Hello, I’m Judith Sandys and along with being a faculty member in the School of Disability Studies, I’m also the Associate Vice-President, Academic, at Ryerson, and I would like to officially welcome you all to this Ryerson event.

I think you have may already picked up that there are a few unusual features to this event [laughter], as you will see as they unfold. We would like—I see very—a lot of familiar faces; I would like to welcome you back to a Disability Studies event and I hope there are some new faces here too and that you will find this an exciting event and come to future ones as well.

This is a very special event for a number of reasons. First of all, we have an outstanding speaker. Followed by a very excellent panel; and, also we have—we are reaching a very broad audience, beyond all the people in this room tonight. This event is being webcast live, in real-time, and I believe again, after that, not in real-time or whatever’s the word for that.

So I would like to again officially welcome you to Ryerson to What I’m sure is going to be a very exciting event and now I will turn it over to Melanie Panitch, the director of the School of Disability Studies, who’ll give the real scoop on this event. Thank you.

[Applause]

Good evening. We have had many peak moments in Ryerson’s School of Disability Studies. But tonight’s lecture is a summit. To host Paul Longmore on the Ryerson campus in such a creative manner, is truly a defining moment. It will leave a mark on our school’s history forever. Future historians, maybe some that even taught by Paul Longmore, will one day want to know what it was we were able to do to attract him. They will want to know what is was about this community of students and teachers; activists and scholars, from Toronto and beyond, who are in our audience here tonight and out there linked to this live webcast.

Scholars and activists, teachers and students so interested in history that you would spend your Friday night listening, watching and pondering. And they will want to know whether, when Ryerson University gave institutional recognition to disability studies and launched us in 1999, anyone could’ve imagined that in six short years, we would be able to command an international profile to attract this highly respected, leading scholar in the field.

When I sent a carefully crafted memo to Paul just a few months ago, trying to lure him here to speak, you can be sure it was a highly polished, spell-checked three times, and the text revised and revised until it was just right. I pushed the “send” button and held my breath. Paul responded within the hour. He knew about our work here; he said he respected what we were doing, and he would be honoured to accept. But the honour is in fact ours. Paul, you will soon be able to see this in a Toronto crowd and they, you. And I’d like to open the evening by welcoming you to Paul and to the audience, in this Harry Foster commemorative lecture.
The Board of Directors of the Harry Foster Charitable Foundation, funded the School of Disability Studies, to organize a lecture series in 2005, to commemorate the hundredth anniversary of the birth of its founder, Harry Red Foster.

I never knew the man, known so popularly as “Red,” though others in the room have done so and have told me much about him. I think the topic this evening would have been of great interest to him. He was an athlete, a highly successful advertising man, a member of the Toronto and the Canadian elite, and he was the brother of a sibling with Down’s Syndrome. And that experience shaped his commitment and work with associations for community living, which have then operated under another label. But he was a brilliant fundraiser and being a product of his time, no doubt participated in the kind of events that we will be reflecting on tonight.

Paul Longmore is a professor of History and the Director of the Institute in Disability at San Francisco State University. He is the author of “Why I burned my book and other essays on disability” and also “The new disability history”. And this seems a good spot to tell you that his books are here for sale, just outside this lecture hall.

No student of disability studies, and that is true of all of us here, could get very far without encountering Paul Longmore. My first encounter was reading his article, published in the Journal of American History in 1987, called “Uncovering the hidden history of people with disabilities.” I was stunned reading this masterful review of three books, about three different disability histories, in which he boldly articulated a common base of experience that cut across the disability experience. His brilliant article called, “The league of the physically handicapped and the Great Depression: a case study in disability history,” took my breath away for its rigor, its passion and exposing the political crusade and the militancy of the disabled job seekers who demanded that government in the 1930s, also needed to include them.

I know you will find this evening’s lecture an equally exciting journey into the complex terrain of charity telethons and disability activism. I know of no one else who is doing this work. But Paul is intellectually fearless. I last saw him at the Society for Disabilities Studies conference in Oakland, California a few years ago. And I remember that at exactly the same time the conference was going on, Peter Singer, the professor of Bioethics at the University Centre for Human Values at Princeton, was in town to take part in the debate on what does it mean to be human? To many of us, the thing to do was to demonstrate outside that lecture hall; after all, this was Berkeley. And so we did, posting—protesting—and parading and waving placards for two hours. When we got back to the conference, I do recall that ball—Paul—was upset. Being outside was not where he wanted to be. He wanted to be inside, on the ground floor, having the debate, however difficult that might be. True to his fashion, tonight Paul takes on another difficult topic, one in which he is on the ground floor again, breaking new ground again, having the debate, however difficult that might be. I’m proud to say that we are the first in Canada to hear it. Paul, we so very warmly welcome you to Ryerson.

[Applause]

>>Thank you, Melanie. I’m—can you all hear me?
In unison

Yeah!

Oh good, okay. Melanie, thank you so much for that . . . well, I’d like to think that’s a humbling introduction. . . . I really appreciate your words. I want to say to all of you there at Ryerson how deeply honoured I am to be invited to present to you, as part of this lecture series, commemorating the life and work of a distinguished Canadian advocate for people with disabilities, Harry “Red” Foster. And I’m also most gratified to have this opportunity to link with my colleagues in the faculty and among the students in Ryerson’s Disabilities Studies program. You’ve done remarkable work in a short time and making a valuable contribution to the international academic field of disability studies, so I’m, I’m very pleased and honoured to get to get to work with you this evening.

I’m on leave of absence from San Francisco State this year, and what I’m trying to do, is finish writing a book. And, as I’ve thought about presenting to you tonight, I decided that what I really want to do is solicit your help in completing that book. In the book, I’m exploring the framing of disability in broadcast charity fundraising. And I’m trying to use that as a way into examining some of the ways in which disability is used in modern cultures. I’m trying to explicate how telethons help to shape a modern ideology and a modern public image of disability.

So what I want to do in the next few minutes, is to present to you some of the ideas, some of the issues, some of the questions I’m asking in this study. I want to offer some of these ideas to you and hopefully get the comments not only of the panelists, but of you in the audience as well. Now, I’ll be honest with you about a couple of things. First of all, I’m not going to leave you with a lot of answers; I’m going to leave probably with more questions than I will answer. In addition, the ideas in the first—in the book—this presentation—are deliberately provocative. But they by no means tell the whole story of what I hope to include in this book. It turns out, to my surprise, as I started to do the research, now years ago, that telethons are . . . much more complicated, multi-layered cultural rituals than I had expected. So anyway, with that, let me launch into some of the ideas that I’m intending to put into this book.

Throughout the modern era, private charity fundraising has played a central role in the historical experience of people with disabilities, in American, Canadian and other Western cultures. Just after World War II, voluntary health charities in the United States, invented the telethon as one fundraising mechanism. And what they intended to do with that invention was to tap into the emerging mass medium of broadcast television. The original telethon aired in New York City in 1949, for the Damon Runyon Cancer Fund.

Telethons, for disability-based causes, soon followed. In 1950, United Cerebral Palsy Association produced an 18-hour broadcast in Chicago. The following year, it was moved to New York. The Muscular Dystrophy Association (MDA) presented a telethon in New York City in 1952. In 1956, Jerry Lewis started to host that Thanksgiving, not Labour 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 United Cerebral Palsy (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 U.S. and Canada. And yet, by the early 1990s, the telethons were in decline. And as the twentieth century ended, the UCP, Easter Seals and the 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, I think, referring to the late twentieth century disability history, as in one respect the age of telethons.

Now most people who have talked about telethons, including disability-rights activists, have focused on Jerry Lewis. But the fixation on Jerry Lewis has diverted attention from telethons as a cultural institution. Dwelling on him, has closed-off consideration of that broadcast genre as a mode of addressing issues of health and welfare, as well as other social, cultural, political and, at bottom, moral concerns. Most important among those matters, have been the cultural meaning and the social and political function of disease and disability in modern society.

Telethon framings of disability and disease reflected larger historical patterns. During the modern era, some medical conditions were brought to public attention as important health problems, while others were comparatively ignored. The greater disability of certain conditions, notes the historian Charles Rosenberg, did not occur spontaneously. Rather, it resulted from what he calls “social negotiations.” Of course, social negotiation did not mean that all historical actors participated in these public discourses on an equal basis, or equally influenced the outcomes. Some exerted more influence than others. During the twentieth century, health charity professionals, health charity professionals, played a major role in social negotiations, regarding an array of diseases and disabilities.

More than any other organizations, the Warm Springs Foundation, for the treatment of Polio and the subsequent allied National Infantile Paralysis, forged during the 1930s, the methods that became the standard fundraising tools of health and disability-related charities. Applying high-pressure public relations techniques as never before, the Polio campaign also innovatively used the mass media, newspapers, radio, and motion pictures for charity solicitation.

With the Damon Runyon Cancer Fund, the United Cerebral Palsy Associations and the Muscular Dystrophy Association launched their telethons in the late 1940s and early 1950s, they carried forward into a new medium, the creative exploitation of modern, mass communications pioneered earlier by the Polio crusade. As they mobilized the mass media, the inventors of modern solicitation devised a central role for media celebrities. From the mid-1930s on, show business stars gleamed at the centre of mass media charity solicitation. From the beginning of telethons in the mid to late 1940s, and early 1950s, there were staple figures on these broadcasts. Celebrity entertainers were marketed as moral exhorters and role models for other donors.

To motivate potential donors, professional charity fundraisers invented, and over time, perfected their techniques. Elaborating on his observation about social negotiations that made some medical positions more visible than others, Charles Rosenberg writes, “What we see and fear what we have been prepared to see.” Well health charity professionals sought to prepare the
public to see particular diseases and disabilities as major health problems which urgently
demanded attention. They instructed prospective donors not only what to fear, but how to fear.
They became skilled at forging and wielding tools that would elicit donations. They learned what
methods worked; what images stirred; what appeals moved; what hopes and fears, concerns
and anxieties motivated their fellow citizens.

