVAL, <http://reelabilities.org/about-us#ourstory> (last visited Oct. 24, 2017).

<sup>67</sup> Rosemarie Garland-Thomson, *Becoming Disabled*, N.Y. TIMES (Aug. 19, 2016), <https://www.nytimes.com/2016/08/21/opinion/sunday/becoming-disabled.html>.

<sup>68</sup> #CripTheVote, *supra* note 15.



RespectAbility, another initiative to get candidates to address disability issues.<sup>69</sup> Both groups underscored the potential power of the disability vote.

A study by political scientists Lisa Schur and Douglas Kruse, well known for their work on disability, law, and social policy, projected that roughly one-sixth of the electorate, more than thirty-five million people with disabilities out of 62.7 million total, were eligible to vote this year.<sup>70</sup> This was heartening, but not surprising. What *was* surprising was that these voters for whom disability is a central concern, identify almost equally with the two major political parties.<sup>71</sup> Given the stark contrast between the Clinton and Trump campaigns around disability issues, we nonetheless assumed, along with many others, that the disability vote would indeed rally for Clinton, whose policy recommendations addressed areas of key importance to this constituency.<sup>72</sup> This was in sharp distinction to the disgraceful behavior of Trump on this issue at a November 2015 rally when he mocked the atypical gestures of the *New York Times* reporter Serge Kovalski who has arthrogyrosis. This was the most widely condemned of all Trump's many insults during the long and nasty campaign season.<sup>73</sup> Moreover, he was silent on disability issues or policy proposals in his campaign. In contrast, in June 2016, Priorities USA ran their pro-Clinton "Dante" ad in which Dante Latchman, a seventeen-year-old African American cancer survivor with a limp, watches Trump's mocking behavior, then speaks to the viewer, saying: "I don't want a president who makes fun of me, I want a president who inspires me. That's not Donald Trump."<sup>74</sup> A month later, at the Democratic National Convention, New York City disability activist Anastasia Somoza was a featured speaker along with others. Throughout, the care given to make the infrastructure of the convention itself accessible was notable. Clearly, the efforts of disability activists in

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<sup>69</sup> Lauren Appelbaum, *Polling Shows People with Disabilities Split Vote Between Trump and Clinton*, RESPECTABILITY (Dec. 14, 2016), <https://www.respectability.org/2016/12/14/polling-shows-people-with-disabilities-split-vote-between-trump-and-clinton>.

<sup>70</sup> Lisa Schur & Douglas Kruse, *Projecting the Number of Eligible Voters with Disabilities in the November 2016 Elections*, RUTGERS SCH. MGMT. & LAB. REL. (Feb. 27, 2017), <http://smlr.rutgers.edu/news/projecting-number-eligible-voters-disabilities-november-2016-elections-research-report>.

<sup>71</sup> *See id.*

<sup>72</sup> Lauren Appelbaum, *DNC Platform Integrates People with Disabilities in Show of Powerful Inclusion*, RESPECTABILITY (July 12, 2016), <http://therespectabilityreport.org/2016/07/12/dnc-platform-integrates-people-with-disabilities-in-show-of-powerful-inclusion>.

<sup>73</sup> Irin Carmon, *Donald Trump's Worst Offense? Mocking Disabled Reporter, Poll Finds*, NBC NEWS (Aug. 11, 2016, 3:24 AM), <https://www.nbcnews.com/politics/2016-election/trump-s-worst-offense-mocking-disabled-reporter-poll-finds-n627736>.

<sup>74</sup> *Priorities USA Action: 'Dante' Campaign 2016*, WASH. POST (June 23, 2016, 8:37 PM), [https://www.washingtonpost.com/video/politics/priorities-usa-action-dante--campaign-2016/2016/06/23/caa20258-393f-11e6-af02-1df55f0c77ff\\_video.html?utm\\_term=.d17ecfc312a1](https://www.washingtonpost.com/video/politics/priorities-usa-action-dante--campaign-2016/2016/06/23/caa20258-393f-11e6-af02-1df55f0c77ff_video.html?utm_term=.d17ecfc312a1).

the 2016 elections had rapidly developed in terms of both political and technological savvy. Hashtag and other forms of online activism created networks and awareness, encouraging disabled Americans and their allies to make their votes count. For a moment, it seemed as if political arithmetic might work to alter the electoral process.

