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From Poster Child to Protester

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Former "Poster Child", Laura Hershey, criticizes and protests fundraising telethons such as Jerry Lewis' Muscular Dystrophy event, claiming they use pity and bigotry and insult people with disabilities. Internet publication URL: www.independentliving.org/docs4/hershey93.html

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Orange, pink, and lavender flyers fluttered in the breeze as we handed them to any passer-by willing to take one. "Tune Out Jerry!" the flyers urged. "Boycott the Telethon!" Some two dozen of us lined up in front of the hotel shouting chants, distributing leaflets, and answering questions from the media, while the local segment of the Jerry Lewis Labor Day Telethon broadcast from a ballroom two floors above. Though I would stay outside all afternoon, I remembered all too well the scene that was taking place inside.

The singers croon. The eyelids droop. The money pours in. The firefighters, the Boy Scouts, the business

executives, the neighborhood kids, all tiredly smiling proud smiles, carry in their collected funds, in jars, in boots, in oversized checks. The camera rolls. The host smiles. The money pours in. The Poster Child gives awkward answers to inane questions. The host smiles. The Poster Child smiles. The host cries. The money pours in.

You have to keep thinking about the money, because as everyone freely admits, that's what this is all about. The money raised represents hope -- year after year, promises of a miracle, the great cure that waits just around the corner. The money manifests faith -- faith in the noble research scientists working desperately to identify, and eliminate, flawed genes. The money testifies to human love and compassion, ruthlessly sentimentalized in songs like "They'll Never Walk Alone" which punctuate the twenty or so hours of the telethon.

The money is what justifies, even sanctifies, this annual ritual of tears and guilt. In 1999 the telethon raised over \$53 million. That massive amount of money that people -- young and old, rich and poor -- feel compelled to donate, giving "till it hurts," as Jerry Lewis insists -- that money makes it very hard to challenge what is actually going on.

But there we were, back in September 1991, on Denver's busy 16th Street Mall, challenging the Jerry Lewis Labor Day Muscular Dystrophy Telethon. Along with activists in cities around the country, including Chicago, Los Angeles, and Las Vegas, we were protesting the telethon's portrayal of people with disabilities as helpless and pathetic. We were asserting publicly that this colossal begging festival, supposedly carried out on our behalf, is offensive to us and damaging to our efforts to become first-class citizens. Our protests were small, but they would become an annual tradition -- much to the annoyance of Jerry Lewis and MDA.

For years we had been protesting against the barriers which keep people with disabilities from using buses, public buildings, and other facilities. Now we were taking on one of the biggest barriers of all: the paternalistic attitudes which prevail in our society, and which are reflected so dramatically in the annual telethon.

It is difficult to raise objections to something like the telethon; people are reluctant to disparage, or even entertain questions about, an effort which they perceive as fundamentally good, or at least well-meaning. That is understandable. It is an uncomfortable truth, in social work, in government activity, and in charitable endeavors, that actions which are intended to help a certain group of people may actually harm them. By harm, I mean -- among other things -- that these actions may reinforce the already devalued status of people with disabilities in this society. Looking closely and critically at the telethon, as some of us have started to do, brings up a number of issues which I feel are essential to understanding the status of people with disabilities as an oppressed minority group in America. These issues include: charity versus civil rights; cure versus accommodation; self-expression and self-determination; and the relationship between pity and bigotry.

The telethon has one goal -- to raise as much money as possible for the Muscular Dystrophy Association, or MDA. Conventional wisdom says that the most effective way to do this is to appeal directly to the emotions of viewers -- to move people so strongly, with stories of tragic suffering, that they will want to help "save Jerry's kids." Money is tight these days; charitable solicitation is a competitive business. Invoking sympathy sufficient to pry open wallets is not an easy task. But those orchestrating the telethon have a foolproof, not-so-secret weapon: children. Never mind that two-thirds of MDA's 1 million clients are adults -- the telethon is not in the business of trying to represent the real lives of people with muscular dystrophy. That's not the point. The point is to paint a picture of a victim so tragic, and at the same time so cute and appealing, that viewers will be compelled to call in a pledge. This victim must also appear helpless, utterly unable to help

him/herself, so that the giver can gain a personal sense of virtue and superiority from the act of giving. Finally, the victim must display something called "courage," which does not resemble the bold, active kind of courage most people aspire to or at least fantasize about, in which one takes one's destiny into one's own hands and, by exercising will and choice, affirms oneself and/or one's place in the universe. No, the "courage" demanded in this instance is the willingness to deprecate oneself; to accept other people's versions of one's own reality; to reject one's own identity in favor of an eagerly anticipated cure (this is also called "hope"); to tolerate and even encourage the assumption that life with a disability is a life scarcely worth carrying on with, except for the generosity of Jerry Lewis and everyone involved in the telethon.