In the latter half of the twentieth century, they developed the telethon as the most visible
instrument of their efforts. Among their most historically most important accomplishments,
modern health charity professionals made disease and disability subjects of public discussion.
Conditions long stigmatized; experiences long made shameful, were less and less hidden.
People shunned to the shadows were increasingly brought into the open. Although Franklin
Roosevelt rarely spoke about his disability experience in public, and kept his wheelchair hidden,
he did on occasion talk about it and appeared frequently in public walking, wearing long leg
braces and using crutches, canes, or personal assistants. As important, the Polio campaigns of
the early and mid-1930s, drew attention to his experience.

Following that precedent in the 1940s and 1950s, the March of Dimes spotlighted individuals
striving to “overcome” Polio disabilities. Meanwhile, charity health professionals at the Cancer
Society fought the cultural taboo at the mention of that disease.

Can you still hear me?

>>Yeah, yeah.

>>Ok, good. I lost your picture. In 1945, publicists working with the American Cancer Society,
persuaded radio executives to drop their policies prohibiting on-air talk about Cancer. As a
result, radio stars, such as Bob Hope and Fibber Magee and Molly, addressed their audiences
about the disease. Likewise, to take a third example, in the mid and late-1940s, parents of
children with Cerebral Palsy founded Cerebral Palsy of New York. Two of them were movie
theatre and finally broadcast executive Leonard Goldenson and his wife, Isabelle. The Cerebral
Palsy campaign not only promoted medical and rehabilitative treatments, it also tried to educate
the public, to dispel superstitious folklore about “spastics” and to stop abusive institutionalization
of people with Cerebral Palsy. Thus, whether the charities focused on Cerebral Palsy, Cancer or
Polio, they helped to erode ancient superstitions about disease and disabilities. By speaking of
these common human experiences in public, they implicitly fought the shame generated and
enforced by cultural silence.

In the 1990s, the UCP telethon . . . would be distinctive among these charity broadcasts in
directly addressing issues of prejudice and discrimination as a whole part of the telethon
message. Now at the same time all this was going on though, charity fundraising messages
framed new limits of their own to public discourse about disease and disability. Telethon image-
making drew on the pathologized view central to modern public policy-making and modern
disability-related health care education and social service professions. That framing did not just
happen; it was carefully contrived by fundraising professionals. So for example, year after year,
at the opening of the MDA telethon, Jerry Lewis implicitly spoke for all health charity fundraisers
when he announced, “We will inform you; we will give you the facts.” But such solicitors did not
simply state “the facts.” They did more than merely convey information: fundraising specialists constructed and interpreted “facts” about disease and disability, in ways designed both to increase the social visibility of particular medical conditions and to promote their own charity crusades. In the process of framing disease and disability on telethons, charity professionals did not work alone. They enlisted as key partners, corporate sponsors. Business executives were the other major historical agents in telethon image-making. And I want to turn to them now.

In the last third of the twentieth century, public confidence in U.S. business and business leaders, plummeted. Average Americans grew suspicious of, as in cynical about, executives and the powerful corporations they ran. While a 1969 Louis Harris poll found 58% of trustful of major companies, just 5 years later in 1974, the percentage had dropped in half, to 29%. Some corporate leaders grew alarmed at this public cynicism. It was “not just an unpleasant fact” one of them warned his colleagues in 1974; it was, he said, dangerous because it threatened the free enterprise system itself. To correct what one marketing expert called the huge communications problem of big business, executives began to “speaking out”, trying to convince audiences that business is not all bad. Some corporations tried to help solve social problems and spent money on cleaning up the environment. What is underway now, and as per a U.S. news world report in 1978, is a concerted drive to improve the corporation’s image and to convince the public that business is not as bad as it is sometimes painted.

Charitable giving has offered one means of repairing corporate images. Big business philanthropy had already skyrocketed during the quarter century following World War II. Executives and their public relations advisors talked much of serving the public interest and playing the role of good corporate citizens. In fact, explained an historian of American philanthropy in the mid-1960s, although they were partly motivated by the fear that creeping socialism threatened free enterprise, they mostly desired to “build that loosely defined asset, ‘good will’ and thus maintain an environment favourable to the profit-making enterprise. The corporations seldom hide their philanthropic life under a bushel,” he wrote “and it is no accident that their contributions committees usually include the director of public relations.”

But even as this highly regarded, publicized beneficence burgeoned, businesses leant only limited support to national health charities. Corporate PR planners had yet to tap the enormous potential of those fundraising drives. Well, in the 1970s and 1980s, as public opinion turned against corporations, public relations strategists cast about for ways to win back public confidence. Meanwhile, charity fundraising professionals forged a means to draw donations from corporations and corporate executives by offering to refurbish their images. They came to call the strategy cause-related marketing. Disability-related charities played a particularly prominent role in leveraging this method of attracting contributions from big business. Telethons could sell to big companies, cared about little people; businesses of all sizes, but especially large corporations, could identify themselves with worthy causes, community needs and family values. They could link themselves in the public mind to those positive concepts by generating donations from their customers and employees, and then offering the donations in the names of the companies. On telethons, business chiefs could declare that far from being aloof and unconcerned, their companies cared about children and families, and got involved helpfully in the local communities where they did business. They could then demonstrate those
commitments by presenting contributions to the charities. Employing the established language of corporate philanthropy, business executives designed their telethon donations as good, corporate citizenship.

Telethons allowed big business to take credit for helping those socially invalidated by disability become fully legitimate citizens. At the same time, this community service revalidated the public identities of the companies as responsible, corporate citizens. Helping people with disabilities enabled corporate spokespersons to position their firms as more than businesses focused on the bottom line. Amway Corporation chairman, Jay Van Andel, concluded a 1992 Easter sales pitch by saying, “Amway distributors are good citizens; they’re neighbours who are concerned with their community’s needs.” Amway, said the narrator of this thought, “We’re your neighbours and your friends.” An Anheuser Busch TV commercial linked to the MDA telethon declared that corporation “glad to be your neighbour; proud to be your friend.” Telethon donation reconstituted huge corporations as good citizens, your neighbours and your friends, committed to the well-being of American families and communities.

Telethon-based special cause marketing, helped to rehabilitate corporations’ public images, in part by humanizing their executives. The charity broadcasts gave business leaders positive visibility as friendly figures. Individual CEOs and vice-presidents became featured performers on the telethon broadcast: not household names but at least familiar faces. Some of them got so comfortable on camera that, no doubt with the producer’s encouragement, they departed from their cue cards and ad-libbed. Joshing with Jerry Lewis or Pat Boone, they showed that they were, after all, regular guys. It was the job of the telethon’s celebrity host to confirm the executive’s humanity. Jerry Lewis would greet them now—by now—as old friends. He would talk about the times he spent with each of the corporate sponsors, at their headquarters, at their conventions, and at their “pump-up” meetings. “Corporate representatives were not strangers”, he said in 1994. Over the years, he and they have built up friendships. Accepting the final $1 million cheque, from Sysco Petroleum Company president, Ron Hall, Lewis said, “Thank you, Ron,” hugged him and assured “I’ll be with you in October.”

The bonhomie was on one level, an anointing. The celebrity hosts transmitted some of their own public good will to the business chieftains. But if charity professionals and corporate executives were the major historical agents in fashioning and propagating a telethon ideology of disease and disability, they were also promoting particular material interests. Special cause marketing did more than humanize business leaders, boost their moral stock and present their companies as responsible corporate citizens. Spokespersons for major companies, airlines and pharmaceutical houses and brewing companies, peddled their products while they made their pledges. The donations paid for airtime that was, in essence, another kind of commercial.

Two major manufacturers of alcoholic beverages had simplified this sales strategy, and I have time for just this example to illustrate my point. Competitors Miller Brewing and Anheuser Busch “raised funds” respectively, for United Cerebral Palsy and the Muscular Dystrophy Association. Using identical methods, they emerged as two of the biggest telethon corporate sponsors. Both enlisted stores and taverns to sell paper emblems to customers. Miller peddled Christmas wreaths; Anheuser Busch hocked St. Patrick’s Day shamrocks. Customers would sign their
names on these paper tokens, which the tavern or store would post in a prominent place. Miller also sold what it called “Big Bucks,” paper deer antlers and nosers—noses—that Miller imbibers actually wore to pose for snapshots that were then mounted in the places of business. The proceeds went to UCP and MDA, in the names of Miller or Anheuser Busch, along with their distributors, retailers and customers, but of course the money came only from the customers, the paying members of these corporate families.

Anheuser Busch announced that between 1980 and 1993, it donated $50 million to MDA. In fact, $47 million, 94% of the donations had come from the St. Patrick’s Day shamrocks promotion. Customers, not the company, had ponied up the contribution. In addition, the putative gifts only represented a share of Anheuser Busch’s bigger profits. Miller and Anheuser Busch also recruited their distributors to make donations through what were called “case commitment” programs. For each case of 12oz. cans sold, during a specified period, distributors passed along a few cents to MDA or UCP. But since the brewers used these promotions to boost the volume of sales, the distributor donations, like the paper wreath and shamrock sales, were really customer contributions.

In advertisements aimed at consumers, the brewing companies touted telethon-related promotions as supporting medical research and treatment, that would transform the lives of children with disabilities, giving them socially valid identities. The annual Budweiser TV commercials, run in the weeks preceding the MDA show, urge consumers to “buy Bud” and help “Jerry’s kids just be kids.” But Anheuser Busch and Miller ads in beverage industry magazines reveal that, in fact, the brewers used telethon-related promotions not just to help disabled children get treatment and therapies, and socially acceptable identities, but to help themselves and their retailers rake in bigger profits. The companies told retailers that telethon-linked marketing would swell the volume of sales.

