

3 “Spread the Word” about Inclusion

Visible protests are, by definition, widely seen. They are attention-grabbing on purpose sending a message that extends beyond their direct targets of action. Visible protests, regardless of issue space – from social welfare to education to media representations – have been critical in publicizing grievances and goals, hoping that these would do more to encourage not only structural change, but cultural change as well. Changing hearts and minds in addition to (or instead of) focusing on specific material gains may be more advantageous if activists encounter insurmountable obstacles with the latter (like influencing policy). Changing the culture could have longer-term positive impacts facilitating material changes as more conscience constituents (and voters) become aware of inequalities and injustice. While visible protests targeting popular culture tend to generate a lot of attention, their outcomes face similar constraints as other protests especially in terms of whether victories have lasting power down the road.

Like many historically marginalized groups, disability representation in print and video media has often been negative, stereotypical, or non-existent (Foster and Pettinicchio 2021). A 2005 UCLA study of Screen Actors Guild members found that only 2 percent of characters on TV identified as having a disability. Another study (Raynor and Hayward 2009) found that only 1 percent of SAG members identify as having a disability.

The 1990s seemed hopeful. There was growing interest by Hollywood to become more inclusive. For example, the hit TV show *Will and Grace* was celebrated for including gay characters on a network primetime show. But the star of the show, Eric McCormack does not identify as LGBTQ. It prompted scholars like Guillermo Avila-Saavedra (2009) to conclude that there’s “Nothing queer about queer television.” While McCormack has said that the show did a lot to “educate” Americans on issues like gay marriage, he could not see himself cast in such a role today.⁶⁷

A decade later, the TV show *Glee* was heralded as ground-breaking for its message of inclusion and equality because it included LGBTQ characters and a character with a disability. Kevin McHale, the actor who played a person with a disability in *Glee* is not in fact a disabled person. Like McCormack, he told reporters in 2022 that he would not reprise his role as a disabled character in a possible reboot of the show: “If ‘Glee’ is ever rebooted, Kevin McHale is not signing up to be canceled.”⁶⁸ And, for good reason: well before the more recent

⁶⁷ Eric McCormack ‘wouldn’t get anywhere near’ his role in ‘Will & Grace’ today, www.gaytimes.co.uk/culture/eric-mccormack-says-he-wouldnt-get-anywhere-near-his-will-grace-role-today/.

⁶⁸ ‘Glee’ alum Kevin McHale says he wouldn’t play a character in a wheelchair now, *Los Angeles Times*, November 16, 2022.

attention to Whitewashing, disability activists had been fighting against non-disabled actors playing disabled characters.

As Castaneda of the Media Access Office reported, “When a person with a disability sees a positive image on TV that looks like them, their whole attitude changes. It gives them hope for what they can do in the future.”⁶⁹ The problem is that doing diversity, equity, and inclusion has generally meant a form of “naïve integration” of disability into mainstream culture (Garland-Thomson 2002). In a 2009 post on disabledfeminists.com, author “Anna” not only commented on the recently aired Glee episode prominently featuring McHale, but the positive reception it received from media and the public. Responding to an Associated Press article praising the “wheelchair episode,” Anna writes “Thanks, Nice Able-Bodied Lady! I will take your words to heart and just ignore what those silly people with disabilities are saying! It will be better that way!” Anna’s comments raised questions about whether these inclusion efforts were just meant to make people without disabilities feel better.

The third disability protest wave therefore coincided with a changing media landscape and greater attention to minority representation. There were both new opportunities for activists to make inroads in this issue area, but also several negative episodes that triggered reactive mobilization by disability activists who used those examples to showcase that their work was nowhere near done.

