

Road Map for Inclusion

Changing the Face of
Disability in Media

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with
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Introduction

We are thrilled to publish *Road Map for Inclusion: Changing the Face of Disability in Media*, a report by Ford Foundation Senior Fellow Judith E. Heumann, with Katherine Salinas and Michellie Hess. The culmination of a year of intensive research and meetings, this remarkable report highlights the scale of a problem that has been overlooked for far too long: media's failure to adequately represent the one-in-four Americans who live with disabilities. Judy methodically documents the evidence and consequences of this problem, and puts forth a radically simple argument: People with disabilities should be represented proportionally, both in front of and behind the camera. To get us closer to that goal, she offers a set of clear, practical recommendations for change.

“It is no longer acceptable to not have women at the table. It is no longer acceptable to not have people of color at the table,” Judy writes here. “But no one thinks to see if the table is accessible.” It is an observation that rings uncomfortably true for me. Two years ago, I was confronted with the fact that the Ford Foundation's work on inequality did not account for the more than one billion people around the world who live with one form of disability or another. It was an unsettling moment, and a humbling one. Since then, we have been thinking seriously about disability issues, and working to confront ableism and expand participation across the foundation. And we have taken concrete steps to integrate an inclusive, accessible perspective across all of our grant making. I am proud of how far we have come, but it is still early in our efforts. We are committed to making a meaningful difference and being a model for the field—and we know we still have a lot to learn.

And that is why I am so grateful for Judy Heumann's expertise and counsel, and the profound impact she has had on the foundation during her tenure as a senior fellow. Through this paper, she extends that impact to the field of philanthropy and the broader media landscape. Regardless of the field you work in, or your experiences with disability inclusion, this paper offers a road map for living up to the ideals of diversity, equity, and inclusion to which we all aspire.

Darren Walker
President, Ford Foundation

Executive summary

WHY?

The media is at a crossroads. Diversity is in the zeitgeist and disability is being left out of the conversation. One in four Americans is disabled, and they should be represented proportionally in front of and behind the camera.

WHAT?

This white paper details the current issues regarding lack of authentic representation of disability in the media. Examples drawn from the experience of other minority groups, such as Asian Americans and the LGBTQI community, offer some insight into steps that can be taken to induce change. Finally, we provide clear recommendations, including supporting a specific entity dedicated to the inclusion of disability in the media, for funders interested in taking critical steps to achieving authentic representation of disability in the media.

WHO?

This white paper is designed for the philanthropic community, particularly those interested in cutting-edge inclusive diversity initiatives. The philanthropic community has the opportunity to be an agent of change by funding an entity focused on the inclusion of disability in the media.

Definitions

MEDIA

For the purposes of this paper, we will be defining media as scripted television and film, broadcast and streaming—and looking at the representation of disabled people both in front of and behind the camera.

DISABILITY

The ADA defines a person with a disability as a person who has a physical or mental impairment that substantially limits one or more major life activity. This includes people who have a record of such an impairment, even if they do not currently have a disability. It also includes individuals who do not have a disability but are regarded as having a disability. The ADA makes it unlawful to discriminate against anyone based on their association with a person with a disability.

DISABLED PEOPLE VS. PEOPLE WITH DISABILITIES

We want to acknowledge one of the significant debates in the disability community: people-first vs. identity-first language. This refers to the difference between the terms “people with disabilities” vs. “disabled people.” For the purposes of this paper, we will be using identity-first language, while respecting both perspectives.

Foreword

When I was a young girl growing up in Brooklyn, New York, in the 1950s, my mother took me to my neighborhood school to register for class. I remember carefully picking out my dress the night before and my mother pushing my wheelchair a few blocks to the school, and then having to pull me up the steps to the entrance as there was no ramp. When my mother went to the front desk to register me, the principal came out to talk to her. He told her I would not be able to attend the school because I was a fire hazard; I could not walk out of the building. I was denied entry because I could not walk. You don't have to guess how that made this little girl feel. Even today, it is difficult for me to recall how painful it was to think that nobody valued my intelligence for the completely unrelated reason that I couldn't walk. Instead, a teacher came to my house two and a half hours a week until the middle of the fourth grade. In my own mind, there were no barriers to what I could learn or what I could achieve. But to society, out of sight, out of mind.

Fast forward to 2017, when Darren Walker invited me to become a senior fellow at the Ford Foundation as part of the foundation's effort to be more disability-inclusive in its work on inequality. I was encouraged to focus on a problem that I had not previously had the opportunity to work on. Having spent my life organizing with other disabled people, advocating for legislative, policy, and programmatic changes to promote the rights and equality of disabled people around the world, I could think of myriad potential issues to address.

We have certainly come a long way from my youth, when disabled children were denied the right to an education because of inaccessible schools or because of low expectations for children with any form of disability. Calling a child a fire hazard and denying them an education is now illegal. There is, to be sure, no shortage of laws and resolutions purporting to make disabled people fully equal participants in mainstream life. The 1990 Americans with Disabilities Act (ADA) and numerous other federal measures prohibit disability discrimination in the United States. In 2006, the United Nations adopted the Convention on the Rights of Persons with Disabilities, which over 175 countries have since ratified and are legally obligated to uphold (unfortunately, the United States is not one of the 175, but that is an issue for another day). But, the fact is, both here in the United States and around the world, disability discrimination remains pervasive—sometimes it's insidious, as is reflected in the vastly lower employment rates among disabled people, and sometimes it's more blatant, as the rates of violence and assault perpetrated against them make clear.¹

However it manifests, this kind of disability discrimination amounts to an “othering” of disabled persons. Boiled down to its essence, such discrimination arises from the inability of non-disabled people to understand, appreciate, empathize with, learn from, and respect the lives of those in our diverse community on an equal basis with their own.