At the age of eleven, I was enlisted into this role of cheerful victim. I was a Poster Child. In 1973-74, I became a mini-celebrity, appearing at fundraisers throughout Colorado. I learned to smile whenever a camera appeared, and to say "thank you" -- in other words, I learned to look, sound, and act cute and grateful. And on Labor Day, I became a prop in the TV studio where the local portion of the telethon was broadcast. To whole families, driving by to drop their contributions in a giant fishbowl outside the studio; to the camera's blinking red light; to the anchorman who squatted next to me, holding a huge microphone in my face; to everyone, I gave the same cute-and-grateful act, because that's what they wanted.

So I am no stranger to the telethon. And in the two decades since then, the telethon doesn't seem to have changed much. I watch it every year, just to make sure. It's still chillingly familiar. The sappy music, the camera close-ups of wistful faces, the voice-overs telling us about that person's dream to walk someday, the tearful stories told by parents "devastated" by their children's disability, and the contributors coming forward in droves -- it was all just the same as I remember it.

But some things have changed; I have changed. I don't know what my politics were as an eleven-year-old, if I had any. But my politics now -- which are not merely political but also personal, spiritual, and practical -- have led me to question and ultimately reject most of the values which the telethon represents.

Let's start with the money. Does it help? Doesn't it make the stereotypes, the appeals to pity, the obnoxious on-air begging worth putting up with?

Yes, the money does help -- some people, with some things. We are talking about a lot of money here. MDA Executive Director Robert Ross asserts that during its 26-year history, the telethon has raised over \$600 million. In 1999, the telethon raised over \$53 million.

With all this money coming in, I would expect the direct services provided to people with neuromuscular diseases to be much more extensive, and more relevant, than they actually are. I would expect, for example, that when a person develops a condition which begins to limit his or her mobility, that MDA might come through with some money for access modifications to the home, so that the family wouldn't have to choose between moving to an accessible house (which are hard to find), or hauling the person up and down stairs all day. I would expect some support services for independent living -- someone to assist with personal and household needs, training in things like cooking and cleaning from a wheelchair, and help with transportation. I would expect MDA to provide a motorized wheelchair for anyone who wants one. Such a chair can boost a disabled person's quality of life enormously. Instead, MDA has very restrictive criteria for determining who receives a motorized wheelchair.

Far be it from me to advise a multimillion-dollar agency on how to spend its money. But when the telethon tells viewers that by donating money to MDA, they are answering the prayers of people with MD -- offering them a friend to turn to in times of need -- it exaggerates.

Okay, say the defenders of the telethon, so maybe the money doesn't help people now as much as it should. Isn't it still laudable that the telethon raises so much money to help find a cure?

Ah, the cure. That's the promise that keeps people sending in those checks. That's what keeps this humiliation going year after year. We're getting closer all the time! Jerry Lewis assures us frenetically. He's been saying it for four decades.

Shortly after my stint as Poster Child was over, I remember meeting a stranger in a store who recognized me from the telethon. He said to me, "I bet you really hope they find a cure soon!" When he said this, I realized that by this time, I almost never even contemplated that possibility anymore, let alone hoped for it. I told him that. I don't think he believed me. I find the same reaction now, when I criticize the telethon for implying that people with disabilities sit around hoping and praying for a cure. I've encountered people who, never having tried it, think that living life with a disability is an endless hardship. For many of us, it's actually quite interesting, though not without its problems. And the majority of those problems result from the barriers, both physical and attitudinal, which surround us, or from the lack of decent support services. These are things that can be changed, but only if we as a society recognize them for what they are. We'll never recognize them if we stay so focused on curing individuals of disability, rather than making changes to accommodate disability into our culture.

