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Making Disability Count: Demography, Futurity, and the Making of Disability Publics

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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. The future of disability in America is not a minority issue. (Institute of Medicine 2007, p. 16)

Disability is an ambiguous demographic, but one that is unambiguously increasing. (Fujiura 2001, p. 1)

Disabled people have more than a dream of accessible futures: we continue to define and demand our place in political discourses, political visions, and political practice, even as we challenge those very questions and demands. More accessible futures depend on it. (Kafer 2013, p. 169)

How are we as a society to successfully incorporate and support the increasing numbers of Americans with disabilities, a future that ultimately includes all of us? What kinds of cultural innovations are expanding our frameworks of inclusion to create “inhabitable worlds”? This question has been fundamental to our research project entitled *Disability, Personhood and the “New Normal” in 21st Century America*. As the quotations above indicate, the number of people with disabilities has been growing dramatically over the last decades. As disability scholar/activist Alison Kafer persuasively argues, the political and existential stakes for the recognition of disability are high, especially in imagining and creating what she calls “accessible futures”. Is it possible to bring the knowledge being produced both by demography and disability studies into conversation, to better understand the relationship between “counting disability” and “making disability count”?

A scant three years after the publication of *The Future of Disability* (2007), the 2010 Census increased its estimate of people with disabilities in the

civilian non-institutionalized population to 57 million, almost 20 percent of the population (Brault 2012). Despite dramatic predictions around specific conditions such as Alzheimers or Autism Spectrum Disorder (ASD), suggesting that people with these disabilities will constitute a rapidly expanding proportion of the U.S. population for the foreseeable future, there is only occasional discussion of the policy implications of these social facts when taken together. Given the mounting demographic projections across the life course — with significant differences across race, class, ethnic, and gender categories — we argue that few will remain untouched by these emerging changes in the body politic.

Yet, as Alison Kafer points out, disability is continually rendered invisible and undesirable, “a perspective colored by histories of ableism and disability oppression” (2013 p. 3). While legislation mandates inclusion of people with disabilities in civic culture, there is still a lack of recognition for people with disabilities not only in the present but also as part of an anticipated future. Our research addresses this concern, and also attends to emerging sites of possibility, which often combine the physical, cultural and political. For example, we regard the work of the Museum Access Consortium in the New York metropolitan area as enacting a politics of possibility through attention to their material and curatorial practices. The commitment of this network to sharing and implementing expertise makes their institutions — sites of shared cultural heritage — widely accessible across a range of disabilities that require specific accommodations. Curators are increasingly engaged in designing shows that feature both the work of artists with disabilities, and exhibits highlighting the historical experience of disability in a way that also invites viewers to imagine more accessible futures, whatever background they bring to the show. Other sites of possibility we focus on in our research include visionary educational experiments; inclusive music, dance and theater projects; and disability film festivals we discuss below. All these cultural locations are “making disability count” to the publics that encounter them.[\[i\]](#)

Who and What Counts?: The Epistemology of Numbers

Most researchers who “count disability” — demographers, statisticians, economists — are rarely in dialogue with scholars in disability studies, whose concern has been to show how “disability counts” across a range of qualitative fields. We have interviewed a handful of demographers whose work engages this situation. In our discussions, we have learned that demonstrating the significance of the dramatic increase in numbers can be difficult. Consider the comments of one of our interlocutors who is one of the exceptions to that generalization, the economist Sophie Mitra. She has done extensive work on parameters for measuring disability cross-nationally. As she told us in an interview:

My take is that there's still the misconception that disability is extremely rare, and there are bigger problems to deal with. To me this misconception is everywhere, [even] here in the U.S. ...So there's a complexity with the very label and perhaps there's the imaginary, you know, what people have in their minds. It's someone in a wheelchair and they don't see people in wheelchairs every day and therefore perhaps it's not that relevant an issue. (Interview, 10/8/14)