In reflecting on the cultural norms that permit such discrimination to continue, I realized that I wanted to focus my time at Ford on the role of the media in shaping these cultural norms. Growing up, I rarely, if ever, saw anyone with a disability on television or in movies. If disabled people were shown at all, they were portrayed as villains to be reviled—Ernst Blofeld in the *James Bond* series and the eponymous Doctor Strangelove of the classic Stanley Kubrick film were both wheelchair riders—or as objects of pity for charitable causes such as the *Jerry Lewis Telethon* and on numerous soap operas where “good” or beloved characters were apt to be miraculously cured of their disability. Without question, there was nobody I could look to and say, “There's a positive, high-achieving disabled person like me,” and certainly no one I could look to as a role model who reflected my actual lived experience. I felt invisible. Ironically, of course, one of the most inspirational political figures of the 20th century was a wheelchair rider himself; four-term US President Franklin Delano Roosevelt could not walk due to having contracted polio, just like me. But almost no American knew it: Roosevelt and his advisers went to fantastic lengths to keep his disability hidden from the American people because of the societal stigma around disability.

It is long past time for this cultural invisibility to end. Media companies, from news outlets to Hollywood studios to the leading social-media platforms, must be held accountable. Disabled people's stories should be standard, presented with a frequency proportional to the community's vast numbers. We must act—now—to make this happen.

Much attention has been given of late to the need to increase diversity and representation in the media, but rarely is disability referenced as part of that diversity. As many in the disability advocacy community are saying, "It's time to put the 'D'—disability—in diversity!" Media must begin to see those of us with all types of disabilities, and from all backgrounds, as a part of society and as meaningful contributors. We need to see reflections of both the diversity and commonality of our stories. Representation of the diversity within our community—including the breadth of apparent and non-apparent disabilities—and the intersection of disability with other identities, is very important, not just for us as disabled people but for families and communities as a whole. Disabled people in film, on television, and in other forms of media should reflect the reality of our lives—our joys, sorrows, struggles, victories, and the everyday issues we all face. Only then will we be able to effectively counteract the themes of our being invisible or seen only as incapable, a drain, a tragedy.

This report then is a foray into the world of media, focusing on television and film. It examines how disability has typically (and problematically) been portrayed, presents examples of progress that has been made in the inclusion of disability, and looks for models from other movements and other countries that have been successful in shifting the way particular groups are represented in the media. It also provides recommendations to further the cause of meaningful and realistic media representation of disabled people. The recommendations in this paper are focused on those within the philanthropic community—both donors and grant recipients—who are engaged in effecting change within and across the media. That said, I hope that the industry more broadly will pay attention to the recommendations and begin or expand efforts to be inclusive of realistic representations of disabled people.

This report draws extensively on a June 2018 convening held at the Ford Foundation, which brought together a diverse group of people from television, film, and organizations focused on advancing the representation of disability in the arts, as well as some of the major organizations focusing on advancing diversity in the media in general. I wanted to learn what other minority groups had been doing over the years to speak out against minimal and stereotypical representation, including how such efforts have been funded. It was a unique group and as far as we can tell, the first convening of its kind.

I am confident that effective implementation of this report's recommendations will lead to tangible changes, ensuring that, over time, disabled people are visibly and accurately represented in the media as an equal part of the diversity of our society. In turn, I strongly believe that the media is capable of positively affecting society's perceptions of disabled people so that authentic representation, over time, can reduce stereotypical perceptions of disability and play an influential role in reducing discrimination and advancing equality.

Disabled people are a part of every other group in society, and we are the one group that anyone can join at any age. After 70 years of waiting, I ought to find the disability experience an intrinsic element of the media's representation of society. Regardless of our age, race, religion, ethnicity, or sexual orientation, whether we were born with or acquired our disabilities, and whether or not our disabilities are apparent or not, I and other disabled people ought finally to be able to point to the presenters and characters on our televisions and in our films and say, "That person's like me—they understand my life, joys, sorrows, and complexities." I want to be able to stop cringing, and with the millions of disabled people, families, and friends—including the thousands of disabled people interested in working in the industry—know that our ever-growing and diverse community is truly being included. There have been endless discussions about *why* the disabled population remains on the margins. The time has come to seriously and comprehensively take steps that will move us from the margins to the main stage.

Introduction

“
The times they are a-changin’.
”
– **BOB DYLAN**

We are at a pivotal point in history. Media is shifting and changing from traditional broadcast and print to the new world of online streaming and social media. With movements like #OscarsSoWhite and Time’s Up, the entertainment industry is galvanizing to create change. Diversity is in the zeitgeist and blockbuster films like *Black Panther* highlight the importance of representation and the need to create a world of inclusion. The economic benefits that inclusion brings don’t hurt either.²

However, one minority that is continually left on the margins of this new wave of representation is disabled people. We saw this with the #MeToo movement, which has created a radical shift in our society. Disabled women were only included after activists from the community called out the Time’s Up movement for not being inclusive of women with disabilities.³ It is no longer acceptable to not have women at the table. It is no longer acceptable to not have people of color at the table. But no one thinks to see if the table is accessible.