Now, I'm not arguing that medical research should halt entirely -- I'm just weighing the cost-benefit value, in my life and in the lives of my friends with disabilities, of the millions of dollars spent on the search for a cure, a search that will take decades, versus the things we really need now, on which society spends far less. We will probably never benefit from the cure. We will benefit from accessible buildings and transportation systems, job opportunities, and attendant services to provide us personal assistance. So will future generations.

We have begun making progress in those areas. In 1990, for example, the Americans with Disabilities Act became law, putting some legal teeth into our fight for civil rights and access.

But for all our progress in the areas of legal protection and accessibility, there's still this lingering attitude that what people with disabilities really need is to be cured. Society wants the problem to go away, so it won't have to accommodate people with long-term disabling conditions. It wants us to go away, or at least to "get better." One of my major objections to the telethon is the way it reinforces that attitude.

Sure, some people with muscular dystrophy do hope and dream of that day when the cure is finally found. As people with disabilities, we're conditioned just like everyone else to believe that disability is our problem. We've been told over and over that our need for accessibility to buses and buildings, and our need for health services, are too expensive, too unreasonable. Our culture considers it shameful to be physically unable to dress oneself, or to need assistance in going to the bathroom. Rather than demanding that the government provide such helping services, many people with disabilities end up hidden in nursing homes or in our own homes, where personal assistance remains the private "burden" of individuals and families. Rather than insisting on having our personal needs and our access needs met, many prefer to keep quiet about these needs, fearful to show ourselves lacking. The telethon itself encourages such self-defeating thinking. We are primed to regard ourselves as substandard. We therefore hesitate to assert our right to have that which, because of our disabilities, we need. The telethon teaches us to think that others will provide for us because they are kind and generous, not because we are a strong and vocal community. When so many of us feel so negative about our disabilities and our needs, it's difficult to develop a political agenda to get our basic needs met. The cure is a simple, magical, non-political solution to all the problems in a disabled person's life. That's

why it's so appealing, and so disempowering. The other solutions we have to work for, even fight for; we only have to dream about the cure.

The idea of a cure is at least in part an effort to homogenize, to make everyone the same. To draw a parallel, when I was a child and first learned about racial discrimination, I thought it would be great if people could all be one color so we wouldn't have problems like prejudice. What color did I envision for this one-color world? White, of course, because I'm white. I didn't bear black people any malice. I just thought they'd be happier, would suffer less, if they were more like me.

We all have our own ideas about which human condition is best, based on our own assumptions about other people's lives. These assumptions don't always jibe with reality. People who assume that I live for the day when a cure is found, when I (or future generations) can live disability-free, simply don't understand my reality. It's a question of priorities. On the list of things I want, a cure for my disability is pretty low. Higher up on the list would be achievement of my personal, professional, and social goals, and these are not in any way dependent on a cure.

Besides, there's an issue of pride involved. Disability is a part of my whole identity, one I'm not eager to change. Especially not at the cost of my dignity and personhood, as the telethon implicitly demands.

This gets to another important issue the telethon raises in relation to the oppression of people with disabilities: Whose job is it to tell the story, or stories, of a group of people? The telethon is full of "profiles" of people with various forms of muscular dystrophy and their families. Yet these stories are packaged as products, not told as truth. Favorite subjects are children, for reasons discussed earlier -- children can be made to appear more helpless, more pathetic, more dependent on the public's generosity. Children are also cute; therefore they seem more deserving of help.

In comparison with my telethon years, recent telethons do profile more adults with muscular dystrophy. Some are successful, competent adults. Yet somehow, even these individuals were made to look desperate and pitiable.

On any given telethon -- both on the national broadcast from Las Vegas, and during the cut-aways to local segments -- you will see profiles of children and adults with muscular dystrophy. These spots are all fairly similar in tone and emphasis. As if by a prescribed formula, each one contains several key ingredients. In each, the parents speak about their reactions upon hearing their child's diagnosis -- even if, as in most cases, this has occurred years, or even decades, before. Naturally, these reactions include disbelief and grief. Yet there is rarely any discussion of how (or whether) the family has since come to accept the knowledge of their child's condition, to find resources (other than those offered by MDA), to plan for the child's future, or to promote the child's self-esteem. The situation is presented as an unmitigated tragedy.