Glenn Fujiura, like Mitra, is another exception. In a trenchant article on the lack of interchange between these two discursive arenas and the consequences of that for “the epistemology of numbers”, Fujiura, a disabilities studies and rehabilitation researcher, offers insights into the dynamics of the application of statistical knowledge to issues of governance, what classically has been called “political arithmetic”:

Perhaps the better perspective on counting disability is to interpret measurement operations as imperfect proxies that capture only a fraction of the complex reality that is disablement. ...In [sociologist and disability studies scholar Irving] Zola's analysis, the “fixity” of numbers is undermined by the inherent dynamism of disability status — changing because of temporality of health status, the importance of context in manifesting a limitation, and the vagaries of conflicting classification systems. ...In short, the issue is recast from one of measurement methodology to one of the epistemology of the numbers. (Fujiura & Rutkowski-Kmitta 2001, p. 40-41)

In other words, Fujiura and his co-author argue that forecasting built on projected numbers is an imperfect but necessary exercise. Certain categories of vulnerable people are “hard to count” and are therefore routinely undercounted. These categories include undocumented immigrants, those with no fixed address, and, of course, people with disabilities. Furthermore, diverse instruments are used for measuring disability, even among U.S. government agencies. For example, the U.S. Census, the Department of Labor, the Social Security Administration, the Center for Disease Control, and the American Community Survey each use distinctive parameters, according to Congressional mandates appropriate to their respective missions. These differences can make an overall counting of particular disability categories difficult to reconcile across agencies as they estimate current numbers of those with their specific categories of concern, and the consequences for their areas of governmental responsibility, including education, health care, labor force participation, and social security. [\[ii\]](#) As a 2012 report on “Americans with Disabilities: 2010” explained:

While there is little doubt about the large economic impact of people with disabilities, estimates of the size and characteristics of this population depend much on the definitions used to classify what it means to be disabled... The agencies and organizations that provide benefits to advocate for, or study these populations, each refer to their targeted group as people with disabilities; but because of the differences in definitions, an individual may be considered to have a disability under one set of criteria but not by another...

Rather than a dichotomous concept, disability is a gradient on which every person functions at different levels due to personal and environmental factors. (Brault 2012: 1)

In short, despite barriers to comparability, by following trends over the last decade in “counting disability”, we can identify an escalation in the overall numbers of Americans living with disabilities. Many complex factors are fueling the expansion in both numbers and visibility, which may include different strategies for identifying people with disabilities. Increased numbers may be the result of changing social attitudes, especially the decrease in stigma that once surrounded many conditions that are now labeled as disabilities.

Other historical trends have played a role. These include deinstitutionalization, improvements in medical care, and the ongoing impact of the Americans with Disabilities Act (ADA). Before the 1970s efforts to provide alternatives to the dehumanizing world of institutions, many people lived, languished and died behind locked doors, segregated from their families and communities. Additionally, medical advances have saved and often improved the quality of life of those diagnosed with life threatening conditions across the life span. These incorporate (among others) low birth weight infants who are NICU beneficiaries but who statistically are at higher risk for cognitive disabilities; military veterans returning from the longest war in American history, often with Post Traumatic Stress Disorder, Traumatic Brain Injury, amputations and a range of other issues; survivors of catastrophic accidents and chronic illness; people living into extreme old age with all the frailties that entails; and those with chronic mental health diagnoses. In short, many people are surviving and living with disabilities who might not have in the past. They are living independently, sometimes with assistants, with families or friends, or in supported environments integrated into community life, or at times in less than desirable circumstances. In tallying this broad and expanding range, we depend on the kind of quantitative work that enables us to “count disability” in ways discussed above. As researchers, we join

forces with others in disability studies to examine not only the expanding numbers of people with disabilities, but also emerging cultural projects that help “make disability count” in many domains of public culture. We argue that these are creating “disability publics,” a term we use to call attention to how people with disabilities and their allies are interpellated and materialized through a range of media, across widely distributed networks of people with shared experiences of disability. These constitute an emergent form of recognition, locations for alternative engagements on the part of both producers and audiences.