Miller counselled tavern keepers and store owners, the Miller advantage: profit from it. Anheuser Busch more blatantly advocated that retailers who enlisted in the shamrocks scheme, would reap financial gain from Jerry’s kids. A trade magazine ad trumpeted, “Bring in the green with America’s number one family of beers. America’s fastest growing brand family!” A graph in the shape of a flowing mug of beer charted the growth of Anheuser Busch’s share of market, from around 22% in 1976, to 33% in 1990. “This year’s St. Patrick’s Day promotion is bigger than ever!” said the ad. “With everything you need for a successful, shamrocking party. And nothing beats the volume or the profit you’ll enjoy with the Bud family of beers. So, talk to Anheuser Busch distributor about shamrocking for MDA and get ready to roll in the greens.”

Telethon-linked promotions yielded the same financial benefits to all corporate sponsors. Business contributors who appeared on the broadcast, often delivered sales pitches. They presented their cheques just after filmed segments that were, in effect, commercials. The charities enabled every sort of business to use disabled kids to advertise its wares and services. But more, what’s going on here, than maudlin commercial exploitation. In deploying those depictions as a sales strategy, the corporations and the telethon producing agencies, redefined the meaning of marketing, consumption and charity. Special marketing strategy transmogrified product promotions from a profit-making stratagem into a philanthropic act. The plan conflated a
corporation’s merchandise, and indeed its very identity, with charitable giving. As one commentator noted—noted—the scheme “positions the company as a caring corporation that’s directly involved in the community.” At the same time, this device boosted public awareness of the company and consumer recognition of its brands. That, in turn, increased sales. In each case, suggested another observer, an element of altruism appears to be wrapped inside an advantage to the business. I would put it the other way around: Special cause marketers used an altruistic wrapping to disguise an advantage-seeking business maneuver.

In addition to serving material interests, telethon image-making could also implicitly shape political discourse about disability and, indirectly, impact public policy-making, affecting people with disabilities. Again, I have time for just one example, but I think it well-illustrates this point.

In the 1980s and 1990s, the Arthritis Foundation telethon provided just that service to the U.S. corporate nursing home industry. Nursing homes incurred enormous negative publicity for subjecting inmates to the sorts of abuses that historically have often been inflicted on institutionalized disabled persons. Not coincidentally, the nursing home system was an arena of fierce corporate competition in the late twentieth century, restructuring of the U.S. health care system. Beverly Enterprises ran a nation-wide chain of nursing homes, with 1,052 facilities and more than 100,000 inmates in 1988. It was the largest nursing home operator in the United States. A Los Angeles Times investigation that year, found appalling conditions in some of the corporation’s California facilities. In Beverly’s Mountainview Centre, staff let ants swarm over the bodies of residents. The creatures even crawled into one woman’s open tracheotomy.

In some Beverly facilities, staff allowed foul-smelling bed sores to develop on inmates’ backsides. These were not simply unsightly or disgusting blemishes. The word bed sores, was the Times’ writer’s words, they were in fact “decubitus ulcers” that, if left untended, developed into gangrene, sometimes require amputation of a limb and can even end in death. Well, according to the LA Times, state health inspectors reported that some patients were so neglected, that their bed sores has blackened and consumed flesh down to the bone.

In other instances, inspectors charged staff with repeatedly leaving patients in urine-soaked beds, raping residents, and committing gross medication errors, including a morphine overdose more than seven times what was prescribed. In a few cases, neglect caused the death of disabled residents. Among them was a woman with significant mental and physical disabilities who, through staff negligence, drowned. Generally, enterprises, facilities were charged with mistreating patients in other states, besides California. Officials in Missouri, Texas and Oregon, found major violations. So Beverly Enterprises was a huge, corporate chain but it typified the problems found throughout the for-profit nursing home industry. For example, in 1994, a much smaller operator, Philadelphia-based, Geriatric and Medical Companies Incorporated, “pleaded no contest to two misdemeanor accounts of involuntary manslaughter, in connection with the deaths of two patients in homes it ran,” reported the New York Times. Well, given all this bad press, the nursing home corporations needed to generate some positive PR. They turned to the Arthritis Foundation. Corporately owned nursing homes began holding fundraisers for the foundation. Then they trumpeted their good deeds on the telethon. On the 1991 telecast, a
Beverly Enterprises representative announced that the corporation had prepared a brochure on what to look for, in selecting a nursing home for a loved one.

Other industry organizations also promoted their good corporate citizenship on the telethon. Spokespersons for both the American Healthcare Association, a national organization of nursing homes, and the New York Health Facilities Association, presented cheques donated to the Arthritis Foundation.

The Arthritis telethon also gave nursing home industry representatives a chance to tap the high quality of care their companies provided. The spokesperson for the New York Health Facilities Association invited everyone to visit a nursing home, during National Nursing Home Week, in May 1990. That year’s theme was "Pride in Caring." The industry wanted everyone to see what an outstanding job nursing homes—nursing homes did, he said. On the 1991 Arthritis broadcast, a spokesperson for the American Healthcare Association declared that the industry as a whole believed America’s elderly deserved the best long-term care.

Well in the 1980s and 1990s, it became critically necessary for the industry to promote an image of quality care, as the Independent Living Movement of disabled activists challenged both the nursing home corporations and federal funding priorities regarding long-term care for adults with disabilities. In 1988, Beverly Enterprises took in over $2 billion in revenue. Two thirds of that money came from public funds. The industry as a whole drew revenues that year of $43.1 billion. Of that total, individuals and families paid $21.6 billion, while federal Medicaid and Medicare contributed $19.9 billion. But the federal government, meanwhile, spent only $3.4 billion on personal assistance services that enabled disabled adults to live in their own homes.

By 1992, the federal government was paying the nursing home industry $23 billion for long-term care. Polishing their public image on the Arthritis telethon helped the corporations (inaudible) substantial economic stake in this arrangement. Well, ADAPT, American Disabled Attendant Programs Today, a national disability rights organization founded in 1982, had many members who previously has been confined in institutions. ADAPT charged that the majority of both private and public funding went for nursing homes and other institutions, rather than for independent living because of the influence of the American Healthcare Association and other industry lobbying groups. Independent Living activists reframed the issue in terms of civil rights and self-determination versus corporate profit. “We are being treated like commodities by a corporate nursing and large group-home industry, that is more concerned about profit than need”, declared ADAPT. ADAPT proposed an alternative to institutionalization. The federal government should redirect one-fourth of Medicaid funding, from nursing homes to community-based personal assistance services. It should mandate such services under Medicaid in every state, “so that disabled and elderly people can live independently if they choose.” This, ADAPT said, would require no new funding. ADAPT demanded, “An immediate end to the policies that routinely shuttle disabled and elderly people into nursing homes, and a beginning to a national attendant services program.”

Underlying this debate over institutionalization versus independent living, raged clashing perspectives about the lives of people with disabilities. The nursing home corporations and the Independent Living activists espoused fundamentally opposing visions of the place of disabled
people in society. ADAPT activists complained, “Services delivered to us are seen as medical services, rather than simply the support we need to live in our own home.” They called for, “A non-medical, user-driven, community-based, attendant services program that will allow us to live in our own homes.”

While the industry talked about long-term care, the activists called for personal assistance services. The two phrases reflected more than semantic preferences. They represented contending policy agendas. No one seemed to notice that in this political debate about public polices, the Arthritis telethon gave the nursing home industry a national media platform, from which to propagate its perspective and protect its economic interests, without challenge from disabled activists.

Unnoticed also was the telethon played an important role in shaping public discourse about how modern societies provide for their citizens’ health and welfare needs. The health care charities have produced telethons, were in fact components, of the hybrid public/private U.S. systems of paying for private health care, social services and medical research. As a result, public debate about the charities became front, in an ongoing American cultural and political contest, over private versus public means of addressing social needs.

In helping to shape public discourse about disability, telethons demarcated the true needs, what were alleged to be the true needs and interests, and ultimately, the identities of people with disabilities. Presented as the afflicted and the less fortunate, people with disabilities saw their problems, needs and identities defined in terms of medical and social pathology. The charities attributed their social marginalization to morbid physiological conditions. Those bodily defects, assumedly incapacitated them, to perform the social roles expected of people in various age groups. We need to keep in mind that the vast majority of individuals the telethons presented as afflicted, were not dying. They had chronic, rather than terminal conditions. The main point of the broadcast was that while 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.

Meanwhile, telethons displayed children as the representative of a disabled person and often treated the disabled adults who appeared on the broadcast as though they were children. On one level, this was simply a tried and true charity fundraising device. Pathetic, adorable children had always drawn donations. But at a deeper and more important level, this portrayal marked what the historian Robert Davidoff has called obsessive infantilization. People with disabilities were relentlessly portrayed as children because modern cultures displaced onto disability some of their deepest fears: helplessness; loss of independence; loss of autonomy. Telethons offered disability and people with disabilities as metaphors for, and means to assuage chronic worry about, loss of autonomy, which was to say loss of a socially valid identity.

The model for this infantilized image was Tiny Tim, in Charles Dickens’s A Christmas Carol. Telethons borrowed traits of the Dickens character, 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 non-disabled people to renew their humanity. The disabled person as invalid or in-valid, helpless, dependent and fundamentally different from normal people. The disabled person as sentimental entertainment; a figure whose pathetic situation or heroic striving, touches the hearts of readers and viewers. And of course the disabled person as perpetual child: sweet, cheerful and brave. In Ebenezer Scrooge’s nightmare in *A Christmas Carol*, Tiny Tim dies and so does the miser. But when Scrooge awakens, which is to say when Scrooge becomes morally conscious with the dawn, he saves the child’s life and his own soul. So, Dickens lets his readers have it both ways: they can have a good cry over poor Tim and they can vicariously share in Scrooge’s salvation when he gives so that the crippled boy can live.