I'm suspicious of this presentation. I'm not trying to minimize the pain a parent might feel upon learning that a child has a disabling, potentially even fatal, diagnosis. There is a very natural grieving process that goes along with disability at any stage. But when I see those emotions exploited so crassly, I can't help wincing. For most of us, our losses, gains, sorrows and joys are simply part of a rich human life. The telethon works very hard to convince people that our suffering is extraordinary. This produces pity, confusion and misunderstanding.

Another common element in these pieces is the emphasis on "what Johnny can't do." A child, usually a boy, is shown sitting at the edge of a playground. The narrator talks about the games the child can't play, and how he

has to watch other children running and jumping. He can only dream, the narrator tells us sadly.

Never mind that the kid might be adept at playing Nintendo, or making rude noises with his mouth. In the real world of children, these skills are valued at least as much as running and jumping. The truth is, all children play at different levels of skill; most can't run as fast as they would like, or jump as high, or play as well. Children in wheelchairs do play with other kids on the playground -- I did. A child in a motorized wheelchair can be mobile, active -- and popular, if willing to give rides now and then. But instead of acknowledging any of this, the telethon encourages viewers to project their own worst fears onto people with muscular dystrophy: "Just imagine what it would be like if your child couldn't play baseball."

Finally, each piece puts forward an archaic and gloomy picture of the disabled family member's role, and of the role of the family in a disabled person's life. All the families are described as "courageous"; and they all seem to bear total responsibility for the care and support of the person with MD. Spouses and parents alike are shown carrying the person with MD up and down stairs, pushing their wheelchair, and so on. Rarely if ever is the disabled family member shown making any positive contribution. In these stories, the disabled person's status is clearly (even if the word was never used) that of "burden."

I am all for supportive families. My own parents and brother have stood by me throughout my life, backing me with assistance and encouragement. But I have also built a life apart from them. Many people with disabilities do so, getting educated, working, and having families of our own. I am able to live independently, working toward the goals I choose, as long as I have access to the support services I need -- primarily attendant services. I am lucky that the state of Colorado pays someone to come to my home and help me get up in the morning and get to bed at night. Most states do not offer this service, forcing people with disabilities to remain in the care of their families, or to enter nursing homes. Indeed, attendant services is the number one disability rights issue of the 1990's. Activists are demanding that the federal government divert a part of the huge budget which currently subsidizes the nursing home industry, and create a national system of attendant services, available to anyone who needs them.

On the telethon, of course, this is a non-issue. Disability is a private problem, demanding faith and fortitude from families, demanding generosity from viewers, demanding nothing from the government, or from society as a whole. If the need for personal assistance is mentioned at all, it is only to highlight, once again, the purported helplessness of people with MD, as in phrases such as "totally dependent on others for the most basic activities the rest of us take for granted." In fact, the opposite is true: With decent attendant services at my disposal, I become more independent, not more dependent. But to present that truth might undermine that vision of the long-suffering, burden-bearing family.

The unvarying tone and content of the pieces made it difficult to distinguish one "patient" from another. The profiles put forward a stereotyped view of what it means to have a disability, rather than any genuine stories of real people. We are all individuals, and families are all different. Not on the telethon, though. There we are made to fit the mold. Even the language used on the telethon distorts our reality and thereby dehumanizes us: We are "victims," we "suffer" from our conditions, we are "desperate."

I have firsthand experience of this distortion effect. Six or seven years after my Poster Childhood was over, just before my second year of college, I was asked to be interviewed for a local pre-telethon TV special. At first I said no. I was by now quite leery of the telethon mentality. I had also started becoming politicized, and was now more interested in civil rights than in charity. And I couldn't see any reason to participate once again in the simple-minded propaganda I remembered from my on-camera appearances as Poster Child. Back then, I had been asked questions like, "What would you like to say to all those nice people who are calling in their

pledges, Laura?" to which the obvious reply was, "Thank you." Such questions left little room for honest expression.

But the local MDA office promised that the interview would be handled differently in this program: The plan was to take a positive, realistic approach and portray the real lives of three real people. So I agreed.

