The Cultural Framing of Disability: Telethons as a Case Study

PAUL K. LONGMORE
San Francisco State University

In various cultures, "disability" has been defined in many ways. Multiple framings were developed in different social institutions and cultural spheres and have served many social, cultural, and political purposes. Disability studies scholars need to examine each of these framings separately and then compare them with one another, for "disability" has never been a monolithic social phenomenon. Instead, it has always been multifarious, complicated, and even contradictory. We need to trace the specific social and cultural locations, historical agents, and processes involved in particular framings of disability. As an example, I offer a case study. Really, it is just a fragment from a larger and more detailed study of telethons and the uses of disability in twentieth-century America.

The telethon was invented just after World War II by private, voluntary health charities as a fund-raising mechanism to tap into the emerging mass medium of broadcast television. The original telethon aired in New York in 1949 for the Damon Runyon Cancer Fund. Telethons for disability-based causes soon followed. In 1950, the United Cerebral Palsy Associations produced an eighteen-hour broadcast in Chicago. The following year, it was moved to New York. The Muscular Dystrophy Association presented a telethon in New York in 1952. In 1956, Jerry Lewis started to host that—Thanksgiving, not Labor Day—show. Lewis and MDA switched holidays and went national in 1966. The National Easter Seals Society launched a national broadcast in 1972, followed by UCP in 1978 and the Arthritis Foundation in 1980. During the 1980s and 1990s, these four major disability-related telethons aired nationally at various times during the year. The charities claimed to reach an audience of more than a quarter of a billion people in the United States and Canada. Yet by the early 1990s, the telethons were in decline, and as the twentieth century ended, the UCP, Easter Seals, and Arthritis Foundation broadcasts disappeared. Only the MDA program remained, but its audience dropped by more than a third. The rise and decline of disability-related telethons warrants referring to late-twentieth-century disability history as, in one respect, the age of telethons.

Rosemarie Garland-Thomson's observations about disability and staring help us build an analytic framework to examine telethons. She writes: "As anyone with a visible disability knows, being looked at is one of the universal social experiences of being disabled. . . . The dominant mode of looking at disability in this culture is staring." Staring involves not simply looking and being looked at. Rather, "staring is an intense form of looking that enacts a relationship of spectator and spectacle between two people" and thereby "manifests the power relations between the subject positions of 'disabled' and 'able-bodied.'" "Constitut[ing] the starer as normal and the object of the stare as different, it creates disability as a state of absolute difference, rather than as simply one more variation in human form." Yet while many "starers gawk with abandon at" the nonstandard body parts that are made to signify "disability," modern culture considers staring "rude," "a form of *inappropriate* looking." "The disabled body thus becomes a visual paradox: it is at once to-be-looked-at and not-to-be-looked-at" (346–48).

Elaborating on Garland-Thomson's insights, I suggest that we need to distinguish between two types of staring: solitary gawk-

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ing, which may incur social disapprobation, and collective gazing, which has always had considerable social sanction. "From antiquity through modernity," Garland-Thomson points out, "the bodies of disabled people considered to be freaks and monsters have been displayed by the likes of medieval kings and P. T. Barnum for entertainment and profit in courts, street fairs, dime museums, and side shows. Moreover, medicine has from its beginnings exhibited the disabled body as what Michel Foucault calls the 'case,' in medical theaters and other clinical settings" (348). These various modes of socially displaying and collectively scrutinizing people with disabilities differ from gawking by individuals.