Telethons too, offered both sentimentality and salvation. The semblance 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 and other fundraising activities. At the least, they glanced at a poster child’s picture on a drug store 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 pack of chewing gum or paid for a restaurant meal, solidified the Tiny Tim image in their mind. And Tiny 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 and roles of people with disabilities, they reciprocally defined the social identities and roles of people without disabilities, too. Each was necessary to rendition of the other; verifications of who and what was “normal”, depended on maintenance of the category “abnormal.” The socially valid could confirm their authenticity only by gazing at, and in some way acting upon, the putatively in-valid. That radical dichotomy 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 cast, they claimed that they were affirming disabled peoples’ common humanity.

So, for example, the 1989 Easter Seals show cued national co-host, actress Mary Fran to say, mixed-in with the music, you’re also going to hear a message. The message was that people with disabilities do belong. But in fact, telethons ceaselessly, ritualistically reiterated that people with disabilities would not, and in fact, could not belong, unless their medical and social pathologies were cured or corrected. As a result, on telethons nondisabled people did almost all the talking. 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 centre, 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 pled, “Please don’t forget these people. They need you so desperately.” “You” and “these people”; “we” and “them”; “they” and “us.” To potential donors like the telethon presenters who are nondisabled, the inevitable charity recipients were disabled. Speaking
through the nondisabled telethon emcees and celebrities who addressed the 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 charity caste, the broadcasts at the same time, pictured people without disabilities as their opposites. Physical healthy and whole, giving rather 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 and roles of people with disabilities. Telethons empowered nondisabled emcees to explain to nondisabled viewers, the daily experience of living with a disability. “We hope to give you a little more understanding of what it’s like for someone with a disability,” announced a local Easter Seals host in 1990. But, said another in 1988, “One of the frustrating things about hosting this show is that we are 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 host talked, on and on.

Well during the latter half of the twentieth century, growing numbers of people with disabilities resisted their relegation to social invalidity. They organized themselves into a movement, or to put it more accurately, an assemblage of movements, that challenged the dominant views of disability. In place of pathology as the explanation of disabled peoples social and economic marginalization, their campaign substituted a minority group perspective. More urgent than the remedial measures that sought to fix individuals, they advocated reform of society through its statement of equal access and reasonable accommodations, along with antidiscrimination protections. Rather than the charity approach beseeching attention to disabled peoples’ needs and social situation, they demanded civil rights enforcement to ensure their 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 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 within the organizations themselves. And so in various ways the telethons sought to co-opt or criticize, address, assimilate or adopt the activists’ perspective. On and off the broadcasts the controversy generated public debate that touched on without deeply exploring, let alone resolving, a clutch of questions; the questions that stand at the core of the modern problem of disability. Is disability inherent defectiveness? Socially constructed devaluation? Or human variation and difference? What roles and identities have modern social norms and cultural values, public policies and professional practices prescribed for people with disabilities? How do those norms and values influence social arrangements, public policies, and professional practices to put it the other way around? How, to quote the historian Douglas Baynton, was the modern, fundamental, binary opposition, normal versus disabled invented and wielded, as what he calls a “signifier for relations of power?” How do we account for the extraordinary intensification of social anxieties about disability within modern cultures? The creation, as Baynton puts it, of that fundamental binary opposition, normal versus disabled. That historical
development rendered people with disabilities socially invisible and at the same time, produced the assumption that this was natural and indeed, inevitable.

No wonder, write John Gliedman and William Roth, in their neglected and now out-of-print classic, *The Unexpected Minority*, no wonder they write, “Few of us find it strange that tens of millions of disabled people are segregated from the mainstream of life. We simply don’t expect to find them among us.” Gliedman and Roth call this perhaps the most radical act of social declassification possible.

Other questions: in what ways have people with disabilities embraced or resisted these definitions? How do they attempt to manage or alter their social careers and social identities and to have an impact on public policies, professional practices and sociocultural beliefs? And then, what are the real needs and real interests of people with disabilities? And who is qualified to determine them? Who will define who and what they are and can be? What values will fit that definition in the future? Could citizens 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 matters of entitlement? Or as civil, social, or human rights? Were disability rights activists refusing, in their protests against the telethons, were they refusing to acknowledge the inherent suffering of people with certain conditions? At the same time, could disabled citizens assert their fundamental equality with nondisabled citizens if they admitted that some conditions involve intrinsic limitation and suffering?

Correspondingly, is it possible for charity publicists to promote amelioration of genuine human suffering, without demeaning the people they ostensibly seek to help? Are modern values about need, justice, equality and difference ultimately compatible with one another, or irreconcilably at odds? And, in the end, what is the meaning of disability and what is the place of people with disabilities in modern society? All those questions, I think, have been involved in the controversy over telethons.

The public clash over the telethons grew out of underlying, opposing ideologies. But two facts muddle the argument. The charities never consciously faced all of the elements that made up their ideology of disability; the activist had not yet fully formulated their alternative outlook.

So I would like to conclude by suggesting that for those of us committed to the social advancement of people with disabilities, the task, I think, is to flesh out that analysis in support of the International Disability Rights movement agenda. That agenda is equal rights, equal justice and equal dignity for people with disabilities everywhere. Thank you for your attention.

[Applause]

>>I want to try and call our panel up? So would the panel just join me please up here. Okay. Why don’t I put myself right here at the corner, okay?

Hi Paul, can you hear me? Paul, are you out there?

>>I’m here, I can hear you.
Alright—I can see you too!

Great. Fantastic. Okay, okay. My notes? Can’t forget my glasses. Okay, I’m just waiting for a couple of panelists who are making their way up. And . . . I’ll just introduce myself to folks here who don’t know me. I’m Catherine Frazee and this is my little piece of technology here that’s working its way—here we go. How’s that? Okay, great.

So I’m Catherine Frazee. I’m the co-director of the Ryerson RBC Institute for Disability Studies. It’s my great pleasure to first of all thank Paul for an extraordinary lecture. Paul, I don’t know, earlier they were saying that . . . the image at SFU was pixelating because there were so many bodies in motion. Well, let me assure you there is some justice perhaps, because you have all of our heads spinning after that lecture that wove together history and politics and philosophy and questions of image and identity so extraordinarily exquisitely. Thank you for that, for that talk, Paul.

What we’re going to do now for the next probably forty minutes is, first of all, invite three panelists to comment briefly in response to Paul’s . . . to Paul’s lecture, and then we’re going to open things up to the audience because I know people will have their own thoughts and their own questions to bring to the . . . to bring to the discussion today and to take advantage of Paul’s presence among us.

I want to say that this panel is really . . . you might think of it as a panel of tangents. Quite often in—and that’s intentional. Our agenda here in Disability Studies is always—I think many of you will know—to take the issues that are of deep and pressing concern, to us as disabled people and to us as scholars in the field. To take those questions and to explode them outward, to demonstrate that this is a small, private party. That this is, in fact, a wave of something much larger. And with that in mind, we’ve invited some folks to the table and suggested that rather than simply, simply—nothing would be simple about absorbing all of what, all of what Paul has had to say and synthesizing it and commenting upon it as a whole. That isn’t, however, what we’ve asked people to do, Paul. Rather than that, what we’ve asked our panelists at least to do, is to select a thread; a single thread from the talk you’ve just presented and to pull on that thread a little, drawing from their own personal and/or professional experience and interests. And let’s just see what kind of a tapestry can be formed from that collection of threads.

So without further ado, what I’m going to do is, I think introduce each panelist as she speaks. And we’re going to hear first from the person from my immediately—my immediate left, who is Jiji Veronka. And let me just take a moment to introduce Jiji for those of you who don’t know her.

Jiji brings to this panel, besides her charisma and her very fine intellect, a taste of the exciting new scholarship emerging in Disability Studies, as Disability Studies meets its cohorts in critical race studies, feminist studies, history—mad history—and critical geography. Jiji, I should say, joined our institute for disability studies, where she works as a project coordinator and research assistant, on a number of projects. She joined us following completion of her Master’s degree at OISE. I’m delighted to say Jiji took the leap of faith in joining this evening’s panel when I caught
her entirely off-guard with my invitation because she came to my door a few days ago, to volunteer for a role wrangling this evening’s talent. Now for those of you who don’t know what that means, it’s an in-house term for making sure that everybody has water and a chair to sit in. Well I think we contemplated a more substantial role for Jiji this evening. And even if we had to go without water, it would be well worth it. Jiji.

>>Thank you very much, Catherine for that lovely intro. I came to the department through Dr. Kathryn Church, who is Research Associate and Assistant Professor at the school. She was a professor of mine. She taught a Disabilities Studies course over at OISE that I took a few years ago. In many of the courses that Dr. Church teaches, she has her students, some of whom I’m sure who are here tonight, write political autobiographies. I have written a short one for tonight, a bit of a rant, that was spurred on by Paul’s talk that I read a couple days ago. A short piece, a little piece of jazz, of reflective practice that the School of Disability Studies is really committed to incorporating into the academic agenda. So, I call it “Producing Normalcy.”

Okay. When asked if I would like to sit-in on this panel, I was mid-day through a “normal” workday. In order to make it through to midday, I had ensured that I got seven hours sleep the night before; woke up early enough to facilitate the hour on the treadmill that prefaces most of my days. Put time and energy in ensuring that my clothes, body, face, even hair, were clean. Makeup, earrings? Check. I drank my protein, shaved my legs, swallowed my pills and dragged my normal body off to work. It was midday. I was already so exhausted producing my normalcy that the thought of taking anything else on made my vitamin-ridden stomach extra queasy.

The thread I would like to pull on from Paul’s work is that all bodies, regardless of ability, carry the work of producing ourselves as bodied subjects. Telethons lead me outwards, to other organized events showcasing body typologies: the freak shows, the fashion shows, beauty pageants, to the more recent television shows Extreme Makeovers, and number of weight loss shows that, for me, showcase just how hard it is to create a normal body. The time, the money and even the medical interventions that have become par for the course and allow us to harness our bodies in order to pass quietly through the social.