The year Glee debuted in 2009, the Alliance for Inclusion in the Arts, National Association of the Deaf, and Deaf West Theatre protested a non-Deaf actor playing a Deaf character in the play, “The Heart is a Lonely Hunter.” While the play debuted four years earlier in Atlanta and generated no public criticism, activists were now demanding that a Deaf actor be cast in the role. Linda Bove, a Deaf actress and member of the Alliance said: “A hearing actor playing a deaf character is tantamount to putting a white actor in blackface.”⁷⁰ The theater workshop met with several Deaf actors and searched for some common ground but could not agree on the central issue: Director Doug Hughes said he would not fire the actor who had played Singer in an earlier production of the play in Atlanta. Apparently, Hughes had auditioned Deaf actors for the role in Atlanta but none spoke “well enough to play the part . . .” There was a general sense of confusion and surprise among those in the theater workshop that this was at all controversial or offensive. It was this general unawareness that activists sought to correct through visible protest.

⁶⁹ www.amsvans.com/blog/glee-wheelchair-actor-kevin-mchale-angers-disability-advocates.

⁷⁰ Hearing Man in Deaf Role Stirs Protests in New York, *New York Times*, October 14, 2009.

Responses to activist protests from Hollywood content creators reveal a more generalized attitude among those in positions of power justifying whether some statuses should be represented, and how they should be included. Glee producers basically argued that they picked who they thought was best for the role, even though they “brought in anyone: white, black, Asian, in a wheelchair . . . It was very hard to find people who could really sing, really act, and have that charisma you need on TV.”⁷¹ Others point to widespread beliefs among those in charge that hiring disabled people is simply too costly. For example, actor Robert David Hall of the show *CSI* who walks on two artificial legs, thinks that “there’s a fear of litigation, that a person with disabilities might slow a production down, fear that viewers might be uncomfortable.”⁷² These are similar arguments made by employers that people with disabilities create awkwardness for other employees, and that the cost of hiring a worker with disabilities outweighs any benefit (Maroto and Pettinicchio 2014). These attitudes limit access to the labor market for people with disabilities.

Activist efforts in this issue area point to positive change but they also show how challenging it is to counteract widespread negative beliefs. Protests went a long way not only in raising awareness about representation but also in re-centering the conversation around what should be considered appropriate or meaningful representation. Activists and SMOs found new opportunities to make salient these long-standing grievances, later finding allies in #MeToo to challenge sexist, racist, and ableist practices in Hollywood. Disability activists would also turn inward, challenging their own organizations and networks to do better when it came to inclusion and empowerment.

3.1 From Jerry’s Orphans to End the “R Word” Campaign

By the third disability protest wave, issue dynamics had changed. Media and culture related protest came to represent a greater share of protest activity. Although the number of visible protests targeting media and negative portrayals of disability reflect less than a third of protests during the third wave, they were pivotal in garnering a lot of public and media attention, especially online. Protests against the Muscular Dystrophy Association’s (MDA) Jerry Lewis Telethon captured early efforts to end pitiable representations of disability and exploiting those depictions to raise money (Shapiro 1993). As early as 1981, activists were already on high alert about the hurtful messages the telethon was broadcasting. June Fine of the group Boston Self-Help told the Boston Globe that the telethon

⁷¹ www.usmagazine.com/entertainment/news/disabled-advocates-protest-glees-wheelchair-episode-20091111/.

⁷² ‘Glee’ episode irks advocates for disabled, *The Hollywood Reporter*, November 10, 2009.

could at least include more adults with muscular dystrophy, “That way, the public would see that handicapped people are self-sufficient.” An MDA spokesperson disagreed with activist criticisms: “We try to depict handicapped people positively. They are not 100 percent useless, and we don’t depict them as such.”⁷³ To activists, these responses were insensitive and showed how some long-time disability service-provision groups, MDA among others, were in denial about their messaging.