Making Disability Count

In our research, “making disability count” requires attention to sites of cultural production that reflect a growing desire to communicate about the reality of living with disability in arenas of representation, while also transforming infrastructures to include audiences with disabilities. In our prior writing, we have attributed the emergence of such projects to what we call “narrative urgency” (Rapp & Ginsburg 2001), a creative response to the experiential pressures that give shape to an understanding of everyday life lived against the grain of “normalcy”. We think of these creative works as inscribing “unnatural histories” (2001) (Rapp & Ginsburg 2011) that reflect the diversity of disability that is still too rarely part of public discourse. These innovative ventures push back against a hegemonic representational economy in which children are easily launched, adults are continuously in the work force, soldiers return seamlessly to viable lives, elders decline gracefully, and unruly sexual desires are invisible outside normate categories, to mention only a few of the vast cascade of tropes in which daily life is typically rendered. The disjuncture between such dominant narratives and the quotidian experiences of those increasing numbers of people living in disability worlds fuels a growing field of counter-public cultural production.

The “disability publics” we are studying are building new social imaginaries in which people with disabilities have horizons of possibility that point toward Kafer’s utopian call for accessible futures. This provides a refiguring of notions of typicality that we think of as “a new normal”, in which the inclusion of disability is no longer considered exceptional, but is simply taken for granted, particularly given the fact that those who “count disability” estimate that this category currently encompasses close to a fifth of the population. For example, curb cuts are now accepted as necessary, a recognized “new normal” for civic space that benefits those using not only wheelchairs and walkers, but also strollers, shopping carts, and skateboards. Other routine forms of accommodation are only beginning to be routinized: closed captioning for film and television shows to accommodate deaf or hard of hearing audiences are increasingly recognized, while audio description for those with low vision or who are

blind has not yet achieved that status. Less visible but equally important are the structures of computer software; the Department of Justice's forthcoming formal regulations are expected to apply ADA accessibility requirements to the web, providing "the digital equivalent of a wheelchair ramp" (Bookman 2015, Effinger 2014). These examples demonstrate that one cannot separate the materiality of the infrastructure of everyday life from the visionary activism that has created the conditions for this reframing.

The Formation of Disability Publics

The rising numbers of people with disabilities encompass a broad and extremely heterogeneous array of circumstances that have profoundly different implications for accommodations that might be required at different points in the life cycle. Clearly, the support systems are different for a dyslexic child entering school, a post-polio adult navigating family life, or a wheelchair user negotiating the workforce. In this section, we explore one particular condition that has grown enormously in numbers and public recognition in the 21st century: Autism Spectrum Disorder (ASD). We focus on this because it raises important questions about escalating needs for accommodations and caretaking that reverberate through the experiences of so many Americans, changing the landscape of normalcy that characterizes contemporary life. In other words, ASD is a case in which counting disability and making disability count intersect in powerful ways. While it brings with it an exquisitely particular set of empirical realities, it raises particularly compelling questions that have spurred widespread discussion across many fields from medicine to the arts, in the process constituting a "disability public".

The ever-growing category of ASD has catalyzed considerable cultural activism, creating its own distinctive disability publics, where lively debates and disagreements reveal complex responses to the widespread occurrence of autism, giving experiential shape to its demographic expansion. Media of all sorts play a large role in this process, including books, websites, blogs, YouTube videos, TED talks, documentaries, feature films, and television shows, to name a few "ASD genres".