A TV news reporter conducted the interview in my parents' home. She asked good questions and allowed me to give complete, intelligent answers. It was certainly a different process from my earlier experiences. Afterward, I felt good about the upcoming show. I had been able to discuss issues, describe my life as a college student, and project a strong, positive personality.

Or so I thought. When the program aired, I was horrified. Through careful editing, it had turned into a sob story entitled "Waiting For A Miracle." From that point on, I vowed to have nothing to do with the telethon.

Until 1991, that is. I learned that two Chicago activists, Chris Matthews and Mike Ervin, were interested in coordinating actions against the Jerry Lewis telethon. Like me, they were both former poster children. I urged people from Denver's community to join the campaign. My decision to organize a protest did not come without some thought. In fact, I had for years contemplated doing something like this, but had not. I knew that our message would not be an easy one to convey to the public. Many people are involved with the telethon, either as volunteers or as contributors. I knew that openly criticizing it would cause confusion and anger. The telethon enjoys widespread acceptance, even acclaim.

But that is exactly why it's so important, I feel, to raise our voices against it. Because it is accepted as our reality. This is my biggest gripe against Jerry Lewis, and against the telethon: the extent to which they claim to tell my story, our stories, without any legitimate authority to do so.

The telethon's hegemony over the image of disability is quite staggering. A 1996 press release issued by MDA states, "According to A.C. Nielsen, last year's Telethon was watched by some 70 million Americans or 27 million households. The MDA Telethon -- considered the granddaddy of all Telethons -- ranks in viewership with the World Series and the Academy Awards. " Those 70 million people are absorbing a message shaped by greed, deception, and bigotry.

The bigotry of Jerry Lewis is worth discussing. I don't necessarily enjoy attacking another person's motives, but I hear defenders saying, "Jerry Lewis is trying to help so many people. How dare you criticize his methods?" This means-justifies-the-ends argument has a long and despicable history, which I don't need to go into here. Even more dangerous is the attitude that people who are "being helped" have no right to say how they want to be helped, or treated, or thought of. This is paternalism at its worst. By being the object of charitable efforts, do we thereby waive our right to respect, and to free speech? If people are really interested in helping me, wouldn't they want to hear me tell my own story, rather than hearing a distorted version of it from someone who not only doesn't share my experience, but who doesn't even seem to want to listen to me? With the stated goal of "helping" his "kids," Jerry Lewis is helping to keep alive the most pernicious myths about people who have disabilities. He ignores our truth, substituting his own distorted assumptions.

If our protest did nothing else, it allowed some of us the opportunity to say, "No, this is not our reality. If you want to know what our lives are like, listen to us. If you want to know what we need, ask us. If you truly want to help us, let us tell you how. And if you pity and fear us, please own that; then let us work together at changing the world so that disability will not be something to fear, but something to try to understand."

The response to our protest has been interesting. Many people seem to resent our daring to object to these distortions, half-truths, and stereotypes. I have been called "ungrateful," "cruel," and "insensitive" -- simply for trying to counter all this with the truth, with my truth. At the very least, I feel that the protest has enabled me and others to begin getting on record our own stories, in contrast to the misleading accounts that come from the telethon.

Media is a powerful thing. It can deceive, or it can enlighten. About a week after that 1991 telethon, a publication arrived in my mailbox called MDA News Magazine, put out by the national Muscular Dystrophy Association office. I started to leaf through it, expecting to find the same kinds of negative stereotypes that permeate the hours of the telethon. Instead, I found articles about job-seeking strategies; profiles of successful individuals who have neuromuscular diseases; honest and thoughtful pieces about families of children with neuromuscular diseases; lists of useful resources; and clinical updates. All of it was written in a positive, realistic tone, using respectful and appropriate language. The phrase "people with disabilities" was used at all times -- never "victims," or "sufferers," and certainly not "cripples."

One article, written by Marie Hite, whose son has muscular dystrophy, stood out. Its basic theme was very similar to some of the telethon spots I had viewed: the difficulties a child has in coping with a progressively disabling condition. But Hite's treatment of the subject couldn't have been more different from that presented on the telethon. In her article, her son confided that he could no longer climb a neighbor's tree; he asked his mother for an explanation. She replied that his muscles didn't work the same as other children's.