Collective gazing at disabled people put on social display has always functioned in ways that set it apart from yet complement individual staring. One-on-one staring is interpersonal, informal, and impromptu. Surprised by the public presence and apparent differentness of a visibly disabled person, a nondisabled individual impulsively gapes at him or her. In contrast, gazing at people with disabilities on display takes place as an organized public or semipublic event. It is communal, planned, and, in the end, ritualized. It carries greater social weight than does individual staring partly because, unlike those momentary encounters, collective gazing is not a casual singular occurrence. Rather, it happens as one of a long series of events produced by social institutions—sideshows and hospitals are prime examples—designated as appropriate arenas for dealing with people defined as physically or physiologically anomalous. Over time, these displays become formalized. This ritualization reflects the power dynamics between nondisabled and disabled people in both the institution and the larger society. It also expresses the institution's, and more broadly society's, dominant ideology of disability. The ritualized display of disabled people eventually develops into a cultural tradition that reinforces the ideology and the power dynamics. One-on-one staring reenacts on a smaller scale not just the social ritual but, more important, the dominant ideology of disability and the dominant power dynamics of collective social relations between disabled and nondisabled people. The cultural and social authoritativeness of collective staring imbues individual interpersonal staring with the elements of spectatorship and spectacle noted by Garland-Thomson. Communal gazing at disabled people put on social display imparts to interpersonal staring the power to define normality and abnormality, full membership in the human community and marginalization in or complete exclusion from it (Garland-Thomson 336).

Garland-Thomson analyzes staring in the context of the "visual rhetorics of disability in popular photography" (349):

> Photography mediates between the viewer and the viewed by authorizing staring. . . . With the actual disabled body absent, photography tends to stylize staring, exaggerating and fixing the conventions of display and eliminating the possibility for interaction or spontaneity. Indeed, photographs of disabled people invite the viewer to stare without inhibition or contrition. They absolve viewers of responsibility to the objects of their stares at the same time that they permit a more intense form of staring than an actual social interchange might support. (339–40)

Telethons, too, authorized uninhibited staring, even while they precluded the possibility of actual interaction between nondisabled and disabled persons. They offered no chance of spontaneous, which is to say, human, connection or exchange. Instead, they displayed people with disabilities according to stylized and fixed conventions. Yet the telethons' formalized mode of staring was more intense than the staring invited by disability photography. If, for example, medical photography sometimes exhibited the naked bodies of people with disabilities, telethons laid bare

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their private lives—or, rather, what the telethons purported to be their private lives.

Photographic images are a particularly powerful form of representation because, as Garland-Thomson puts it, "we think of photographs as being closer to reality, as a more reliable source of truth than, say, drawings or even verbal representations." But even though photos may seem "transparent windows into reality," they, "like all representations," construct and shape "the object they represent . . . through the conventions of presentation and through cultural ideas and expectations about such pictures." And they shape our perceptions without announcing that they are doing so (Garland-Thomson 335–36, 349).

It is arguable that live television seems to possess even more truth-value than photography. Animated rather than still, fluid rather than frozen, happening in this moment rather than recording a past event, a live program appears to viewers as not a near representation of reality but reality itself. Here are real people in real time actually interacting with one another. But as with photography, the seeming veraciousness of television masks the extent to which the makers of live TV manufacture the "reality" they present.

In addition, photographs, argues Garland-Thomson, recapitulate and perpetuate "cultural ideas about disability." Likewise, telethons reinforced conventional cultural ideas about philanthropy and America, about people with illnesses and disabilities, and about potential charity contributors themselves. Though those perceptions operated in American culture at large, the telethon-producing charities played a particular role in shaping and mobilizing them. And they engaged in this fabrication without alerting their audiences that this was not reality but a representation of reality. Telethon representations also performed a specific "task" by serving the charities' fund-raising agendas. As with the license to stare inherent in disability photography, the organized collective staring on telethons became "a powerful rhetorical device . . . mobilized in the interest of persuasion." And as with the photos Garland-Thomson studies, we can analyze telethon images for their rhetorical content, for "how and what [they] intended to persuade their audiences to believe or do." The telethons' "cultural work" involved the marketing of both an image of disabled people and an ideology of disease and disability (Garland-Thomson 336, 335, 339).