This quiet work of which I am deeply engaged, requires a huge amount of energy that is rarely talked about. My whiteness, my precarious and quickly ebbing youth, my class, gender, illness and various other social identities, position me in a particular way to the work of being normal. Creating this everyday girl takes work. This is something that people, and women in particular, seem reluctant to admit.

Could you put the first image up, please?

There’s an ongoing and very open dialogue, padded with much love, between me and my best friend, Ally, who is up there with me, in regards to our embodiment and relationship to public space. In simple terms, I belong to the beauty pageant while she is a walking freak show. Understanding our contrasts took me years and I would often argue that I didn’t feel pretty; didn’t dress pretty; didn’t feel thin, unless experienced the same hostile public that she did when outside the safe haven of home. But she angrily pointed out to me, over and over and over, that
my personal feelings of self and the public gaze are very different. I can feel ugly but I'm still afforded the graces that normal is granted when stepping out.

On the other hand, Ally is only seen as a fat body. And her culturally embodied enfreakment essentializes her every moment and movement. And when we walk down the street together, our bodies act as visual representations of what is cherished and abhorred. As Rosemary Garland Thomson has said, "The beauty and the freak whose contrasting visual presence gives shape and definition to the figure of the normative citizen of a democratic order."

I have to come to understand that regardless of feeling, my body is perceived as safe and able, while Ally's is perceived as unruly and constantly vulnerable to the public's disgust, which is often disguised through pity and hope. People often say to her, "But you have such a pretty face."

The categorization of bodies within the binaries of normal and abnormal: the disabled body, the ill body, the healthy body, the homeless body, the white body, the black body, the homosexual body, the beauty, the freak, are presented as absolutes. But nuances of course exist between these binaries; ones that are not always immediately apparent to the discerning eyes of the public.

Could you put the second image up, please?

My brother, at first glance the common man, could at times act safely as universal subject. People sat beside him on subway cars, reassured by his white skin and masculine traits. But the brain behind his esteemed physicality was one that was diagnosed paranoid schizophrenic. And once that invisible disability became apparent, the fear and anger that the public displayed by being tricked, was often greeted with even more hostility than the abnormal bodies that are easier to identify. Subway passengers never want to sit beside the disabled or fat body. But with my brother, they were fooled and had to make the public display of changing seats once he was found out. A very uncomfortable act of acknowledging their own fear.

People like the quiet, normal body. They want it to be a natural state. To admit that normalcy is an active process that is precarious and constantly being negotiated, is to recognize that all bodies will eventually fail; that bodies are simply not built to last. The difference between the disabled body, the fat body, the mad body, and my own normal body is that, as Paul noted, "bodies are signifiers for relations of power."

I often move through the social in very privileged ways because of this body that is read as normal. I am weak with power. To speak of this power makes me even weaker. But to query normalcy is a requirement if binaries are to be broken and scholars are beginning to work on breaking down the idea of the ideal universal subject, reflecting on sameness and problematizing the idea of whiteness, heteronormativity and the like, as the natural, given from which everything else is an aberration.

So I guess my question to Paul would be: in your talk you ask, in what ways do disabled people embrace or resist definitions of their identities? And I just wonder in what ways can normal bodies—so-called normal bodies—actively resist the idea that our selves are in their natural
states, and instead tug on recognizing that normal bodies do take a lot of work. And what kinds of roles normal bodies, who are engaged with disability studies, can play in breaking down the binary opposition of normal versus disabled?

>>Great. Thank you, Jiji. That’s great. Paul—

>>—Thank you. That’s very provocative and stimulating. I appreciate the issue you’re raising. Before I try to answer the question you posed at the end, let me offer another comment. There’s a . . . I have another chapter I’m working on in a—not another chapter, a chapter I’m working on in this book on telethons that’s going to try to address issues of gender. There’s a lot of gender stuff on the broadcasts. What I was thinking about as you were reading your, your comments was about some of the ways in which people with disabilities, particularly children with disabilities, are presented on the telethons and then contrasted with adults, men and women, in different ways. So presented as socially valid and normal. And that leads me to think about the function of disability and of images of, not just normality but of ideal body types and ideal personal identities, particularly sexual and gendered identities. So, for instance, I’ll try to be brief in this because I know . . . well. . . we don’t have a whole lot of time.

For instance, on the Easter Seals telethon, for a couple of years Jenny Craig weight loss alliance was a corporate sponsor of the telethon. And they presented young, very attractive women, who worked on the Jenny Craig program and these women were contrasted with little girls with physical disability. Just to take that as one example and not provide other examples. It seems to me that one of the functions of disability is to be presented at one end of a spectrum and; at the other end is people who are ideal types, in terms of attractiveness and beauty and sexuality. And to say to people who are anywhere along where I think you’re really implicitly describing as a spectrum, in between those two polar opposites, to say to them, “Well here is what you absolutely must not become if you want to remain in any way valid. And here’s what you ought to strive toward, even if you can never achieve it, and insofar as you slip back toward that disabled end of the spectrum, you will lose some of, if not most of, your social legitimacy and validity. And insofar as you move toward that ideal type, you will . . . you’ll increase in social value.

The gendered images of males are somewhat different. They tend to be images that focus not so much on appearance and attractiveness, but more on fulfilling patriarchal roles. I’ll also handle that in that chapter. With regards to the . . . questions you’ve put to me, at the end of your comment, those are really important questions that are part of a larger set of issues about what is, I think, a perpetual tension in disability studies, as well as in disability rights activism, which has to do with the respective roles of people with and without disabilities. It has to do with, I think, recognitions of the typical arrangements of power and opportunities and privileges. And it—I think part of that recognition needs to be about all of us of recognizing, as we’re interacting with one another, all of us recognizing that given those . . . given that structuring of power and privilege, there will always be unconscious tendencies on the part of all of us to fall into the, the roles that have been prescribed and that we usually unconsciously operate from. So we need to guard against over-wielding power, or disempowering or passivity on the part of people with disabilities. At the same time, you’re valuably and pertinently pointing out, I think, that . . .
is an enormous amount of energy that’s required of every person, wherever they are on that spectrum, wherever . . . whatever kind of social conditions they occupy, there’s an enormous amount of energy enforced on all of us to live up to social and cultural expectations and requirements. And that in the end, the oppressiveness of the ideologies of disability injure everyone; harm everyone and that what we’re ultimately aiming at is a cultural transformation and social and economic and political transformation that will liberate everyone, whether or not they’re currently labeled as disabled or normal. So I appreciate you’re raising that complex and tough set of issues.

>>Thanks Paul.

>>Thank you.

>>Thank you.

>>Thank you. Thanks both. Thank you, Jiji.

>>Thanks.

>>Next Paul, let me introduce you to our next panelist, Sandra Carpenter, who’s sitting in the middle on the panel. Sandra welcome! Sandra is a founder for our Centre for Independent Living here in Toronto. Was its first executive director when CILT first gained its independence in 1986. Sandra has a long history of leadership, both in the Independent Living movement and in the Disability movement more broadly but also a distinguished career in the public sector. Sandra has held management positions with disability portfolios; has been one of the disability policy-makers in the good sense, as opposed to the telethon sense, at the Ontario Ministry of Labour and in the Ontario Ministry of Citizenship. While in the Ontario government, she played a key role in Ontario’s state-of-the-art direct funding program for consumer-managed, attendant services, personal assistant services in the U.S. Sandra is currently, or has recently returned as to CILT, where she manages the Independent Living program. And in her spare time, she is pursuing studies as an MA-candidate in the Critical Disability Studies program at York University. She wants me to be quite clear that she’s not here tonight in any official role representing any official organization, but rather, bringing her own voice, I think, as a well-recovered pathetic and adorable child.

[Laughter and applause]

>>Thank you, Catherine. Yeah, I’ve . . . I can’t emphasize enough my remarks tonight are just going to be my . . . are personal, not officially representative of the organization I work for. Last time I talked on this topic, which was perceived as critical about telethons, I got in big, big trouble from a big telethon—

——Could I ask you to move the mic a little closer? I’m having trouble hearing from this end.

>>Can you move that? Okay Paul can you hear me?

>>That’s better. Thank you.
Okay. Yes, I got in a lot of trouble from an organization that raises their money through a telethon so I don’t, I don’t want to get into that confusion again tonight. Basically, Paul’s remarks reminded me of a story and I have the good fortune that I wrote this story down. So, I’m just going to read it out to you. A lot of you have heard this story before so just bear with me, those who know me in the audience. But, anyway, I call this little story “Hope.”

I met Bob Hope once. I was eleven years old, and I had just moved to Toronto from Ottawa. My new home was a residence for disabled children. In those days, there were forty-eight of us living there, and as I was soon to discover, mass outings were a common occurrence. In those days, I was generally a very trusting and honest child who still believed in most of what I had been taught by my parents.

Moreover, I was under the impression that the reason I was taught these things, was because they were part of a package for rules for living, that all people subscribe to. In short, I was way up there on the naïve scale. This is a story of my descent from my naïveté.

First off, they rolled us up a big wooden plank into the back of a transport truck. I think it was a beer truck; which probably donate, but I never asked about that. Was all quite safe: staff rode in the back with us. And there were three or four police escorts. It must have looked strange from the outside. People must have wondered why beer suddenly became important enough to warrant assignment for the men in blue.

[Laughter]

I’m turning the page; it takes me a while. The other thing is I lost my reading glasses. So if I’m squinting a lot trying to read this, you’ll understand. I am over fifty after all.