Whereas the telethon would have used this situation to create pity, this article used it to tell a touching, upbeat story. In it, the focus was not so much on how the boy differs from other children, but on how the author helped her son understand his disability, and on his own resourcefulness in adapting to it. The grief was not denied, but neither was it overdone.

Tears instantly flowed down Petey's cheeks. 'But, Mom, I want to climb trees, too,' his voice pleaded.

Silence....

What to say?...

I let him know that it was OK to feel sad, and I stayed with him.

Five minutes later, he was OK again.

'Petey, I'm going to help you climb Mrs. Kurly's tree when I get home from work,' I said. His face lit up....

Her conclusion emphasized the boy's fundamental similarity to other children in struggling to understand and come to terms with himself and his world:

He had accepted his limitation as only a 6-year-old can, with childish grace and fantasy.

There are limits -- and tree trunks -- that love, with a little ingenuity, can rise above. Like other 6-year-olds, Petey just wanted to play in the tree.

In Hite's piece, Petey got what he wanted, with some assistance and adaptation; in fact, this describes fairly well how most people with severe disabilities live -- with assistance and adaptation. Petey was portrayed as a real child, full of humanity. What a different view from that to which telethon viewers are exposed annually!

I was impressed by the sophistication and sensitivity of the writing in this magazine -- but also a little baffled. How could the same organization that edits this publication, with its realism and insight, also produce the Jerry Lewis telethon? They know better! I thought.

Then I realized the reason for the apparent split personality within MDA. I was seeing two very different presentations, intended for two very different audiences. The magazine is aimed at people with neuromuscular diseases and their families. I commend MDA for offering their clients such a high-quality forum for education, information, and the sharing of experiences.

However, I am dismayed that when it comes to informing the general public, MDA chooses to take the opposite approach. Does the organization fear exposing potential donors to the truths revealed so eloquently in its magazine? Does it foresee a decline in contributions if nondisabled people start to see people with disabilities as we really are? Is respect and awareness bad for the bottom line? Is raising consciousness incompatible with raising money?

Images of people with disabilities sink into the public mind every Labor Day, images of helplessness and eternal childhood. We see children frolicking at summer camp, while an announcer tells us how miserable those children are the rest of the year. We hear tear-jerking stories from parents lamenting their child's condition. Pity is the name of the game in telethonland. Pity brings in big bucks.

So what's wrong with that?

Pity is a complex and deceptive emotion. It pretends to care, to have an interest in another human being. It seems to want to take away pain and suffering. But if you look at pity up close, you notice that it also wants to distance itself from its object. A woman calls in a pledge and boasts, "My two children are perfectly healthy, thank God!" Pity does not share another's reality, only remark upon it.

Pity can be very hostile to the achievement of equality and respect. If you feel sorry for someone, you might pledge a donation, but you are not likely to offer them a good job, or approve of them dating your sister or brother. If emotions were to be grouped into families, pity has some rather unsavory kin. On this emotional family tree, pity is very close to -- sometimes indistinguishable from -- contempt and fear, which are uncomfortably near to hatred.

That might sound like a strong statement. But I would argue that any reaction which creates separation and inequality between people -- which pity certainly does, however benevolent it might appear -- is destructive. People cannot live together in community, recognizing and respecting each other as human beings, if one group feels superior to the other for any reason.

Pity paves the way for paternalism, for the attempt to control people on the basis of disability. I have lived with the implications of this reaction, this assumption that I am less able to, have less of a right to, run my own life. I saw it in the eyes of the high school journalism teacher who didn't want me in her class. I see it on the faces of people who pass me on the street, and wonder (perhaps) what I am doing out in public.

Of course, many experiences and many emotions go into the formation of bigotry. I cannot blame all discrimination on pity. Nor can I blame all tendencies toward pity on the Jerry Lewis Telethon. But we need to analyze the way this annual event capitalizes on, and feeds, those tendencies. We need to ask ourselves whether all that money, tracked exuberantly on those giant tally boards, is worth it.

I say it's not.

The effects of our protests on the Jerry Lewis Labor Day Telethon have been mixed. It has become a TV show with a split personality.