According to GLAAD’s *Where We Are on TV ’18-’19*,⁴ only 2.1 percent of primetime broadcast TV series regulars—or a total of 16 characters—have disabilities. A recent Annenberg study⁵ found that, across the 100 top-grossing movies of 2016, only 2.7 percent of characters were depicted with a disability, only 2.5 percent of characters were depicted with a disability over the past 10 years, and nearly half of the films across the top 100 did not include a single character with a disability. Of those small numbers of characters, 95 percent are played by non-disabled actors on television.⁶ This has critical ramifications for media and society. Media reflects society and society can reflect the media. Society has its own issues with disability that it must grapple with. A study in the United Kingdom found that “two thirds (67%) of the British public feel uncomfortable talking to disabled people.”⁷ It is unlikely that the United States numbers are dramatically different. However, there is evidence that the media can play a part in changing these attitudes. When London hosted the 2012 Paralympics, a strong media push by Channel 4 demonstrated that media can make an impact. A study regarding attitudes before and after the London 2012 Paralympics showed that this media push was successful in shifting short-term perceptions surrounding disability, with one disabled person explaining, “There was like a two-week or something period when it was very positive to be disabled... Suddenly they [non-disabled people] realised it’s not a scary thing to talk to me... Cause [the Paralympics] educated them.”⁸ Unfortunately, the Paralympics are only every two years, with the Summer and Winter Paralympics alternating, and we need sustained change now.

We have seen that the media has the potential to create lasting change in the hearts and minds of the public with respect to other minority groups. This is clearly evident in Ellen DeGeneres’s coming out 20 years ago and the subsequent growth in acceptance of the gay rights movement. As Eric Marcus, creator and host of the podcast *Making Gay History* explains: “For everyday people, Ellen made gay OK.”⁹ Ellen visited the homes of millions of people every afternoon, people who may have never been exposed to an LGBTQI person otherwise. In a study conducted in 2015, Ellen was cited as a more influential figure in the LGBTQI movement than any politician, even President Barack Obama.¹⁰ Imagine if a disabled person could do what Ellen did for the disability community.

As Darren Walker, president of the Ford Foundation, said in a 2015 speech at the Skoll World Forum, “The media cannot serve our representative democracy if it isn’t representative of our democracy.”¹¹ So where does disability fit in?

What's wrong with media representations of disability?

“
The goal is that everyone should get to turn on the TV and see someone who looks like them and loves like them. And just as important, everyone should turn on the TV and see someone who doesn't look like them and love like them. Because perhaps then they will learn from them. Perhaps then they will not isolate them. Marginalize them. Erase them. Perhaps they will even come to recognize themselves in them. Perhaps they will even learn to love them.”
~ SHONDA RHIMES, *YEAR OF YES*¹²

One out every four Americans has a disability.¹³ However, far fewer than 25 percent of characters in the media today are depicted with a disability—and those who are, most often are not portrayed by a disabled actor.

Moreover, media makers do not seem to be cognizant of disabled people's absence. Why would they be? The current system is working for them. According to the film website IndieWire, “59 non-disabled actors have earned Oscar nominations for playing disabled characters. History suggests that those nominees have nearly a 50% shot at a win.”¹⁴

Representation of disability in the media should be one in four, in front of and behind the camera, in characters, in actors, in directors, in writers' rooms, and more. Disabled people come in all shapes and sizes, from wheelchair riders to people with psychosocial disabilities to those with chronic illnesses. From the Hispanic deaf person to the legally blind African American who has albinism to the Asian lesbian wheelchair rider, diversity is intersectional and the media must reflect this. Not only do disabled people need to see themselves, but their families and communities need to see disability on their screens. Most people acquire their disabilities as they become older, so people should be given the opportunity to learn about the diversity in this community.

We are seeing small changes. There are now primetime shows such as *Speechless*, which features a young, physically disabled actor playing a lead character with a disability.¹⁵ *Switched at Birth* gives the audience a small peek into deaf community and culture.¹⁶ *Sesame Street* (which has been on the air for 49 years with more than 1,400 episodes,) introduced a puppet character with a disability in 2017, and the character of Julia, who has autism, was highly celebrated and accepted.¹⁷ *Breaking Bad* is considered by some to be one of the best dramas ever on television,¹⁸ and the main character's son has cerebral palsy and is played by an actor with that disability.

One of the best examples of disability representation was a recent Comedy Central *Drunk History* episode highlighting the Section 504 demonstrations in 1977 that eventually led to the Americans with Disabilities Act in 1990.¹⁹ It was part of a collection of stories focused on civil rights activists, from suffragettes to African Americans in the South, demonstrating how each group simply wanted access to equal citizenship. Every disabled character in the episode was played by a disabled actor and it illustrated an actual event in disability history, one that is seldom discussed in mainstream media.

However, while we are seeing these advancements we are also seeing movies like *Million Dollar Baby* and *Me Before You* continuing to be made. These films were not written or acted in by disabled people and they feature actors portraying disabled people who believe that death is better than living with a disability. There are some disabled people who may share these sentiments, but a portrayal like this completely negates the experiences of other disabled people whose lives are valued by themselves and others. The disability community has pointed this out by protesting both films, yet all that uninformed audiences

see is that *Million Dollar Baby* went on to win the Best Picture Oscar and is considered one of the best films of the 21st century.²⁰ While discussing the “romantic” *Me Before You*, one reviewer commented that “death is the ultimate aphrodisiac.”²¹

Hollywood has made critical first steps toward authentic representation, but it still has many miles to go.