We ended up at the O’Keefe Centre, which is now called, I think, the Hummingbird Centre? But I think they want to change the name of it again. Anyway, it was called the O’Keefe Centre then. There was an air of excitement; we were going to watch Bob Hope emcee the Easter Seals show. I mean, this was great. Something you only got to see on television. Disappointment soon followed, however. As we were ushered into a lobby, with hundreds of other people, and placed in front of large, television monitors. We felt as though we’d been conned. My keep-your-eyes-open-for-anything radar, was fully activated. Something was wrong here: they had cameras on us. One minute we’d see the show on the monitor, and the next minute we’d see ourselves laughing after something Bob Hope said. Or looking mesmerized while dancers leaped across the stage. Slowly it dawned on me that we were seeing the same thing on the monitors that people at home were. And they would have been thinking that we were sitting right up there, in the front row . . . within kissing distance of Bob. It was all planned, I realized; calculated. Manipulation of the situation which achieved the desired effect. This was turning out to be a real education for me, but the main event was yet to come.

Intermission. I saw these people talking to the kids way down the row. They gave the kids something and moved on to the next one. When they got to me, they stared saying how lucky I was because I was going to meet Bob Hope. And when I met him, I was going to give him this present. They showed me a blue, cardboard box, with tissue paper in it, cradling one of those
tacky maple leaf ashtrays, and said to me, “On behalf of all the crippled children from Saskatchewan, I would like to present you with this gift. [Laughing]. Could I remember that?”

“Uh, but I’m not from Saskatchewan,” I meekly protested.

“That doesn’t matter,” they told me with authority. Laughing their “Isn’t she just precious?” laugh, and moved on. I felt totally stupid. I would have thought a representative from Saskatchewan should be from Saskatchewan or at least appointed or selected by people from Saskatchewan.

[Laughter]

Feeling stupid soon dissolved into feeling guilty. I was lying to Bob. I had never even seen a prairie or wheat field. And yet, adults had given me my assignment, and I have been taught to respect adults—faulty childhood lesson number one or two. I swallowed my ethics and prepared to meet Bob. My performance was impeccable. I gave Bob the ashtray, even though I would have been embarrassed to give it to a dog. Sorry Ann, you’ll have to apologize to your dog. I let Bob think I was poor Sandy from Saskatchewan. He must have felt honoured, thinking that kids had flown from all over Canada to present his gifts. Yes indeed, it must have made old Bob think it was all worthwhile.

As the years went by, the memories faded and threatened to erode into fantasy. I became less sure and less sure that I had ever actually met Mr. Hope. But on my grandmother’s wall is a framed photograph of Bob and me and the blue box. In the picture of Mr. Hope—In the picture, Mr. Hope is bent over a little girl in a wheelchair. His hand is outstretched, almost touching the box. The girl has her hair pulled back in a braid, tied at the top and bottom by bows. She wears a white blouse, a dark jumper and white knee socks. The two faces are in profile and the more you look at them, the more similarities emerge: the hairline; the chin; ski jump noses. The both gaze intently into the box, as though the object inside it were a living thing. Her mouth is open as though she’s saying something. She looks happy and slightly awed by the proximity of the star. But I know what’s really in her mind: What’s a polite word for bullshit?

[Laughter]

On a serious level though, Paul, perhaps you could consider and comment on why it is that there is such animosity when people from the disabled community say anything negative about telethons? The venomous reaction that they get from those institutions is quite extreme so I don’t know if you’ve uncovered any of that in your work so far?

>>The recipients of any kind of charity are supposed to be grateful. And when you’re not grateful, and in fact, when you are not only ungrateful but you seriously challenge the fundamental premises of the act of charity, and try to radically alter the terms of the relationship between the society that offers the charity and you as one of the people who receive the charity, when you assert instead these—these are not matters of philanthropy or condescending patronage or charity but, in fact, involve fundamental civil and social and human rights. Everyone ought to be entitled to appropriate and adequate health care and to other kinds of supports and services that people with disabilities indeed have the right to reasonable accommodations and equal access and that there’s a fundamental problem with prejudice and
discrimination that people with disabilities are being safeguarded from those things and guaranteed their rights as citizens on an equivalent basis, in all instances. When you start doing all that, that calls into question some really well-established patterns of social relations and calls into question the basis of quite a vast array of social institutions. Calls into question the fundamental suppositions of the modern era. So, it’s surprising to me that there’s not more hostility.

As I read the criticisms of the telethon protests, the protests of disability activists against the telethons, what strikes me more than anything is that in a fundamental way, that the hostile critics in responding don’t begin to understand what it is that has these disability rights activists so exorcised; so . . . so indignant. They don’t understand what the criticism is all about. It . . . it just, it goes right over their heads.

I guess in addition, to what I . . . the, the challenges that I listed a moment ago, there is also some even more fundamental ideas that are being challenged by disability rights activism, in protesting the telethons, as there is—as we all know there are—in activism regarding other issues. One of the things that telethons do is to reinforce the notion that the social marginalization and deprivation of the vast majority of people with disabilities is rooted in biological conditions; rooted in physiological pathology, and is therefore, natural and predictable. And when you start to say—when we start to say—this isn’t natural, it’s not inevitable; it’s socially, culturally and politically constructed, you’re challenging—we’re challenging—again, those kinds of fundamental ideas that Doug Baynton was referring to, in the statement I quoted from him. It doesn’t make sense to people. Worse than that, it seems scandalous to a lot of people. So even people who have some grasp of the socially constructed nature of other disadvantaging social statuses, don’t begin to get it when it comes to disability. It just makes no sense to them and that, I think outrages them. So you got a whole series of layers of responses—of reactions—I think.

The most obvious one is . . . that we’re ungrateful. That’s, that’s the first, I think, the initial reaction. We’re just, we’re just ungrateful and, and of course that then also triggers a counter-image. If the image pervading in charity fundraising is of the disabled person as pathetic but adorable, recipient of charitable goodwill, then the image that is triggered by protest against the telethons is the counter-image that’s always there of the bitter, self-pitying, ungrateful, burdensome, trouble-making disabled person, who, who really stirs things up and causes hardship for the nondisabled people who only mean them goodwill. I guess that’s what I’d say in response.

>>Thank you. Thank you, Paul.

>>Aren’t you glad you asked?

>>Thank you—

>>--I didn’t hear the last thing you said.

>>On, that was just a one-liner. I said “Aren’t you glad you asked?” And we are. Okay, Paul. I want to introduce you-- thank you, Sandra—I want to introduce you to our third panelist. The
woman at my far right, at the end of the table, is a colleague, Dr. Akua Benjamin. Akua is the director of the Faculty of Social Work here at Ryerson University and she is so much more. Akua Benjamin is a warrior. She brings to her position here at Ryerson and to all of her work, what our new university president Sheldon Levy calls “street cred”. Akua’s name is a household word in Canada’s feminist, anti-racist, and anti-poverty spheres. Not coincidentally, that same name also strikes terror into the hearts of the forces of evil in our country.

[Laughter]

Akua has been at the forefront of initiatives like the Racism, Violence and Health Project, studying the impact of racism and other forms of violence on the human—on the health and well-being of African-Canadians. She is a respected educator, activist, and coalition builder, whose dance card is almost always full, but, who on this Friday night, made herself available to dance with us, and we’re very honoured to have her with us. Akua Benjamin.

[Applause]

>>Catherine, I don’t think anybody has ever introduced me as wonderful, wonderful. Thank you. Okay, thank you very much. Good evening, everybody. Unlike my, the former speakers who focus very much in terms of disability, I do not pretend to know much about this issue yes—

>>Could you hold the mic a little closer?

>>Uh—

>>—I’m sorry—

>>Okay, go ahead.

>>It’s not the best—

>>Okay.

>>Okay, thank you—

>>—Alright. I’m saying that unlike the former speakers who spoke eloquently about the issues of disability, I pretend not to know much about all the, the nuances and details of disability. A champion yes, for the rights of people with disabilities but I’m coming, as Catherine says, to the issues in terms of reading your paper and being triggered by some of the messages, some of the statements, about the media: not, not looking at it simply at the telethon, but looking very much in terms of the media images, particularly the philanthropic messages that the media perpetrates around raising monies for black African children. Children who are, who are overwhelmingly presented not in the way I think that you describe as children are sweet, cheerful and brave, but children as overwhelmingly destitute, overwhelmingly needy. Sometimes these images show children as victims of circumstances of famine or drought. Sometimes the child is shown as a parent or caregiver for siblings, for surviving against all odds. These are black African children and so they’re presented in terms of a trope about deserving the charity of whites; deserving the charity and pity of us living in the North; deserving of
charitable goodwill. And so we’re asked over and over again by media images to dig deep into our pockets and to save these children with our kindness, or goodwill or dollars.

And one may say this is indeed the reality of Africans, African children, particularly in the face of famine, drought, the, the pandemic of HIV and AIDS in Africa, genocide, wars that that continue yes, to lead to death and destruction of these children, their families and communities. This is indeed the case and so the question that you raised at the end, professor, about, about the question should we, on the one hand, and I’m sort of not reading the question directly but I think you allude to the fact about what’s kinds of images in reality do we—does the media portray—in order then to . . . for the society to respond philanthropically if you will, to suffering, right? And so there is a reality about Africans and African children with what’s been happening but at the, it seems to me at these images.

The images or messages are tropes. What we see they serve to obfuscate the corporatization of racism, intersected with historical and contemporary issues of colonialism and globalism, globalization that continue to socially disable, not only these children, but to socially disable the continent of Africa. So the images yes, they portray illness and disease, but they do not sufficiently highlight the diseases and illnesses of the result of history—this history—that is embedded of colonialization; embedded with a healthy, healthy ongoing dose of racism and the ongoing exploitation and domination by Western corporations, aided and abetted by some African leaders to plunder the rich minerals and other resources of Africa leaving little for people in that part of the world to survive and to survive well. Or to survive in such a way that they can have the, the much needed medical supplies for these destitute children in this part of the world.