Longmore’s (2015) account of telethons described these American inventions as orchestrated by “charity professionals.” He emphasized that telethons were not just about economic and political opportunities, they “shaped popular perceptions” of disability (p. xiv). Throughout the early-to-mid-1990s, activists, many affiliated with the group Jerry’s Orphans/Jerry’s Protesters, regularly held demonstrations in different cities usually Labor Day weekend when the MDA Telethon hosted by Lewis was held. They were some of the earliest well-publicized examples of visible protests challenging negative portrayals of disability. In 1991, Kris Matthews and Mike Ervin, two former 1960s MDA poster children, began a boycott against the telethon, targeting the telethon’s corporate sponsors. Dozens of people protested at a Los Angeles TV station with a simultaneous protest in Las Vegas and Chicago. Protesters held banners reading “Jerry’s telethon, annual ritual of shame,” and “Jerry maligns the disabled.” In a statement, Matthews said “Jerry Lewis keeps perpetuating all those myths and stereotypes about people with disabilities, particularly people with neuromuscular diseases. He uses language like ‘cripple’ and ‘half a person.’”⁷⁴

The following year, Jerry’s Orphans protested in Oakland “saying the sentimental extravaganza makes them look pitiful and childlike.”⁷⁵ In 1993, DIA joined Jerry’s Orphans in organizing protests. MDA’s Chris Rosa who himself has muscular dystrophy said the organization was doing nothing wrong and that most of the money raised went to patient programs and research. The organization continued to deny they were perpetuating harmful stereotypes about disability. Again, at a 1995 demonstration, twenty-five activists blocked entrances to CBS Television City. They wanted to get their message out to celebrities who participated in the telethon – that it was a “charity racket, schmaltzy, and pity-on-parade.”⁷⁶ Protesters were doubly outraged that telethon organizers were parking in blue spaces reserved for disabled people.

⁷³ Advocate for handicapped raps Jerry Lewis “telethon,” *Boston Globe*, September 5, 1981.

⁷⁴ www.upi.com/Archives/1991/09/02/Jerry-Lewis-telethon-hit-by-protests/2331683784000/.

⁷⁵ Jerry Lewis Telethon Protested in Oakland, *San Francisco Chronicle*, September 7, 1992.

⁷⁶ Protesters Crash Barriers at Jerry Lewis Benefit Telethon, *Los Angeles Times*, September 5, 1995.

By the mid-1990s, groups like DIA and Jerry's Orphans had made their position clear: end the telethon. The MDA continued to claim it was portraying disabled people in a positive light, and there were those who preferred a reform to the telethon rather than ending it entirely.⁷⁷ The telethon would still go on for years until 2014. Yet, the telethon protests were important for the disability movement as they carved a path for more systematic challenges against pervasive biases and beliefs deeply embedded in culture. Disability activists continue to challenge negative imagery, taken-for-granted harmful tropes and language, and inauthentic representations of disability. Throughout the third protest wave, most of these efforts were episodic, precipitated by specific events and actions. Organizations and activist networks, though, were ready to act.

The mid-2000s saw several visible protests around the r-word which was still widely used in mainstream films (in fact, several newspaper articles included in the dataset on which my analyses are based use the r-word in their headlines). In 2008, groups like Special Olympics and the American Association of People with Disabilities (AAPD) protested the movie theater premiering Ben Stiller's *Tropic Thunder* which repeatedly uses the r-word. In addition to the LA protest, groups and activists called for a nationwide boycott of the movie. Quickly, a coalition of groups including NARC, National Down Syndrome Congress, and AAPD took mass action against the film. After screening the movie, the executive director of National Down Syndrome Congress said he "felt personally assaulted." The executive director of NARC told the *New York Times* reporter that he could not recall a mass campaign by disability groups against a movie like this one, although he did note some objections made against the 2004 film *Napoleon Dynamite*. Surely, part of the motivation for visible protest was driven by how blatant, unabashedly, and unapologetically the r-word was used.

Timothy Shriver of Special Olympics was especially outraged that no one in production raised issues with the repeated use of the word. In fact, original promotional posters included the line "Once upon a time there was a retard" which was later removed when some disability groups rallied against it.⁷⁸ He pointed to how producers showed more care and sensitivity around race when the Robert Downey Jr. character (a White soldier) is effectively appearing in blackface. But activists had now grown accustomed to dismissive replies by cultural producers and elites. The response from the studio was that the movie is meant to be satirical and over the top. They would not be editing out the r-word from the movie. They did say they would work with disability groups in the future. The movie brought in 195 million and currently has a 7/10 rating on

⁷⁷ In *Wheelchairs and on Crutches, Some Disabled Protest a Telethon*, *New York Times*, September 7, 1993.