Stereotypical portrayals of disability

In order to understand how disability has been portrayed over the years, one need only look at depictions of disabled people on TV and in movies, which tend to fall into one of four stereotypes: the Super Crip, the Villain, the Victim, or the Innocent Fool.

THE SUPER CRIP

Examples: *Daredevil* in the *Daredevil* TV series
Professor X in the *X-Men* film series
Jaime Sommers in *The Bionic Woman* TV series

Super Crips are disabled characters who triumph over their disability. At face value, this may seem like a positive stereotype: Who doesn't want to be seen as a hero? *Daredevil* overcomes his blindness to become a badass superhero who defeats the bad guys. He is a superhero *despite* his disability. But the Super Crip stereotype reinforces the idea that disability is something that must be overcome. Super Crips tends to appear in “inspiration porn,” because they're portrayed as being inspirational by virtue of prevailing over their disability.²²

THE VILLAIN

Examples: the villains in most James Bond movies, including *You Only Live Twice*, *GoldenEye*, *Casino Royale*, *Die Another Day*, and *Skyfall*
Darth Vader in *Star Wars*
The Joker in *The Dark Knight*
Voldemort in the *Harry Potter* movies
Dr. Poison in the *Wonder Woman* movie

This stereotype plays on people's inherent discomfort with those who do not look the same as them, telling them that disfigurement—and disability, in general—makes characters revolting and morally wrong and reinforcing the notion that “we should be afraid of people whose faces and bodies are different from our own.”²³

THE VICTIM

Examples: *Will Traynor* in *Me Before You*
Maggie Fitzgerald in *Million Dollar Baby*

Disabled characters are often portrayed as one-dimensional victims of their disability. Their disability becomes their defining feature and their lives revolve around it, rendering them failures and objects of pity.²⁴ Movies like *Me Before You* and *Million Dollar Baby* depict disability as an insurmountable hurdle, and a disabled life as not worth living, presenting suicide as a better option.

THE INNOCENT FOOL

Examples: **Raymond in *Rain Man***
Lenny in *Of Mice and Men*
Forrest Gump in *Forrest Gump*

Characters with intellectual disabilities are often portrayed as childlike, unable to make rational decisions for themselves and needing to be cared for by others. They're presented as unavoidably constrained by their circumstances and often are seen as people to laugh at, or as the butt of jokes.²⁵

Lessons from other minority groups and how they've organized

Other minority groups have had to counter their own underrepresentation and stereotyped representation in the media, and there are lessons to be learned from the progress that has been made by such groups. To be sure, there is still more to be done to move the needle for African Americans, Asian Americans, Latinos, Native Americans, LGBTQI people, and others. *Black Panther*, with its majority-black cast, just arrived in 2018, as did *Crazy Rich Asians*. However, while these communities have had monumental and impactful moments, disability seems to be decades behind. So how did these groups make it this far?

We consider here two specific cases: the Center for Asian American Media and GLAAD. Recognizing that there is extensive literature looking at both organizations in much greater depth, what follows is a necessarily brief examination of the activities, successes, and lessons learned from each group.

CENTER FOR ASIAN AMERICAN MEDIA

In order to outline an accurate history of the Center for Asian American Media, it is necessary to briefly address the genesis of the Corporation for Public Broadcasting (CPB). CPB was founded in 1967 to be “the steward of the federal government’s investment in public broadcasting and the largest single source of funding for public radio, television.”²⁶ In 1977, after a decade of social and political unrest, much of it fueled by racial injustice, a task force created to evaluate the status of minorities at CPB found that “the public broadcast system is asleep at the transmitter.” Congress therefore began to fund minority group organizations working to advance their representation in the media—some of which eventually joined forces to develop the National Minority Consortia. Today, the National Minority Consortia consists of five independent organizations: Latino Public Broadcasting, Vision Maker Media, Black Public Media, Pacific Islanders in Communications, and the Center for Asian American Media (CAAM).

CAAM describes itself as “dedicated to presenting stories that convey the richness and diversity of Asian American experiences to the broadest audience possible.”²⁸ Its award-winning films are seen by millions of public television viewers a year across the United States. The organization has supported 47 documentary shows since 2014 and more than 200 films since 1982.²⁹

CAAM was founded in 1980, after CPB funded a three-day conference at the University of California, Berkeley.³⁰ As the organization’s executive director Stephen Gong explains, “the founding group was composed by TV and radio producers,

a very few of them, filmmakers, community activists, funders, and educators.”³¹ At the three-day conference, the creation of an entity that could benefit from CPB’s policies was discussed, and CAAM was formed later that year. Gong pointed out that “when we started, we were just trying to find a place at the table, and some way of inclusion. And now we see a much greater purpose and it’s a shared purpose with many colleagues and allies.”³² As CAAM’s website explains:

CAAM’s general mission approached Asian American media in two different ways. Part of the organization’s priorities included social advocacy to confront and challenge negative images of Asians within mainstream media. At the same time, CAAM also invested its resources into creating new work, especially for public broadcasting.³³

CAAM works in tandem with other members of the National Minority Consortia to mentor several filmmakers of color every year because “bringing filmmakers of color together has provided a foundation for opportunity and collaboration that lasts for years.”³⁴

GLAAD

Although the creation of a majority of minority organizations is a result of government funding from CPB and foundations such as the Ford and MacArthur Foundations, the LGBTQI community took a different approach with GLAAD. GLAAD was founded on November 14, 1985. At the time, coverage of the community and the HIV/AIDS epidemic was often defamatory and sensationalized.³⁵ Unlike groups within the National Minority Consortia, GLAAD was established and funded from within the LGBTQI community. Over the years, GLAAD has evolved from a gay and lesbian alliance against defamation to address a full range of issues in the community. GLAAD’s Senior Director of Education and Learning, Ross Murray, describes the expanded scope of their work this way:

“We call GLAAD the voice for LGBTQI acceptance. GLAAD started as a protest movement in 1985 in response to defamatory coverage of the LGBTQI community, particularly around HIV and AIDS. Occasionally, we still have to be a media watchdog, but today GLAAD is much more proactive. We help media outlets tell the story of LGBTQI people in a way that is fair, accurate and inclusive. We also train people how to use the media as a tool to build acceptance for the LGBTQI community in society.”³⁶

Acknowledging the importance of media and the role it plays in shaping our society, GLAAD established the GLAAD Media Institute. The GLAAD Media Institute enables communities to effect positive cultural change through media in three ways: first, by training spokespeople and media engagement education; second, consulting with industries, corporations, and organizations positioned to take a stand for justice; and third, conducting research in evaluating data and developing metrics to strengthen their mission.³⁷ Over the past couple of years, GLAAD has published various reports examining the status of the field—perhaps most notably, its annual *Where We Are on TV*, which examines primetime scripted series regulars on broadcast networks and streaming and tracks the number of LGBTQI characters through a diversity lens that is inclusive of disability.³⁸ As explained by Murray, “If they’re all white, gay, men, cisgendered, that’s not really representation.”³⁹ GLAAD has also learned from other movements trying to make a difference in media. Murray cites the example of the Vito Russo Test:

GLAAD’s Studio Responsibility Index created the Vito Russo Test, based on the Bechdel Test. To pass the Vito Russo Test, a film must include these three criteria: The film must include an identifiable LGBTQI person on screen. The character must have full complexity, not just the butt of a joke and not urban authenticity. And third, the character has to matter to the plot; if you removed this character, would the plot change?⁴⁰

GLAAD is now working to use the lessons it has learned to help support the disability rights movement.

What has already worked in disability: Lessons from the United Kingdom

We can look to the United Kingdom for examples of how disability can become more integrated into television—from programming to casting to production—and the benefits that can result. Beyond the efforts of specific channels, it should be noted that there is an underlying regulatory framework that has contributed to the level of inclusion attained thus far. For example, in the UK media system, there is a communications regulator known as Ofcom. Operating under the Parliamentary Communications Act of 2003, Ofcom regulates television, video-on-demand sectors, fixed-line telecoms, and mobile and postal services.⁴¹ Ofcom oversees operating licenses for both the BBC and Channel 4, and its diversity targets explicitly include disability. There is even a system known as Diamond that is used by the BBC, ITV, Channel 4, Channel 5 and Sky to catalog and distribute consistent diversity data on programmes they commission.⁴²

Within the context of this regulatory framework, the efforts of two channels in particular —the BBC and Channel 4— offer powerful examples of what is possible with respect to the representation of disability.

THE BBC

The British Broadcasting Corporation, better known as the BBC, is the UK's largest broadcaster, and it is funded by a license fee that is mandatory for any household whose residents watch, record, or download programs as they're being aired on TV, live streamed on an online TV service, or downloaded and made available through the BBC's iPlayer app.⁴³ One of the "public purposes" outlined in the BBC's founding charter is "to reflect, represent and serve the diverse communities of all of the United Kingdom's nations and regions and, in doing so, support the creative economy across the United Kingdom."⁴⁴

In 2017, Ofcom became the BBC's first independent external regulator, offering the BBC a new operating license with all the obligations attendant to such a license. This includes, for the first time, the BBC being held publicly accountable for achieving workplace diversity targets.⁴⁵ In response, the BBC declared that "by 2020, the BBC wants its employees to comprise 50% women, 8% disabled people, 8% lesbian, gay, bisexual or transgender people and 15% people from Black, Asian and ethnic minority backgrounds."⁴⁶

That is not to say that the BBC has not been including disability in its programming for decades. One clear example of this is *See Hear*, described on the *BBC Blog* as a travel show with "a Deaf presenter, a Deaf director, Deaf picture editors, Deaf animators ... and all in sign language ... On air since 1981, *See Hear* is the first and longest running deaf programme in the world. It is the BBC's only programme broadcast in full British Sign Language, covering issues of interest to the Deaf community."⁴⁷

Already today, 10 percent of the BBC's stars have a disability.⁴⁸ Training programs have been developed such as *Class Act*, which "aims to shine a light on experienced disabled actors already working in the industry, as well as discover and develop the potential of up-and-coming talent."⁴⁹

As *Ouch!* Editor Damon Rose of the BBC explains, "The great thing is you now have the queue for the accessible toilet [at the BBC] which is very interesting, and I don't know if that happens in many places."⁵⁰

CHANNEL 4

Channel 4 was founded in 1982 to “challenge the status quo, and appeal to a diverse, young audience.”⁵¹ It was only the second independent commercially funded television franchise in the UK, following ITV which was founded in 1955 to provide competition to the BBC. Channel 4 is funded entirely by advertising, and all of its programming is made by independent production companies.⁵²

Channel 4 has demonstrated a significant dedication to including disability in its programming. This can be seen clearly in Channel 4’s coverage of the London 2012 Paralympics. (Although the Paralympics technically falls outside this paper’s focus on scripted media, Channel 4’s extensive work to make the London Paralympics such a broadcasting success illustrates numerous lessons of potential relevance to the scripted media industry.)