As media portrayals a certain image then, as deeply inscribed in the Black body image of the suffering child. This image is one of deficit, helplessness, the need to be rescued, the need for charity, wittingly or unwittingly, this, as Philomena Essed calls it “is everyday racism.” Also a form of systemic racism perpetrated by the media. Now, I think all of us know that racism is a tool of division, white against black, the binary of inferiority versus superiority, the “have” against the “have nots”, and in these discourses, a certain ideology is produced and reproduced by this Black body image, not only of the child, but I believe of Africa itself. They show a modernist discourse that I believe essentializes Africa. Not just the child. Africa is, is always this poor, starving, underdeveloped, this sick, this destitute place. So the strength of survival of the African community—the supports in the community—just the everyday laughter and resilience of Africa and Africans, are not seen in these images. What we see then, continuously are these images of illness and sickness. And I raise the question about, about the language—the trope—of these media discourses.

And one of the, the issues here is, is just around language itself that is missing. So as persons with disabilities around the globe struggle for recognition, to be heard, to be seen, not with deficits but resilience, with rights, with strengths, this kind of view of persons, just the language of people with disabilities would do well to be extended to the body politic of African children and Africa. There’s a need to depose the images and to replace these images with an anti-racist language that shows these strengths and this resilience and this everydayness with people who survive. And as a matter of fact, just in—I was in Africa earlier this year, and so the language of
persons with disabilities, even in that part of the world, I heard very little about that language. That language of a meaning, of persons with disabilities appear to be absent in media discourses, as well as in the continent. So I believe that the concept of itself, of persons with disabilities, it is much more fluid; it is much more respectful; it is much more open to intersectionality. It opens up intersections of identity and social locations of individuals in society, so it's not one-dimensional. We're not talking just about persons with disabilities when we, I think, open that language. I think it affords to kind of really interrogate and to bring into that discourse, issues about race and issues about other forms of difference. Issues about strengths, rather than just deficits. It really moves the issue I think, in terms of, of deploying this essentialized image of the sick, suffering child.

Living in Africa, are persons yes, with disabilities, not just sick folks, and as we know, they're carrying out many of the everyday chores with dignity, like most human beings. I believe this is the image as in your last question, when you take up the issue around the international image, the struggle for people with disabilities, to, to push this language forward. I believe that one of the things in this work that you've done, to take on telethons, is to push the question further to broader kinds of media images and really to part of the struggle I would see in places like Africa is just even to open up that language about persons with disabilities, instead of this image about sickness and destitution.

This is the image—this is the discourse I think that I would like to see a struggle to bring about by the media. Thank you.

[Applause]

>>Thank you. That was eloquent . . . again . . . raises really important issues.

Well the . . . part of the difficulty for people with disabilities is in getting enough of a platform to recast the language, recast the image-making; to get a disability rights message out to the public. I was speaking earlier in response to the previous comments about how we’re challenging some deeply embedded perceptions and ideologies and that makes it extremely hard to, to propagate an alternative perspective. I think it’s also . . . I’m sorry to say . . . due to the connection, some of your comments, some were fading in, fading out for me, please correct me if I misunderstood things or missed things that you would like me to respond to. The—one of the things that strikes me about the—as a parallel in the images you were referring to and there’s a charitable fundraising for children in Africa and charitable fundraising regarding people with disabilities, is that at a deep level, all oppressive ideologies end up—it seems like—reiterating the same kinds of themes of infantilization, among other things, of pathologies located in individuals and all ideologies that are oppressive have as their ultimate goal, to reinforce existing structures of power and distribution of material resources. And I think that’s one point of connection here.

It’s also the case by the way, I don’t know if you’re all aware of it, but telethons have been internationalized now. As the telethons have declined in the U.S., they’ve also begun to get bigger audiences in Europe and Latin America. That the MDA telethon, for example, is streamed over the web to Latin America and there are telethons now on the, this same model
broadcast, regarding diseases and disabilities in European countries. This occurs at the same time that Disability Rights Movement has become increasingly internationalized.

Let me mention one other point: And that is that Disability Rights Movement has to an egregious extent, not adequately addressed issues of race and class. That’s a serious neglect and it’s been a serious neglect also in Disability Studies. And it needs to be rectified. There needs to be a lot more research and a lot more analysis and a lot more incorporation of issues specific to people of colour and people of various classes in the work of the Disability Rights Movement. One of the other chapters that I’m going to include in this book is how the telethons did and did not address issues of race, ethnicity and class, as a way, as part of the way in which they framed the meaning of disability and reinforced structural arrangement.

I don’t know if I really responded adequately to your, your powerful comment. If there’s more you would like me to speak to, I would be very glad to do that.

>>I think you have responded well, thank you.

>>Alright, thank you Akua and thank you, Paul. Now I know—

>>Yeah, yeah Catherine was a little worried when you started out when you said that each of the panelists was going to take a thread and pull on it. I’m really glad my clothes are still intact.

[Laughter]

>>Yes, right well that’s important when you’re being broadcast around the world, isn’t it? Um Paul, I know we started late and I don’t want to wear you out, but on the other hand, we have a group of very enthusiastic folks here who I think would like to engage in a little bit of an exchange with you. Can we go for another fifteen minutes? Is there anyone—

>>—fifteen, fifteen minutes would be fine. Are you going to take me out to dinner?

[Laughter]

>>That’s right and we’re going to present you with a small gift. It’s in the shape of a maple leaf—[laughter]—are you a smoker by any chance, Paul?

[Laughter]

>>Am I a smoker? No.

>>—Okay, alright.

>>—It’s definitely looks like an electric hookah though, doesn’t it?

>> Okay, the floor is now open. Is there anyone in the audience who has a comment, a thread they would like to pull on? Laura Arndt. Oh we might hand you a microphone, Laura; hold on.

>>Test, test, test.
I like the choice of words on “pulling a thread”. One of—

—I’m sorry, I’m having trouble hearing you.

Sorry. I like the reference to “pulling a thread” on your earlier talk. One of the questions I have is, as I heard you speak, and the flow of corporations and the flow of its relationship with charities and that link to policy, a couple of things came to mind. And I guess once we start taking away the façade of corporations and their involvement with charity, I guess the struggle becomes what we’re left with. Corporations, while they are not giving their own money, in their own name, are giving funds that are often donated by citizens and if you open up the sore that is the corporation’s role, will citizens, in reaction, stop giving, therefore affect valuable causes that may support disability work and activism as they move forward?

And one of the other things I wanted to talk about is that will corporations, as we’ve seen in many of the great movies that have come out in the last couple of years, be that The Corporation or some of Michael Moore’s work, we see that corporations have a tendency to become very protective of their territory. And the concern then becomes the demonization of disability. If disability groups challenge their roles, what roles will corporations play in making it difficult to advance disability issues, and I say it more from the more deeper issues on larger debates on genetic testing, the issues of euthanasia, the issues of stem cell testing, that are highly supported right now by many corporations. And again, the other question is where this links back to social policy is that, as we know, there is less positive light on a lot of social policy work that’s being done and the demonization of disabled people and people who are disadvantaged, be they of colour, be they of poverty and I guess the question becomes because we politicians becoming more influenced by corporations, when you start taking away the façades of charity and telethons and those kinds of things, will there be more negative impacts for social policy development, than there will be positive impacts on trying to advance the issues of disability and disability rights movements?

God, you guys ask tough questions.

And I wish I had better answers. I’ve got two responses. What if—the fact is, we’re challenging corporations, as we’re challenging every institution in our societies. Quite apart from the issue of charity and telethons, we’re challenging corporations about employment issues and employment discrimination. We’re calling for protection from employment discrimination; we’re talking—we’re calling for recruitment and advancement; development of employees with disabilities at all levels. Those are serious challenges. And . . . some . . . a lot of companies have resisted and will continue to resist. And I think it’s probably inevitable that we have to simultaneously call into question what a lot of charity fundraising does, the impact it has in terms of understandings on the part of businesses, and say particularly, personnel managers, regarding the capabilities of people with disabilities to do productive work.

But then there’s another question that’s a part of—another issue that’s a part of your question—and that is, I think it has to do with how do disability-related agencies and organizations get the funding they need? What will happen if this source of money, as you point out, is cut off, whether it’s the corporations withdrawing or individual private donors giving? What happens
then? Let me tell you two stories and this is my response: I don’t have a good answer. But let me tell you two stories that make me... that give me pause and make me stop and think twice.

Not to back off but to at least to want to think about what we’re doing and what I’m doing in writing this book. Years ago, I... I should tell you guys, I’ve been working on this book for god only knows how long.

I started working on it 1988 doing research and... a few years into the research, I gave a talk at a national convention of people who work in disabled student services programs and probably talked I about telethons. And I was very critical and at that point, I had not been able to calm down enough from my outrage at what I was seeing on these shows I was studying. After my talk at this convention, a middle-aged woman came up to me and she said to me, almost on the verge of tears, We’ve got to make these telethons work—and by work, I took it to mean not stereotyping, demeaning people with disabilities. We have to make these telethons work, she said. And I said, “You have a son—you have a child with muscular—don’t you?” And she said, “Yeah, my son.” And I said, “Look, I want you to know I’m not criticizing you for being a volunteer or working with MDA. You’re doing what you have to do for the well-being of your child.” And that encounter with her reminded me of something that had happened a couple of years earlier. This was not too long after I started doing this research and I was hearing more outrage then than I still felt later. One day, I was riding in the car with my mother and I went off on a tirade about telethons. And she turned on me and she erupted. With tears in her eyes, angry, hot tears. And she really chewed me out. And it was then that I found out for the first time that when I was a kid, after I had contracted Polio and was still in the rehabilitation hospital, my mother had gone door-to-door soliciting funds for the March of Dimes. That’s what she felt she had to do to get me the kind of help I needed. But it was still, thirty years later. a demeaning memory. It was an act of humiliation that she engaged in because she wanted to take care of her son.

So when I think about those two women, the woman I met at the convention and my own mother, I think I’m not in a position as a disability rights activist to condemn them. And then I think about all the people with disabilities who at this point in history, have no other means to get the kinds of services and assistance they need. Some of them, medical services they need in order to live. And yet I know, that we’ve got to try and transform the social and health care systems in our countries so that there will come a day when people don’t have to demean themselves by essentially begging alms, whether it’s on a telethon or at somebody’s doorstep. So I find myself in a quandary. I guess that’s the best response I can give.