A distinctively American cultural invention, telethons were a combination variety show and infomercial, patriotic pageant and revival-tent meeting, sideshow and pep rally. The broadcasts that defined telethons as a genre were produced by disability-related charities. Some commentators snickered at these shows for their mawkishness, their sentimental excesses. Defenders of telethons sometimes derided the detractors as "snooty arbiters of good taste." They claimed the tastelessness was necessary because it "work[ed]," it pulled in the bucks. "How agonizing it is to see people parade their afflictions in order to solicit money," argued the authors of *The Encyclopedia of Bad Taste*, "but the mendicancy works. Who can see the afflicted . . . and not feel the urge to help?" (Stern and Stern 290–91).

In the end, though, some of the critics agreed with the defenders that the desirable results justified the disagreeable means. For years, syndicated columnist Bob Greene was "critical of the way [Jerry Lewis] conducts his telethon" but at last came to understand "that he is, indeed, doing a good thing, and doing it in the only way that will work." "You may be appalled at how he does it. But you can't stop thinking about what he wants you to think about" (Greene). As with most people who talked about telethons—including disability rights activists—Greene focused on Jerry Lewis. But that fixation diverted attention from telethons as a mode of addressing issues of health and welfare, as well as a number of other social, cultural, political, and moral concerns. Most important among

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those matters were the cultural meaning and the social and political function of "disease" and "disability" in American society. Moreover, in keeping the spotlight on Lewis rather than scrutinizing disability-related telethons as a whole, Greene and other commentators overlooked that the emcees and celebrities were communicating not so much their own thoughts as preachments devised by the charities that produced the shows. Most of the content of the broadcasts was purposefully prepared by the professionals who ran the disability-related charities. Bob Greene was right about perhaps more than he recognized. Many telethon watchers probably were made to think about what the charities wanted them to think about.

But what *did* those charities want Americans to think? What *was* the message of the telethons? Observers like Greene and the authors of *The Encyclopedia of Bad Taste* referred only generally to the broadcasts as getting viewers to give some thought to those regarded as "less fortunate" because they had been "afflicted" by illness or injury. In fact, telethons got their audiences to "think about" much more than medical conditions and medical treatments and medical research and the money to pay for those things.

The telethons conveyed implicit political messages about the American system of provision for public health and welfare. They communicated explicit messages about corporate benevolence aimed at countering the negative image of big business, even while they offered advertising pitches that marketed those corporations' products. Telethons also spoke to widespread worries regarding what seemed to be mounting materialism and self-centeredness and interpersonal disconnection, a general fear that Americans had lost the sense of moral community they believed had once bound them to one another. The broadcasts addressed the unease among many Americans about changes in their social status and tensions among the country's socioeconomic classes, as well as alterations in gender identities and gender relations. They also alluded to the troubled state of contemporary American family life.

More than any other message, telethons explained the social meaning of disability. Presented as "the afflicted" and "the less fortunate," people with disabilities saw their problems, their needs, and, indeed, their identities defined in terms of medical and social pathology. The charities attributed the social marginalization of disabled people to morbid physiological conditions. Those bodily defects assumedly incapacitated them to perform the social roles expected of Americans in various age groups. Medical pathology doomed a few of them to physical death; social pathology condemned all of them to social invalidity, which was to say, social death. Their only hope lay in medical cures or medical and vocational rehabilitation. They needed to be fixed as individuals, on a case-by-case basis.

Telethons also displayed children as the representative type of disabled person and often treated the disabled adults who appeared on the broadcasts as though they were children. On one level, this was simply a tried-and-true fund-raising device. Pathetic, adorable children had always drawn donations. But at a deeper and more important level, this portrayal marked what the historian Robert Dawidoff has called "obsessive infantilization." "Beyond race, gender, ethnicity, sexual orientation," he notes, "disability is a culture-wide metaphor for the vulnerable, the pitiable, the weak, and thus unacceptable and panicking in an American culture in which identity is formed in constant fear of the loss of autonomy" (3). Telethons offered "disability" and people with disabilities as metaphors for—and means to assuage chronic worry about—loss of autonomy, loss of American identity.