First-person accounts of people with autism have had a huge impact, initially emerging with the notable autobiographical works of autistic activist and professor of animal science Temple Grandin, whose 1996 book *Thinking in Pictures* offered a groundbreaking account of her experience of neurodiversity (Grandin 2010). Similarly, Australian writer, artist and singer-songwriter Donna Williams' 1992 memoir *Nobody Nowhere*, helped change the conversation on autism and build an emerging disability public around this form of difference (Williams 1998). Both have gone on to author many more books, have had their writings adapted as television

dramas, and most importantly, have inspired countless others who identify as having ASD to tell their own stories. More recently, in 2010, for example, Jesse Saperstein, an Asperger's self-advocate, wrote *Atypical: A Life in 20 and 1/3 Chapters*, a memoir from childhood through his early 20s in which he chronicles his outsider status, overcoming bullying and rejection, and finding a path toward self-acceptance and the making of a young adult life (Saperstein 2010). Two years later, David Finch published his account of his late discovery of his own Asperger's from a different point in the life cycle, well described in his title: *The Journal of Best Practices: A Memoir of Marriage, Asperger Syndrome, and One Man's Quest to Be a Better Husband* (Finch 2012). In 2014, *Been There, Done that, Try This! An Aspie's Guide to Life on Earth* appeared, a collection in which "Aspie mentors" provide advice on coping with the daily stressors that they themselves have identified as being the most significant (Attwood 2014). These articulate self-advocates are doing more than illuminating their lives as part of the arc of human difference. Beyond reaching and building a disability public, they have designs on the future, throwing a lifeline to others who share their experiences and are struggling to find their place.

One of the most notable locations is found in the work of the Autistic Self Advocacy Network (ASAN). Among their many outreach projects, they have a growing catalog of publications meant to benefit their community, especially via The Autistic Press, which they describe as "a micropress serving the cross-disability community."^[iii] The most powerful of these works is *Loud Hands: autistic people, speaking*, "a collection of essays written by and for Autistic people... from the dawn of the Neurodiversity movement" to contemporary blog posts of today, "preserving the community's foundational documents" (Bascom 2012).

The title *Loud Hands* is profoundly instructive. As the editor Julia Bascom explains in the foreword:

Abuse and silencing is a constant, pervasive theme in the lives of autistic people, and for many people it is best expressed by that old familiar phrase from special education: *Quiet hands! Loud Hands* means resisting. *Loud Hands* means speaking however we do, *anyway* – and doing so in a way that can be very obviously Autistic. It means finding ways to talk and think about ourselves on our own terms... The diversity of voices here is truly incredible. People of all ages, genders, backgrounds, and abilities, responded with grace, passion, and clarity, articulating brutally honest accounts of the world as it is and shining visions of what we can make it into. It starts with the basic foundational idea that *there is nothing wrong with us*... To say that flapping can be communication, that autistic people have voices regardless of

whether or not we speak orally, and that our obviously autistic communication and thoughts have intrinsic worth is an inherently revolutionary thing...Bit by bit, piece by piece we're rewriting the world into one where our voices are heard. (Bascom 2012: 8, 10)

Autistic voices are literally audible on The Autism Channel (TAC), launched in 2012 in West Palm Beach, Florida as a streaming cable station. With hosts on the spectrum, and the goal of covering "the whole autism world", The Autism Channel is alone in the media world in its commitment to not only reaching people with and interested in autism, but also in putting people with ASD in front of the camera, a powerful instantiation of an expanding ASD "disability public". Daniel Heinlein, for example, diagnosed with Asperger's, hosts a show called "I Am Autistic" in which he interviews people in the autistic world, both on and off the spectrum (Neary 2013). Like many of the projects we are studying, The Autism Channel is clearly propelled by a sense of social justice and "narrative urgency" to construct a more radically inclusive future; as the demographers remind us, numbers are on their side. As is the case with all media, a dedicated and expanding audience is fundamental to survival and success. With an every-growing number of people and their allies identified as ASD and seeking like-minded others, The Autism Channel points towards a mediated future that we identify as a cultural activity that contributes to the eventual construction of "the new normal".