Beginning with the 1992 telethon, we began to see some changes from previous years. We saw lawyers, accountants, teachers and journalists with muscular dystrophy, receiving recognition as winners of Personal Achievement Awards. We heard the words "dignity" and "self-respect" used over and over, sometimes in strange contexts -- as in "Please call in your pledge to help us save these kids' dignity and self-respect." We heard talk about the Americans with Disabilities Act and the need for a personal assistance program.

But we also saw the old familiar scenes: tuxedo-clad local hosts sweating and beaming, well-groomed two-parent families poised to look brave and desperate, Jerry Lewis mugging and weeping.

The Muscular Dystrophy Association has consistently, obstinately refused to acknowledge the validity of our concerns. Marshalling all its defenses, MDA feverishly protects the decades-old tradition. Those of us identified as the telethon's chief critics continue to be told how ungrateful, unreasonable, vicious, and emotionally disturbed we are.

Yet we'll continue to critique this twenty-plus-hour-long epic. It's a microcosm of so many of our society's attitudes towards disability. It's the details which, for me, sum up the telethon perfectly -- both its attempts to change and its intrinsic flaws.

A few examples:

The telethon has often featured a Florida woman named Shelley, an obviously intelligent person with a graduate degree and a professional career. In one typical segment, Shelley and her mother were both interviewed about their hope for a cure for muscular dystrophy. Her mother raised one hand a few inches and, near tears, said something like, "If only she could do this, that would be all I would ask for her." While other mothers wish for their grown children to have personal happiness, professional success, and a family, the telethon encourages the belief that the mother of a disabled adult can only hope for one thing -- either total or partial cure.

The mother also stated that she is afraid to leave Shelley at home alone, because she can't use the telephone, or answer the doorbell, by herself. I had to wonder why Shelley did not have access to the relatively simple and inexpensive devices now available, such as hands-free telephones, and doorbell intercoms.

This scene was typical of several telethon segments: In presenting an individual with a neuromuscular disorder, the focus would be on functions the person couldn't do. When I see a story like that, I start this mental process of problem-solving -- thinking about adaptive equipment, attendant services, access modifications, etc. -- things which could help the person function more independently.

But apparently, the general public takes these things at face value: If Shelley can't answer her own telephone, the only possible solution is to cure her disability.

The telethon certainly doesn't encourage viewers to think of other options. If the person can use equipment and personal assistance to live more independently, then viewers may not feel as sorry for her.

There was another vignette about a family with two sons, one of whom has MD. In focusing on the younger, non-disabled son, the narrator made a statement to the effect that he doesn't have a big brother who can take him places and teach him things -- he has a brother he has to take care of.

This statement implies that people with disabilities are incapable of giving to any kind of relationship, that we are undesirable even as siblings. (The telethon also promotes the idea that people with disabilities are miserable parents: Fathers and mothers are shown passively watching as their kids run and play, as if someone in a wheelchair could never provide children with affection, discipline, or moral or financial support. And forget any notion that people with MD can be sexual. The telethon presents even spouses as caretakers, not lovers. The denigration of our potential for relationships is perhaps one of the most dehumanizing and negative aspects of the telethon.

The next day, a different family appeared on the local segment of the telethon. Like the first family, there were two teenage boys, one, named Paul, with MD. The brothers were obviously very close. Again, the host made a major point of talking about how the non-disabled boy "takes care of" and assists his brother Paul. At this statement, the father leaned over to the microphone and said pointedly, "Paul helps him a lot too."

The host ignored this attempt to set the record straight, but I was very moved by it. I feel real compassion for people like that family, who participate in the telethon, yet try (usually in vain) to preserve their own dignity and truth.

MDA representatives have stated again and again that pity works, it makes people give money. They might be willing to change a few things, add some references to the ADA here and there, recognize some "achievers" with MD. But they are not about to tone down, in any significant way, their appeals to pity.

We can take credit, though MDA would never acknowledge it, for the changes that have occurred -- they are certainly a direct result of our criticism and protests. But we have to increase the pressure, keep raising awareness, and stop this annual insult once and for all.

Read more of Laura's writing at: [Laura Hershey's Weekly Web Column](#)

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