⁷⁸ *Nationwide 'Thunder' Boycott in the Works*, *New York Times*, August 11, 2008.

IMDB and 82 percent rating on Rotten Tomatoes. It can still be viewed unedited on streaming services.

That same year, a contestant of reality show, *Big Brother*, Adam Jasinski, who worked for United Autism Foundation was recorded saying that if he won the reality show, he would use the money to open a hair salon for disabled people “so retards can get it together and get their hair done.” Despite its efforts, another group, Autism United, could neither get a formal apology nor a meeting with CBS who aired the show. CBS believed that because another contestant challenged Adam’s use of the term, it was allowed to remain in the show. CBS seemed to think they were doing a good thing, treating the incident as a teachable moment. Although Jasinski was fired by the United Autism Foundation, CBS did not alert the cast member as he was sequestered during production of the show.⁷⁹ Activists then turned to the show’s sponsors. The case received considerable media attention and Autism United was successful in getting sponsors like Lowe’s to pull their ads. This also became loosely connected to the “Spread the Word to end the Word” (referring to the r-word) campaign which began a year earlier in 2007.

These examples represent protest’s successes as well as ongoing challenges. In 2010, Obama signed a law that would remove the word “mental retardation” from programs and policies. And the r-word is rarely if ever used in contemporary mainstream films or television. Still, nearly a decade later in 2017, students involved with a NARC-run program mobilized to end the use of the r-word. They too were part of the now almost 10-year old “Spread the Word” campaign. One person involved with the program said, “Language affects attitudes and attitudes affect action.” They protested at San Francisco City Hall although the protest was not specifically directed at local government. They sought to raise awareness and get people to pledge never to use the word. Protesters said there are alternatives to the r-word: rambunctious, resourceful, resplendent, radiant, and respect.⁸⁰

3.2 Not about Us without Us

The Jerry Lewis Telethon protests had wider meaning for the disability movement. The focus of visible protest was not just on the images and negative portrayals of the telethon itself, but that groups in the disability nonprofit sector used or supported this fundraising strategy. It was emblematic of a broader tension among disability groups on inclusion, control, and decision-making,

⁷⁹ ‘BB’ Angers Autistic Group, *New York Post*, February 19, 2008.

⁸⁰ San Francisco students push to end use of the r-word, *SFGate*, March 1, 2017.

and which groups empowered disabled people, and which promoted harmful depictions and stereotypes.

As early as the 1970s, many groups purportedly representing disabled people's interests came under fire for being run by non-disabled people, engaging in questionable practices, and perpetuating stereotypes about disability (e.g., Goodwill's reliance on sheltered workshops suggesting people with disabilities cannot be integrated into competitive labor, [Friedman 2019](#); [Maroto and Pettinicchio 2022](#)). In short, as former Office of Civil Rights director Martin Gerry said, groups like Goodwill and Easter Seals were increasingly seen as derelicts ([Scotch 2001](#)). They were effectively charity groups that were out of touch with the civil rights and minority rights focus of the nascent disability rights movement. Easter Seals and March of Dimes were groups that in the 1950s and 1960s used pity-driven charity campaigns to raise money. In one 1965 campaign, Easter Seals used a photograph of a boy in crutches with the text: "Lend me a dollar to help me walk and I'll make you feel good all Day. P.S. I'll pay you back when I'm rich" ([Pettinicchio 2019](#)).

It was in this vein that protesters in the 1990s criticized the MDA – that it is "making millions of dollars and they haven't found anything in all their years of research." Gary Clifra of the Alliance for Research Accountability called the MDA an "institution that just basically processes money and offers false hope."⁸¹ Activists were critical, as they had been with groups like Easter Seals years ago, about the focus on cure and normalization; on changing people with disabilities rather than changing social norms.

Activists increasingly questioned whose interests established disability groups represented, and where voices of people with disabilities were among them. Visible protests played an important part in challenging groups by bringing internal struggles and discontent to light, airing what positions different groups and activists took on issues, and how institutions understood inclusion and representation. The disability cause field was changing from within.