One of our longstanding fieldsites, NY City's Reelabilities Film Festival, is also part of this process. Now in its seventh year, this event offers an international showcase for outstanding films by, for and about people with disabilities. Cinema occupies one of the more influential roles in contemporary American culture; to virtually encounter the lives of those with specific impairments as they engage the world is a particularly compelling way to build disability publics. We have been following the Festival's remarkable growth since its inaugural year. Screenings are followed by discussions with filmmakers as well as representatives of the disability worlds portrayed in the film itself. Intensive planning and preparation for festival success requires off-screen recognition of the needs of diverse audiences. The requisite accommodations of the viewing space include audio description for those with visual impairments, closed captioning and signing for deaf audience members, seating that allowed for as many power chairs as necessary in the theater, with room for a few guide dogs, a large percentage of people on the autism spectrum using assistive communication devices, and a high tolerance for audience unruliness. As regular attendees, we found that experiencing this infrastructural welcome made us acutely aware of the unaccommodating and ableist arrangements of typical commercial cinema spaces.

One of the featured screenings for the 2014 festival was exemplary of the sense of inclusion the festival embodies and creates. The New York premiere of *Invitation to Dance*, the bio-doc about the life of disability activist Simi Linton that she made with Christian Von Tippelskirch, was sitting and standing room only. The film tells the story of Linton's post-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".^[iv] As we joined the crowd walking, rolling, and limping into the theater for the film's debut, the sense of celebration was electric. The responsiveness of this disability public to the film was palpable, creating a kind of *jouissance* produced by the audience's recursive recognition of disability accomplishments reflected in the story line. Everyone in the packed house stayed on for lively post-screening conversation, followed by a reception and dance party with wheelchair dancers featured in the film taking the lead.

We focus on Reelabilities as a representative field site, demonstrating the productive intersection of demography and the creation of disability publics. The dramatic expansion of interest in the festival is indicative of both growing numbers of people with disabilities and their allies as participants, and the increasing cultural consciousness they represent that together make disability count. Since its inception in 2008, the festival – which began in a single location in Manhattan – has now proliferated, with 37 venues in the NY metropolitan area and festival partnership in 15 American cities.^[v]

In all these locations, the presence of diverse audiences, from the unmarked category of the temporarily able-bodied, to people with a remarkable range of differences, enable a kind of existential repositioning, laying the groundwork that is essential to "the new normal". This, we argue is essential to the making of disability publics and accessible futures. As Alison Kafer reminds us,

...disabled people are continually being written out of the future, rendered as the sign of the future no one wants....It is my loss, our loss, not to take care of, embrace, and desire all of us. We must begin to anticipate presents and to imagine futures that include all of us. (Kafer 2014, p. 46)

Resignifying a hegemonic frame takes time, even when those who count disability demonstrate that numbers increasingly are on "our side". Yet expanding numbers are not enough. Kafer's powerful and inclusive vision of futurity in which disabled subjects are fully recognized and participatory as part of projects of social justice is essential to making disability count.

As anthropologists, our job is to show how these processes, whether by counting disability or making it count, are creating more inhabitable worlds.

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Notes

[i] Our research includes a much broader universe: intensive longitudinal interviews with families affected by disability, long-term research in biomedical research labs studying “atypical brains”, and emerging transition programs for young adults with disabilities who are leaving the public education system. Of course, in focusing on sites of innovation, we do not lose track of the overwhelming lack of everyday support and ongoing discrimination faced by so many who identify with the disability label.

[ii] We are grateful to Martin Vega for his insights into the complexities of census data.

[iii] For further information, please see <http://autisticadvocacy.org/home/resource-library/#books>, Accessed May 9, 2015.

[iv] For information, see <http://www.invitationtodancemovie.com/>, Accessed 18 March 2015.

[5] For information, see <http://newyork.reelabilities.org/>, Accessed 18 March 2015.

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[Inhabitable Worlds](#) is a series that examines the theoretical tools and approaches that scholars bring to the study of disability in the social sciences and humanities. It is edited by [Michele Friedner](#) (Stony Brook University) and [Emily Cohen](#) (New York University).

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