Channel 4 won the bid to cover the London 2012 Paralympics over competing bids from the BBC and others, with comprehensive commitments to, among other things, discover a new generation of disabled talent, deliver more comprehensive coverage than ever before, and challenge attitudes about disability.⁵³ It delivered, with a 251 percent increase in daily reach during the games compared to that of the 2008 Paralympics,⁵⁴ and it continued its support in subsequent Paralympics as well.

At the end of July 2012, UK awareness of the 2012 Paralympics was at 16 percent. By the end of August it was at 77 percent.⁵⁵ This is because Channel 4 contributed significant resources to a major advertising campaign known as *Meet the Superhumans*, which aired across 78 channels and appeared on 2,000 billboards.⁵⁶ This campaign’s impact continues to this day. During multiple research interviews for this project, when sources were asked to point out an example of good disability coverage, *Superhumans* was almost always mentioned.

Moreover, in 2016, Channel 4 held a competition for advertisers, awarding £1 million worth of airtime to the best campaign featuring disabled people, with winning ads to be shown during Channel 4’s coverage of the opening ceremonies of the Rio Paralympics. The confectionery manufacturer Mars won for its Maltesers brand of chocolates, beating a short list of other notable brands, including Amazon, Barclays, Dove, H&M, Lloyds Bank, Lynx, and Purdey’s. Mars partnered with the disability organization Scope, which assisted in identifying disabled actors to perform in the adverts.⁵⁷ The resulting campaign included three ads that featured disabled actors, and it turned out to be the most successful campaign for Maltesers in a decade.⁵⁸ (The campaign was also one of the most complained about that year, in part because one of the ads, “New Boyfriend,” was slightly risqué; the Advertising Standards Authority received 151 complaints that the content was offensive to disabled people or of an overly sexual nature. None of the complaints, however, was upheld by the ASA.) Having set a target of four percent sales growth, Maltesers achieved 8.1 percent growth while the campaign was on the air, illustrating that there is a real economic benefit to including disability.⁵⁹

Channel 4 also kept its promises regarding discovering disabled talent, as at least half the members of the on-air team during the London Paralympic Games were disabled.⁶⁰ Two years before the games aired, there was a nationwide search with over 300 applicants. Final contenders were put through rigorous boot camps and work placements in order to provide real world experience and be sure they could handle the demands of a fast-paced live show. The newcomers played a major role in the coverage of the games, and 82 percent of viewers surveyed after the games said they enjoyed the fact that there were disabled presenters.⁶¹

This commitment to including disability has continued beyond the conclusion of the Paralympics. According to Channel 4’s Head of Creative Diversity, “it changes from year to year but a proportion of [her] training budget is set aside for production talent with disabilities each year (about 20%) goes directly to individuals or to indies supporting them into work.”⁶² In addition, Channel 4 features non-sports-related disability content, from dating shows to late-night comedy shows (such as *The Last Leg*), and went so far as to call 2016 “The Year of Disability,” as the network doubled the number of disabled people on the 20 most popular TV shows that year.⁶³ Channel 4 has clearly taken great strides to include disability on the screen, while also working behind the scenes to train and support new disabled talent.

Conclusions

The philanthropic community has served as an agent of change through its funding of the projects and work of historically marginalized groups. The Ford Foundation, in particular, has always strongly believed in investing in innovative ideas, visionary individuals, and frontline institutions that are advancing human dignity around the world. Media, as we know it, is at a crucial tipping point. Similar to the introduction of printed press, radio, and broadcast television, the lightning-speed evolution of technology is creating societal shifts through media due to greater access to more diverse points of view and information. In the Internet age, it is increasingly unacceptable for media outlets to fail to represent the diversity of the population.

The disability community is a vibrant mix of all minority communities. Disability doesn't discriminate between, race, religion, gender, sexual orientation, or socioeconomic status. Which is why the inclusion of disability must be addressed and enforced in a dynamic and holistic manner. In order for the disability community to make sure that it is not forgotten and left behind (yet again) as media evolves and changes, it is imperative to have investments be made to support the disability community's efforts to stake a claim in this arena.

The disability community needs a central hub that is a hybrid of organizations like CAAM and GLAAD, to ensure the visible and proper representation of disabled people. It is not enough to merely encourage current programs to become inclusive of disability. The disability community needs a space where its members can come together and work on changing the narrative around disability, and where community leaders can help nurture and support artists in developing their craft with the support of both federal and foundation funding.

Currently, the work in this area is limited and scattered. The burden of an entire movement rests on the shoulders of the few individuals who have broken into the field. There is need for a sustainable solution that allows for further growth and development within mass media and pushes the industry beyond its historic reliance on tokenistic and stereotypical representations of disability.

IN AN IDEAL WORLD

What, then, could and should the industry look like when full inclusion has been achieved?

Programming

- More on-screen representation
- Disabled people comprise around 25 percent of the characters in media, representative of the one in four Americans who have a disability. Their roles take all forms, from a romantic lead to a dodgy drug dealer to a barista.
- Stories are not centered solely on their disabilities and do not perpetuate harmful stereotypes.
- Non-disabled writers are paired with disabled writers to be sure of authentic representation.

Talent pipeline

- More people with disabilities work in media at all levels, establishing an ecosystem of disabled people owning, leading, and participating, from executives to show runners to production assistants.
- There's no more just hiring people who "look like you"—all candidates are given a fair chance based on talent.
- Expertise and resources are universally available, so there can be highly qualified disabled people for the more than 200 career paths in media.
- It is no longer acceptable for people to claim that hiring disabled people is too expensive or too hard.