A well-known example involved the appointment of a non-Deaf President, Elisabeth Zinser, to Gallaudet University in 1988 (see Christiansen and Barnartt's account in *Deaf President Now*). Protesters organized by DUCK, a more radical branch of the National Association of the Deaf, were victorious. I. King Jordan instead became the first Deaf president of the university. The university also planned on adding more Deaf trustees to eventually make the board majority Deaf.⁸²

⁸¹ www.upi.com/Archives/1991/09/02/Jerry-Lewis-telethon-hit-by-protests/2331683784000/.

⁸² Deaf Students Shut College, Demanding Deaf President, *Los Angeles Times*, March 8, 1988.

That same year, a group of disability activists led by Jane Small who had also been involved in then LA Council member Tom Bradley's mayoral campaigns came to protest Bradley's appointment of a non-disabled psychologist to run the Office for the Disabled. As a reporter for the LA Times wrote, "To some disabled people, the hiring was as surprising as if Bradley named a man to run the city Commissions on the Status of Women or designated a white aide as his liaison to black neighborhoods in South-Central Los Angeles."⁸³ One protester said, "We the disabled people of Los Angeles just want to speak for ourselves." The mayor's office cast those resigning from council in protest as an ungrateful few who should credit Bradley for creating the office in the first place.

A few years later, blind people protested the charity Lighthouse for not having blind people on its board of directors. As one protester said, "The Lighthouse is a failure and has always been a failure because you are not in touch with blind people."⁸⁴ Groups like the National Federation of the Blind continue to keep vigil over representation among service-provision organizations. And organizations have made important changes to how they are governed. A 2019 Braille Monitor article written by Lighthouse's president, Bryan Bashin, says much about the organization's current structure and identity: "Led by the Blind: Bringing Authenticity to Services for the Blind and Making Them Relevant to the Lives We Want to Live."⁸⁵

Autism is another important area peppered with visible protest events which showcase struggles not only with challenging broader social norms around disability, but also challenging other groups within the immediate field. For years, the National Society for Autistic Children founded in 1965 and later renamed Autism Society of America dominated the advocacy and service-provision field. Forty years later, the proliferation of autism-related groups brought new perspectives sometimes on long-time grievances, and other times, new issues more prominent in the third disability protest wave including misperceptions and negative images. Over the last decade, organizations in the disability cause field increasingly heeded the movement rallying cry "not about us without us" in challenging what they see as organizations *for* the disabled but not *by* people with disabilities.

For example, like Autism United, Autism Self-Advocacy Network (ASAN) also founded in 2006 was organized by and for people with Autism. In 2008, Autism United organized a protest of over fifty people against Michael Savage's radio show, "The Savage Nation" for "spiteful and harmfully misleading

⁸³ Group of Disabled Assail Bradley; 6 Quit as Advisers, *Los Angeles Times*, April 22, 1988.

⁸⁴ Blind People Protest To Lighthouse Board, *San Francisco Chronicle*, April 26, 1990.

⁸⁵ <https://nfb.org/images/nfb/publications/fr/fr38/4/fr380413.htm>.

comments about autistic children as a result of bad parenting.”⁸⁶ In 2010, the organization made headlines when its founder, Ari Ne’eman, was nominated by President Obama to Autism Speaks – a nonprofit autism awareness organization. He would be its first nominee to have autism.

Ironically, Ne’eman and his organization had protested Autism Speaks just a year prior over their fundraising video. Autism Speaks had merged with Cure Autism Now, founded by Jonathan Shestack who openly criticized Ne’eman’s 2010 nomination. The 2009 fundraising campaign used Shestack’s “kidnapped” analogy: “If 1 in 150 American children were kidnapped, we’d have a national emergency. We do. Autism.” Ne’eman told the *York Daily Record*⁸⁷ that:

Advocacy groups need to learn from the physical disability community, which stopped using scare tactics because they only widened the understanding gap between those with disabilities and those who don’t have them, which in turn actually increased discrimination.