Like many, we were stunned when Trump won the election. We had to revisit our overly optimistic assumptions about a unified disability constituency and scrutinize what actually happened. Clearly, there were issues of turnout and accessibility, but more importantly, data show that the disability vote was split along party lines, as, indeed, it has always been, despite Trump's egregious behavior. What does this portend for the next four years? This government seems determined to undermine the gains of the last quarter century, if we are to take seriously the confirmation of Secretary of Education Betsy DeVos, whose profound ignorance about public education extends to total lack of knowledge of decades-old national legal entitlements to special education for children with disabilities. While our new Attorney General Jeff Sessions is more knowledgeable, his contempt for legal guarantees for free and appropriate public education for American children with disabilities is stunning. These are indeed grim times.

Clearly, we cannot take longstanding federal legislation for granted; the ADA is under threat as is the very recognition of the personhood of those with disabilities. At the time of this writing, July 2017, "deep cuts to Medicaid and other programs that people with disabilities rely on are at the heart of President Donald Trump's first budget proposal."<sup>75</sup> Indeed, in late June:

protesters with disabilities gathered outside Senate Majority Leader Mitch McConnell's office to stage a die-in calling attention to Trumpcare's massive cuts to Medicaid. It was a shocking scene as Capitol police dragged them away and arrested them. But when you find out what was at stake, it's clear why people would risk harm and arrest to protest this. The foundation of millions of people's ability to live independent lives is at stake . . .<sup>76</sup>

As scholars and activists, we need to understand what happened, as we collectively imagine how to defend the rights of the heterogeneous forms of embodiment that shape our body politic. One way to begin is to look at some key findings about the election. *FiveThirtyEight* reporter

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<sup>75</sup> Michelle Diamant, *Trump Budget Guts Medicaid, Disability Programs*, DISABILITY SCOOP (May 23, 2017), <https://www.disabilityscoop.com/2017/05/23/trump-medicaid-disability-programs/23746>.

<sup>76</sup> Laura Clawson, *Here's Why Disabled People Faced Arrest To Protest Medicaid Cuts: Their Lives Were at Stake*, DAILY KOS (June 23, 2017, 9:48 PM), <https://www.dailykos.com/story/2017/6/23/1674535/-Here-s-why-disabled-people-faced-arrest-to-protest-Medicaid-cuts-Their-lives-were-at-stake>.

Amelia Thomson-DeVeaux reminded us that:

For years, their growing numbers have led disability rights activists to claim that voters with disabilities are a “sleeping giant” that could, one day, decide national elections . . . . People with disabilities tend to support Republicans and Democrats in fairly equal numbers, which complicates efforts to tailor political messages to them (and compounds their appeal as a potential swing demographic).<sup>77</sup>

In addition, lack of accessibility at polling places remains an important issue:

In previous research, Schur estimated that the turnout gap between people with disabilities and people without disabilities is close to 12 percentage points, which amounts to about three million voters. Despite the passage of several laws designed to make polling places more accessible, the Government Accountability Office reported in 2008 that . . . 30 percent of people with disabilities reported difficulty in voting, compared with 8 percent of people without disabilities. The turnout gap in 2012 was largest for people with cognitive impairments and smallest among people with visual impairments.<sup>78</sup>

Further, “two separate bipartisan polls showed results that voters with disabilities and their family and friends . . . split their votes between President-elect Trump (46 percent) and Secretary Hillary Clinton (49 percent).”<sup>79</sup>

Clearly, there is more world making to be done in the disability community, from attending to cultural innovation and accessible infrastructure, to rendering political ideologies and platforms more transparent in terms of disability rights. We would like to give the last word to neurodiversity activist Ari Ne’eman, whose words also introduced this Article. Like all world-changing activists, he persists in finding hope despite bleak times.

[I]t may very well be that disability rights activists will achieve greater solidarity . . . after four years of shared opposition to the outrages of President Trump. Compared with the potentially game-changing strides forward promised by the Clinton campaign, this is cold comfort—but it is something we can cling to as we prepare for the fights to come. With the lives of millions of Americans with disabilities at stake—as well as those of people of color, Jews, Muslims, low-income persons, LGBTQ Americans, and members of other marginalized groups—we need all the silver lining we can find.

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<sup>77</sup> Amelia Thomson-DeVeaux, *One in Six Eligible Voters Has a Disability*, FIFETHIRTYEIGHT (Sept. 12, 2016, 9:00 AM), <https://fivethirtyeight.com/features/one-in-six-eligible-voters-has-a-disability>.

<sup>78</sup> *Id.*

<sup>79</sup> Appelbaum, *supra* note 69.

The next four years will be difficult ones.<sup>80</sup>

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<sup>80</sup> Ari Ne'eman, *I'm a Disabled American. Trump's Policies Will Be a Disaster for People Like Me*, VOX (Nov. 9, 2016), <http://www.vox.com/first-person/2016/11/9/13576712/trump-disability-policy-affordable-care-act>.