- Commitments and benchmarks are set by industry groups.
- Industry monitors and provides opportunities for professional development of disabled people.

Accessibility

- All production locations, industry offices, professional development events, etc., are accessible.
- Closed-captioning and video descriptions are standard throughout production.

US media on the world stage

- The United States, as a prolific exporter of influential media content, is an inclusion leader internationally, sharing how these meaningful changes were orchestrated.

Recommendations

CREATE AN ENTITY FOCUSED ON THE INCLUSION OF DISABILITY IN THE MEDIA.

We envision, with the support of funders, building a collaborative entity or initiative (alliance, center, consortium, etc.) dedicated to:

- nurturing and connecting leaders across the ecosystem
- convening the community
- galvanizing champions and the broader community to advocate for change
- aggregating existing resources
- identifying gaps and opportunities
- creating or commissioning needed research, tools, and processes to accelerate change in the field
- creating opportunities for fellowships, mentorships, and support for creation of media
- collaborating with various organizations working to advance diversity

We look to groups like CAAM and GLAAD as potential models. Such organizations highlight the importance of establishing entities whose sole purpose is to advance positive, authentic representation and inclusion of historically marginalized groups. CAAM has helped Asian American artists and activists find and raise their voices, and has established a more cohesive sense of community across the Asian American communities of the United States. GLAAD has successfully worked to change the outward image of the LGBTQI community, transforming negative misrepresentations into broad understandings of a diverse, vibrant, positive, and more socially accepted community.

Due to the breadth of diversity within the disability community, and lack of sustained work in this area to date, it is proposed here that any entity created have a dual mandate to address *both* the nurturing of artists *and* the changing of narratives around disability. This hybridized approach was emphasized during the June 26 convening at the Ford Foundation, at which Stephen Gong of CAAM and the National Minority Consortium had the following to say:

This is the area where authorship and self-representation are vital to a fully realized commitment to diversity. I would love to see a media organization dedicated to producers and filmmakers with disabilities. Such an organization would find enthusiastic collaborators with the NMC organizations but would, I'm sure, develop projects, initiatives, and strategies different from what we in the NMC would develop alone. I think the NMC leaders are fully supportive of including the disability lens in our work but there is no doubt that having support for an initiative would go a long way to making something real and measurable happen—and would, I hope, spur the development of a distinct organization to continue the work.⁶⁴

There currently is no such entity, and this is greatly hindering the progress of the disability community within this arena.

INSTITUTIONS AND ORGANIZATIONS EXPAND THEIR DEFINITIONS OF “DIVERSITY” TO INCLUDE DISABILITY. THEY OPERATIONALIZE AND SHARE THIS APPROACH AND ENCOURAGE OTHERS TO DO THE SAME.

All organizations (funders, studios, advocacy organizations, industry organizations) explicitly include disability and people with disabilities in their published diversity statements.

- Assess current efforts and set clear targets for ongoing improvement.
- Do you have a way to measure diversity, equity, and inclusion efforts with women, LGBTQI people, or people of color? If so, are you doing the same with disability? Commit to establishing benchmarks, setting goals, and measuring progress regularly for all categories of diversity.
- Review internal materials and processes regarding issues, such as reasonable accommodations, to ensure that they support real inclusion; leverage existing channels and materials to operationalize it; adjust as necessary.
- Share what you’ve learned and what you’ve done with others within your organization and with other organizations, and encourage them to do the same.

In 2016, the Ford Foundation began this process of self-reflection with Darren Walker’s September 12, 2016, blog post, “Ignorance is the enemy within: On the power of our privilege, and the privilege of our power.”⁶⁵ In it he describes his growing awareness of the problem:

In my own life, I have not been forced to consider whether or not there were ramps before entering a building, or whether a website could be used by people who were hearing or visually impaired. In the same way that I have asked my white friends to step outside their own privileged experience to consider the inequalities endured by people of color, I was being held accountable to do the same thing for a group of people I had not fully considered. Moreover, by recognizing my *individual* privilege and ignorance, I began to more clearly perceive the Ford Foundation’s *institutional* privilege and ignorance as well.

Since the publication of this blog, the Ford Foundation has begun an internal audit to assess its approach to disability in its culture and grant making. It has also conducted staff trainings on disability as a social justice issue, with the goal of incorporating disability across grant-making processes. Essentially, the Ford Foundation has been in a learning mode for the past year and hopes to share what it has learned with the rest of the philanthropic community in the coming years. Ford Foundation grantees, like the Sundance Institute, are also beginning to include disability in their work. It is critical that funders not only examine disability inclusion within their own institutional structure and programming but that they strongly encourage their grantees to do the same.

ALLIES AND ADVOCATES LOOK WITHIN THEIR COMMUNITIES TO DRIVE CHANGE

Nearly one in four people in the US has a disability. That means a percentage of your community (be it LGBTQI, people of color, women, etc.) is a part of the broader disability community, as well. Seek out the people with disabilities (visible/apparent and invisible/non-apparent) within your community, make space for their voices to be heard, and actively support their leadership. As actress Ali Stroker explains:

People are afraid to make a mistake around our community. They want to be careful. They don’t want to offend. So oftentimes, they love the idea of casting somebody with a disability but they’re too afraid to have conversations around accommodations or something as simple as, “Does this content feel representative of your truth?”