The model for this infantilized image was Tiny Tim in Charles Dickens's *A Christmas Carol*. Telethons borrowed and Americanized the traits of the Dickens character: the disabled

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person as perpetual child, sweet, cheerful, and brave; the disabled person as invalid, helpless, dependent, and fundamentally different from "normal" people; the disabled person as object of charity, grateful but hopeless and doomed unless those who are healthy and normal "give"; the disabled person as vehicle of others' redemption, existing not for himself or herself, not as a human being in her or his own right, but to provide the occasion for nondisabled people to renew their humanity; the disabled person as sentimental entertainment, a figure whose pathetic situation or heroic striving touches the hearts of readers and viewers.

The siblings of Tiny Tim begotten by the charities appeared everywhere, and everywhere their image structured how nondisabled people saw and treated people with disabilities. Enormous numbers of nondisabled people watched the telethons or joined in the charities' other fund-raising activities. At the least, they glanced at a poster child's picture on a drugstore display or on a bank beside a cash register. Those few seconds of exposure, which were repeated every time they bought a bottle of aspirin or a pack of chewing gum or paid for a restaurant meal, solidified the Tiny Tim image in their minds.

And Tim's ubiquitous brothers and sisters instructed people with disabilities too. They taught disabled people what society expected, indeed required, of them. They told disabled people how they should look at themselves. Telethons not only defined the social identities of people with disabilities but reciprocally defined the social identities of people without disabilities. Each was necessary to rendition of the other. Just as black created white in American culture, verifications of what and who was "normal" depended on maintenance of the category "abnormal." The socially valid could confirm their authenticity only by gazing at and acting on the putatively invalid.

That representation propagated the notion that people with disabilities were simultaneously recipients of medical and rehabilitative treatments and objects of charity. Yet even while the telethons relegated people with disabilities to the medical-charity caste, they claimed that they were affirming disabled people's common humanity. The 1989 Easter Seals show cued national cohost Mary Frann to say, "Mixed in with the music you're also going to hear a message, the message that people with disabilities do belong." In fact, telethons ceaselessly, ritualistically reiterated that people with disabilities would not and could not "belong" unless their medical and social pathologies were cured or corrected. The shows pounded on the message that disabled people were not "like everyone else," not like the supposedly normal people hosting the telethons or watching them at home. That dichotomy between normal and disabled, which was to say, between socially legitimate and socially invalidated, became a central feature and core message of the telethons. As a result, on telethons nondisabled people did almost all the talking. They did not talk *to* disabled people. They talked *about* them. The emcees, who were nondisabled, announced what "we" can do to help "them."

On the 1991 Easter Seals broadcast, as viewers watched a film of kids receiving physical therapy at an Easter Seals Center, a host asked, "If we don't help these children, who will?" She assured prospective donors: "You're really contributing to the quality of life for these people." In 1989, she pleaded, "Please don't forget these people. They need you so desperately."

"You" and "these people." "We" and "them." "They" and "us." The potential donors, like the charity agencies themselves, were nondisabled; the inevitable charity recipients were disabled. Speaking through the nondisabled telethon emcees and celebrities, who addressed a viewing audience the charities obviously assumed was nondisabled too, the charities propagated that radical separation over and over and over again. If telethons defined the social identities of people with disabilities in terms of their membership in the medical-

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charity caste, the broadcasts at the same time pictured people without disabilities as their opposites: physically healthy and whole, giving rather than receiving charity, socially valid.

And by having nondisabled presenters do almost all the talking, the charities reinforced the power of nondisabled people in general to define the social meaning of "disability" and the social identities of people with disabilities. Telethons empowered nondisabled emcees to explain to nondisabled viewers the daily experience of disability. "We hope to give you a little more understanding of what life is like for someone with a disability," announced a local Easter Seals host in 1990. But, admitted another in 1988, one of the frustrating things about hosting this show is that one is often asked "to describe what someone in a wheelchair is going through, and frankly we can only imagine what it is like." Yet, undaunted by their ignorance and authorized by the charities, the hosts talked on and on.