Shestack stood by the slogan while Susan Wallace of Autism Speaks diplomatically proclaimed “Groups of people who mean well get into arguments, and autism advocacy suffers. Until different organizations can unite that won’t change.”

These divisions would however deepen. A year later, Lee Grossman of Autism Society of America noted the split in the autism advocacy community: either one accepts neurodiversity as part of one’s identity, or they search for a cure and genetic screening. Autism Speaks still used language like “struggling with autism” and focused on awareness rather than acceptance. ASAN continued to challenge Autism Speaks’ yearly campaigns as sending the wrong message, like for example, 2015’s “Light It Up Blue.”⁸⁸

In 2017, the ASAN condemned World Autism Awareness Day and White House participation in Autism Speaks’ Light It Up Blue. President Trump proclaimed his administration will encourage “innovation that will lead to new treatments and cures for autism.” In response, ASAN’s news brief stated that the “Trump administration’s attempt to revive the idea of cure is a dangerous fringe position.” ASAN also sought to connect their grievances to the broader issue of homecare which regained salience because of threats of retrenchment and the involvement of Resisters in challenging ACA repeal efforts. ASAN argued that Autism Speaks had aligned themselves with a government that has sought to repeal ACA and Medicaid.⁸⁹

⁸⁶ Some call for firing of radio talk show host, *Boston Herald*, July 22, 2008.

⁸⁷ Critics topple billboard Autism York said it did not intend to offend anybody with the sign, *York Daily Record*, August 28, 2009.

⁸⁸ Speaking Out against Autism Speaks, Even If It Means No Ice Cream, *New York Times*, June 4, 2015.

⁸⁹ ASAN Condemns White House Autism Proclamation, *Targeted News Service*, April 1, 2017.

ASAN acknowledged that progress in fighting negative images of autism had been made over the last ten years but more needed to be done. In 2019, the group condemned Sesame Street's ties to Autism Speaks. The children's educational program consulted with Autism Speaks on the Muppet who has autism. ASAN contends that Autism Speaks encourages parents "to view autism as a terrible disease from which their child can 'get better.'"⁹⁰

When it came to raising awareness and challenging taken-for-granted stereotypes perpetuated by media and other cultural sites and beyond, disability organizations and especially, visible protests, were successful over the long-term. Attitudes are often evasive and difficult to challenge in the abstract, but activists learned how to focus and channel their grievances toward specific targets – from telethons to TV and radio shows, to other nonprofit and service-provision groups. It is true that visible protests alone did not end telethons. TV stations began dropping them as they had more competition in overnight hours and started charging charities to air them (Longmore 2015). And while the r-word is rarely if ever used in mainstream content, the r-word is still used a great deal in social media.⁹¹ Nevertheless, these protests started a public conversation continuing to keep the issue current and in the spotlight.

4 The Outcomes of Visible Protest

Visible protest waves involve activists and groups mobilizing resources in response to a mix of opportunity and threat activating grievances across interconnected issue areas aimed at multiple targets. Political opportunities and resources may be shared across issue areas not only because issue areas and corresponding grievances are intertwined, but also because the same organizations engaged in one issue area are also engaged in others (e.g., DIA, AAPD, and PVA were involved in everything from transit to health protests, to Jerry's Orphans). Groups and networks drew from the same tactical repertoires in considering their goals, activities, and targets across issue areas. Yet, outcomes of visible protest vary considerably across waves and issue areas.

Protest outcomes are often difficult to define. It requires analyzing issue developments and movement goals before and after protest events which can mean a wide time interval around that given protest event. Outcomes can result in both short- and long-term gains. Additionally, activist beliefs about success and failure may not always coincide with more "objective" appraisals of social movement outcomes. Analyses of protest outcomes must consider the more

⁹⁰ How a 'Sesame Street' Muppet became embroiled in a controversy over autism, *Washington Post*, September 19, 2019.

⁹¹ www.specialolympics.org/discriminatory-language-about-people-with-intellectual-disabilities-particularly-the-r-word-remains-prevalent-across-social-media.

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