Paul, I guess this is—

—Wait for the mic

—You’ve already been skirting around this issue in your, in your last—

—Keep the mic up close.
In your last response to Laura, you’ve already been skirting around this, and I guess it’s building on your quandary. I grew up in—

—Put the mic closer to your mouth, please.

I grew up in the same place as Sandra and was often an object of charity—

—Yeah

As a poster child and I struggle everyday now, as an adult in my day job, as someone who helps people to access funding for assistive devices, primarily. And I guess it’s just a matter of this tension and how to reconcile the need for assisted devices, that give us our freedom and independence and help us to access the world and well . . . it’s what you’ve just been talking about. In the people that I assist or help to access funding, that is to say I don’t fundraise but I help people to access funding. There are people who are veterans, people who require assistive devices as a result of workplace accidents. And then there are people who have, who require assisted devices as a result of no one’s fault and there’s a real difference, what’s been called the worthy and unworthy disabled.

And then there’s the issue of, it’s been said that disabled people are like cats: we’re cute when we’re kittens, you know it’s, you’re good ‘till you’re eighteen and then you drop off the edge of the earth. So I guess it’s just a matter of the tension, reconciling this and I guess the other part of that issue is it’s because assisted devices like prostheses and wheelchairs and braces are a commercial item that, a commercial product, that they’ve gotten better and better. It’s just another thing that’s part of that because people make money off of them, they’ve advanced. So I don’t know what the answer is. I’m just wondering what your response is to that. Sorry to be so muddled.

—Yeah, oh god. I’m dealing with that kind of thing right now. I’m, I’m finding a device to hold the flat screen of my computer and a keyboard so I can work in a different position and the device to hold it is going to cost as much as the computer. It’s designed just for people with disabilities.

One of the reasons that people with disabilities are so disadvantaged economically and socially and so marginalized is because of the enormous costliness of living with disabilities, for people with many kinds of conditions.

In the U.S. what it means is that a substantial percent of adults have to live on some kind of government assistance, because they can’t afford to pay for the things they need. And so they get exploited and they kept—they are kept marginalized in that economy of disablement. So I don’t know what the answers are, except to try to get those devices and services for people as best as possible in the present system and meanwhile, try to transform it.

I think one of the things we’ve begun to have some effectiveness with is getting people in general to begin to recognize that access features and at least certain kind of accommodations make sense and are matters of equity. Couple of years back, ADAPT was challenging Greyhound Bus Lines, about their failure to put wheelchair lifts on buses. And I read the diary of one ADAPTER who travelled on a Greyhound bus line in Maryland and she said she was talking to a guy on the bus who was quite supportive of the protest demonstration. And basically, some
of his reaction . . . he said, “Damn, it’s just not right that they don’t provide wheelchair access to these buses.” And when I read that, I thought, That’s the impact of the Disability Rights Movement. If you had to talked to this guy or anybody else twenty years ago, twenty-five, thirty years ago, the assumption would have been that a person in a wheelchair—riding a wheelchair—of course can’t get into a lot of places, including bus lines that are available to everybody else. But now, we’ve gotten at least some people, and I think it’s a majority percentage of people that think that people with disabilities ought to have, have a right to have these kinds of access features. And maybe we can do that, regarding the devices that you’re working on so that people can live their lives and live more meaningfully and satisfyingly and make their contribution to their communities.

>>Great. Okay, there was one more hand and then we’ll take one last one and that’ll be it. Katherine Woodcock.

>>Hi. I just wondered, you, you portrayed the whole telethon scheme in an interesting way and also Sandra brought up the point about the people with disabilities being co-opted by that whole telethon mechanism to give the message. I was kind of interested in what you thought about the entrepreneurial people with disabilities, like in my community, the deaf community, the finger-spelling, alphabet card peddlers, who decide to create their own personal little telethon and the impact that I see personally is people with acquired hearing loss, deafened people, often find themselves traumatized because the only encounter they’ve ever had up until that—the point that they become deaf themselves is the finger-spelling card guy and Oh my god, I’m not going to be that guy. And I just wondered—I mean, I understand about the economics, although I’m not so sure that the social programs are so bad that you actually have to stand on a street corner and, you know, do that. But the impact on other people with acquired disabilities, I wonder if you had any thoughts about that.

>>Well yeah, one of the problems with the those kinds of public images on the telethons or people soliciting like that on the street is, those are the, perceived as the representative or typical of person with a disability so that someone who acquires a disability then assumes that this is what life is going to be like. I think the, the horror of acquiring a disability is that you know already. That whatever the disability is, you know already what it will be like because you have already been socialized into those prejudicial attitudes; you already have those images in your head.

The corresponding impact of the telethon images has been that kids with disabilities are taught what it will be like for them later on. I came across a number of interviews with poster children from the MDA telethon who thought that they would not live to adulthood because the only things they knew about kids with intermuscular disabilities was from the MDA telethon and what they were told was that those kids died.

Well, in fact what happened was on the MDA telethon, they selected to highlight boys with (inaudible) Muscular Dystrophy which at the time was presented as eventually terminal before the boy reached adulthood. And they also highlight adults, usually adult men with ALS. So that was again conveying a public image that then shapes the expectations and the assumptions and the nightmares, indeed, of all kinds of people, whether they acquired disabilities early in life
or later on. So these, these telethon images have a tremendous kind of impact. And it's very revealing of what sorts of public images, in all sorts of situations, like people with the alphabet cards, what that does to reinforce common stereotypes and the impact that has on so many other people with disabilities. Which makes it all the more imperative for us to try to get a disability rights message into the public media, into education; into people’s minds as an alternative perspective. And I think that is slowly making inroads.

>>Great. Paul, this is the last question, I promise. Esther Ignani, I saw your hand up, do you want to identify yourself—

Was it not up, really? Am I not—you—it was up. Yeah, it was up. Okay, out your hand up so the mic man can find you. There we go. Esther Ignani.

>>Hi. I think you probably responded to this question implicitly throughout your talk but I wondered if you (mic reverb) could um (mic reverb) what am I doing? I wondered if you could talk a little more about why you think telethons—disability telethons—are in decline right now?

>>Are in the what?

>>In decline?

>>Oh, in decline. Oh yeah. It has to do with the economics of broadcasting. In the late... in the late 1980s, it had become much less financially practical for the charities to put on these telethons. For one thing, the Reagan administration deregulated broadcasting. Prior to that time, broadcasters had, had an obligation to do community service programming. The Reagan administration eliminated that. In addition, it came to be the case that all time slots for television broadcasters or local broadcasters became profitable. So they wanted to sell time, rather than give it away, so they started to charge the charities. Sometimes they gave them a discount but still, the costs were substantial. Some of them didn't want—some local broadcasters didn't want to sell time at reduced rates or even regular rates to the charities for their telethons because they thought they would get a bigger audience and do better with commercial programming.

In addition to that, the size of the audiences began to diminish because, in the early days, in the 60s and 70s, the telethons were unusual shows. The range of programming available to the viewers was much narrower. But by the 80s and 90s there was not only a great proliferation of broadcast channels but cable programming. So that people had other alternatives, other things to watch. In addition to that, disability-related telethons had pretty much had the telethon business to themselves; but by the 80s and 90s, there were a good number of other telethons for other causes that were, again, diminishing the appeal, the audience appeal, of telethons. So by the early 90s, some of the telethons were fighting themselves having to switch from the network-affiliated stations in their local broadcast areas to independent stations that got smaller audiences. They switched from VHF to UHF or even cable and that further reduced their audiences. Reduction in their audiences reduced the, the draw in terms of donations.

And finally, by the end of the 1990s, the Arthritis Foundation, the ECP and the Easter Seals, were finding that it wasn’t worth the effort. Their corporate sponsors were tending to pull back and in addition to that, the telethons were all getting criticism from inside and outside from
disability activists. There’re some activists within those charities, particularly ECP and Easter Seals, who were very critical of, of the telethons. So for all those reasons, the telethons went into decline. The only reason the MDA telethon is still around is because Jerry Lewis is still around and the corporate sponsors find some public relations benefit from him. I think once he’s gone, that one will disappear as well.

>Okay. Paul, this has been a wonderful evening and it is indeed a measure of your qualities as a teacher, that you have kept a lecture hall full until 10pm on a Friday night, in downtown Toronto. That’s quite an accomplishment. In, in closing I want to say a few words of thanks just to all of the people who made this evening possible. Thanks, of course, to our sponsors at the Harry E. Foster Foundation. Thanks to our captioner, Joanne Anderson; to our ASL interpreters, Gus Mancini and Carrie Granfield. And finally, thanks to the video conferencing and web streaming wizards, Doug Smith and his crew at San Francisco State University and; Laurie Harrison and her crew at Ryerson. Too many, too many folks to mention but many of you, and you know who you are, have done a tremendous job this evening.

To our respondent panelists, Jiji Veronka, Sandra Carpenter, and Akua Benjamin: many, many thanks for your most thoughtful contributions. And finally, last but not least, to Paul Longmore. Paul, you have, as Melanie says, you have honoured us with your presence and you’ve challenged us on many, many levels, with the depth and breadth of your thinking in this area. You are indeed a scandalous scholar and we love you for it.

[Applause]

>>May I just say to you all that I think some of the best work being done in disability studies is being done by Canadian scholars. So I’m a great admirer of all the work you’re doing. And I am constantly encouraged, heartened, by disability rights activists in Canada for the advocacy work you’re doing. I want you to know that you guys are my heroes and I’m really honoured to get to hang out with you for an evening.

>>Wow! Likewise. Okay, thanks Paul.

[Applause]

Over and out. Well that was great. Thank you, Jiji