During the latter half of the twentieth century, growing numbers of Americans with disabilities resisted their relegation to social invalidity. They organized themselves into a movement—more accurately, an assemblage of movements—that challenged dominant views of disability. Instead of attributing disabled people's social and economic marginalization to pathology, their campaign adopted a minority-group perspective. More urgent than remedial measures to fix individuals was the instatement of equal access, reasonable accommodations, and antidiscrimination protections. Rejecting the charity approach that beseeched attention to disabled people's needs, the movement demanded civil rights enforcement to ensure their right of access to society.

This activism led in the 1980s and 1990s to criticism of and then protests against the telethons. Whereas those broadcasts assumed that "affliction" and "misfortune" were inevitably and self-evidently the state of being of anyone with a disability, disabled activists scorned those suppositions as not objective statements of biological facts but social prejudices that justified discriminatory practices. The charities could not ignore the demonstrations or the emergent minority-group mentality that fueled them. In fact, some of the agitation came from activist constituents in the organizations themselves. And so, in various ways, the telethons sought to co-opt or criticize, address, assimilate, or adopt the activist perspective.

On and off the broadcasts, the controversy generated public debate that touched on, without deeply exploring, let alone resolving, a clutch of questions: Is disability inherent defectiveness, socially constructed devaluation, or human variation and difference? What are the real needs and interests of people with disabilities, and who is qualified to determine them? Could Americans with disabilities legitimately demand equal dignity and equal rights while insisting that society provide for their distinctive disability-related needs and alternative modes of functioning as a matter of right? Could disabled citizens assert their fundamental equality if they admitted that some conditions involve intrinsic limitation and suffering? Is it possible for charity publicists to promote amelioration of genuine human suffering without demeaning the people they ostensibly seek to help? Are American values about need, justice, equality, and difference compatible with one another or irreconcilably at odds?

Neither the critics of the telethons outside the disability rights movement nor the broadcasts' apologists examined the complexity or significance of these issues, ideologies, and messages. They didn't wonder why the infantilizing and sentimentalizing of disabled people had such appeal with the American public. They didn't seek to explain why and how these forms of mendicancy worked. They didn't ask if the telethons' solicitation techniques were, in fact, "the only way" to fund medical research and medical treatments and social services, as Bob Greene and others had learned to take for granted. They did not ponder what the telethon mode of fund-

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raising might reveal about America. Unable to comprehend the activists' point of view, they seemed baffled, even incensed, by the disability rights protests against the telethons.

That incomprehension, misunderstanding, and clash of perspectives, that talking past one another, mark telethons as an important cultural arena in which competing definitions of disability contended. That contest also makes explication of telethons an important subject of analysis.

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Talking Culture: Deaf People and Disability Studies

CAROL A. PADDEN
University of California, San Diego

The history of disability studies overlaps nicely with the history of deaf studies. Both came into being roughly at the same time, in the last two decades. Just as there are new programs of disability studies in universities across the United States and around the world, there are new programs of deaf studies at places like the University of Iowa, Gallaudet University, Northeastern University, and California State University, Northridge. The idea of a "deaf studies" is still so new that the phrase feels novel and unexpected, but the idea gained a certain inevitability as a field of inquiry began to develop around the history of deaf people, their lives, their communities and cultures.

Truth be told, deaf people see themselves an odd fit in disability studies. We've been segregated for such a long time that we see our history as set apart from others, and it feels strange to have the company of other disabled people. For most of America's history, deaf children have lived in institutions designed exclusively for them in nearly every state of the country. Some states had more than one institution: New York, for example, had as many as eight schools for deaf children through most of the twentieth century. By the late 1970s, these institutions began to decline as deaf children were moved into public schools with hearing children as part of a wider trend toward deinstitutionalization. Considering that the first school for deaf children in the United States was founded in 1817, we have little experience outside deaf schools and the segregated lives that developed around them. Without question, mainstreaming has had a huge effect on deaf people, but it is part of a much broader social change.

I intend with my brief overview of the recent history of deaf people to show how disability studies as a field will need to acknowledge that different disabilities have their own histories, each defined by unique trajectories. This might seem like a confusing cacophony of voices, but these different

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