Before tackling larger systematic changes, a simple first step is examining our own personal experiences with the disability community (whether that be in film, television, or our own family and community). By becoming more attuned to our own explicit and implicit biases regarding disabled people, we can better formulate practical approaches to enhancing the realistic and inclusive representation of disabled people in the media.

Appendices

DISABILITY AND MEDIA CONVENING ATTENDEES FORD FOUNDATION, NEW YORK CITY, JUNE 26, 2018

Karim Ahmad *Director, Inclusion and Outreach, Sundance*
Lauren Appelbaum *Communications Director, RespectAbility*
Russell Boast *President, Casting Society of America*
Sara Bolder *Producer*
Lawrence Carter-Long *Director of Communications, Disability Rights Education @ Defense Fund*
Thomas Crockett *PBS Vice President for Stations Services, PBS*
Jax Deluca *Media Arts Director, National Endowment for the Arts*
Brigit Evans *Executive, Director, Pop Culture Collaborative*
Sally JoFifer *President and CEO, Independent Television Service*
Corrie Frasier *Facilitator*
Stephen Gong *Executive Director, Center for Asian Americans in Media*
Dan Habib *Filmmaker*
Tari Hartman Squire *Founding CEO, EIN SOF Communications, Inc.*
Michellie Hess *Researcher, Ford Foundation*
Judy Heumann *Senior Fellow Ford Foundation*
James LeBrecht *Sound Editor and Producer*
Wendy Levy *Executive Director, The Alliance*
Ross Murray *Senior Director of Education and Training, GLAAD*
Nicole Newnham *Documentary filmmaker and producer, Coco Films*
Katherine Pieper *Ph.D. Research Scientist, Annenberg Inclusion Initiative at U.S.C.*
Damon Rose *Editor of Ouch!, British Broadcasting Corporation*
Katherine Salinas *Researcher, Ford Foundation*
Betty Siegel *Director of VSA, Kennedy Center for the Arts*
Judith Smith *Founder and Director Emerita, Axis Dance*
Storm Smith *Art Director, BBDO*
Ali Stroker *Actress*
Catherine Townsend *Ford Foundation*
Graeme Whippy *Disability Specialist, Channel 4*
Alice Wong *Founder, Disability Visibility Project*
Kaitlyn Yang *Founder, Alpha Studios*
Chi-hui Yang *Program Officer, JustFilms, Ford Foundation*

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Throughout this journey, I have had an incredible rock and touchstone in my advisory group. Those who have heard me speak of them know that I lovingly call them my "Kitchen Cabinet." It was this group of amazing individuals who, on the days that this project seemed too much, provided warmth and sustenance in the form of thoughtful advice and direction. Thank you Jim LeBrecht, Sara Bolder, Lawrence Carter-Long, Nicole Newnham, Dan Habib, Corrie Frasier, Katherine Salinas, and Michellie Hess. Some of you were there from that first conversation over a meal in the Bay Area that led to the creation of this project and continued as we all huddled around computer screens every few weeks from all across the country to discuss this project and share insights on what is happening in the field. I would also like to thank my brother, Joe Heumann, for always picking up the phone and answering my random questions, day or night.

I have always found a large part of my strength and motivation from the community I have spent my life serving and advocating with others. Special thank you to the disabled artists and allies in the field that we had the opportunity to talk with who are contributing to what we want the future to look like: Becky Curran, Jason DaSilva, Reid Davenport, Nyle DiMarco, Simi Linton, Ali Stroker, Alice Wong, Judith Smith, and Selina Mills.

This project has been an emotional one for me. Having spent my life advocating for the rights of disabled people, I take every conversation as an opportunity to break down larger barriers. This project has further confirmed what my life experience had already taught me, which is that in any field there is normally a gaping absence of disability. Pointing out this absence can sometimes be a particularly difficult conversation. However, it is leaders such as Sally Fifer (ITVS), Paula Kerger (PBS), and Stephen Gong and Don Young (CAAM), who remind me that there are engaged individuals who may have had limited involvement with my community, but are eager to learn and make it a part of theirs.

Corrie Frasier fell from heaven after Nicole Newnham recommended her to act as the facilitator for our convening. Our convening would not have been as smooth and dynamic without Corrie's passion for the subject matter, fighter jet pilot execution, and attention to detail. She has got others engaged in our work and introduced us to many people, including Sam Howe Verhovek. I will miss our weekly calls discussing our work and her son's wheelchair basketball team.

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The Gruesome Threesome. This is a journey I did not intend to make, as it was my expectation that I would continue my previous work at the State Department under a newly elected President Clinton. When she did not win the election, I was out of a job and looking for new challenges. I have always loved working with intergenerational teams. I am thankful to my friend Curtis Richards who recommended that I interview Katherine Salinas. Because of this, I have been working with Katherine and with Michellie Hess, whose contribution to the development and completion of my Ford fellowship has been invaluable. They taught me about social media and pop culture, and I taught them about good old Brooklyn gumption and chutzpah. They came to me with Human Rights backgrounds and no knowledge about the Disability Rights Movement here in the US or around the world. This past year has been one of learning for us all.

Finally, to my number one supporter throughout this journey and many others I have taken throughout my career, my loving husband, Jorge Pineda, who constantly reminds me to take time for myself, take a break to spend time with his family in Mexico, and enjoy the simple things in life. It has been his constant support of my work throughout our marriage that has made what I do possible. When I turned our home into an office and held conference calls and meetings, he was more than understanding and his input on this project has been of great importance to me.

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