

A Test of Wills

Jerry Lewis, Jerry's Orphans and the Telethon

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"The very human desire for cures . . . can never justify a television show that reinforces a stigma against disabled people." It was 11 years ago when those lines appeared on the opinion page of the New York Times — September 3, 1981. Labor Day. On the tube, the annual Jerry Lewis Labor Day Telethon was in full swing. The article was by Evan J. Kemp, Jr., now chairman of the U.S. Equal Employment Opportunity Commission. At the time Kemp was Director of the Ralph Nader-inspired Disability Rights Center. "Aiding the Disabled: No Pity, Please," read its headline.

Evan J. Kemp, a man with one of the neuromuscular diseases the Muscular Dystrophy Association said it was fighting to cure, was criticizing its star-studded fundraiser. Kemp was also criticizing MDA's star and savior, comedian Jerry Lewis.

Society, Kemp charged, saw disabled people as "childlike, helpless, hopeless, nonfunctioning and noncontributing members of society." And, he charged, "the Jerry Lewis Muscular Dystrophy Association Telethon with its pity approach to fund raising, has contributed to these prejudices."

Kemp contended that such prejudices "create vast frustration and anger" among disabled Americans, then numbered at 36 million. Kemp charged that disabled people suffered far more

from lack of jobs, housing — lack of access to society — than from the diseases MDA sought to cure. He accused the Telethon's "pity approach . . . with its emphasis on 'poster children' and 'Jerry's Kids' " — of creating prejudice. He called upon the Telethon to reform; to portray disabled people "in the light of our very real accomplishments, capabilities and rights." The Telethon, he insisted, "must inform the public of the great waste of money and human life that comes from policies promoting dependence rather than independence."

Kemp took out ads in daily *Variety*, the entertainment newspaper. "Color Us Useful," they read. They called upon Lewis to reform his telethon.

The following year, Kemp was invited onto the MDA Telethon. His on-air pitch was mild: "Your pledge to this Telethon can help create meaningful, productive lives for many. It can also help save the lives of others. I urge you to phone in your pledge right now."

After that, Telethon criticism died down. Other telethons — the Easter Seals', United Cerebral Palsy's — changed somewhat, adding more disabled adults and offering more segments on things like "independent living" which those in the disability rights movement had urged.

MDA briefly hired a disabled man, Steve Lockman, in an effort to deflect criticism that they had no one on staff with the disease they were seeking to cure. But Lockman stayed on the job only a short time, quitting in disgust and accusing MDA of lacking any intention of reforming.

And Jerry Lewis kept on being Jerry.

Perhaps MDA had simply hired a new ghostwriter for the annual pap piece that ran each Labor Day weekend in *Parade* magazine under Lewis's byline. But the 1990 one, published in the September 2 issue of *Parade* magazine, took a new twist: "What if the twist of fate that we hear so much about really happened? What if, when the gifts and the pains were being handed out, I was in the wrong line?" Lewis began. "What if I had Muscular Dystrophy?" was its title.

"I decided after 41 years of battling this curse that attacks children of all ages, I would put myself in that chair, that steel imprisonment that long has been deemed the dystrophic child's plight," he continued.

"I know the courage it takes to get on the court with other

cripples and play wheelchair basketball, but I'm not as fortunate as they are," Lewis wrote, halfway into the piece. He had so far managed to include nearly every term or concept offensive to disability rights advocates, and his next sentences would work in the others: "I'd like to play basketball like normal, healthy, vital and energetic people. I really don't want the substitute. I just can't half-do anything. When I sit back and think a little more rationally," he continued, "I realize my life *is* half, so I must learn to do things halfway. I just have to learn to try to be good at being half a person."

The article outraged disability rights activists nationwide — in a way little else has. *The Rag* received countless copies of the article for our "We wish we wouldn't see . . ." pages. In Chicago, Cris Matthews and Mike Ervin, a brother and sister who both had forms of Muscular Dystrophy and had been MDA poster children in 1961 and who had been active in ADAPT actions and had started a group called AccessAbility Associates, decided to do something about it.

Two months before the 1991 Telethon, Matthews wrote to Robert Ross, Executive Director of the Association, a deceptively simple letter. "The wheels are in motion to begin the campaign to remove Jerry Lewis from your Telethon," she told him, by way of introduction. "We intend to keep at it until he is no longer associated with MDA, and the negative, degrading nature of the Telethon is changed to reflect the truth about life with muscular dystrophy and disability in general."

The Association, she charged, was "expert in exploiting the worst side of disability and, with the eager assistance of Lewis, has made us out to be nothing more than pathetic burdens to society, whose only desire is to walk. Much attention is given to the kids who may not live to adulthood, but for those of us who do live on, not one word or one dime is devoted to the concept of independence." Lewis's *Parade* article, "full of the condescending paternalism the Association foists on the viewing public, is an outrage and an insult," she told Ross.

"No one is negating research or the individual's desire to be cured," she wrote. What they objected to was the paternalism, "the attitude that stresses that, no matter what one does, life is meaningless in a wheelchair."

Ervin went further. In an October letter to Ross, he threw down the gauntlet. "[Jerry Lewis] is never going to change his

stripes. He will continue to be a liability to you as long as you keep him around."

Jerry Lewis must go, Ervin said; there would be no negotiating the point.

In announcing the kickoff of their fight against MDA, Matthews and Ervin, who had dubbed themselves "Jerry's Orphans," listed the group's demands: MDA would have to "enter into negotiations with a group of consumers with disabilities of our choosing to determine how or if the Telethon can be restructured so that it does not continue to sabotage the hard work of those in disability rights"; the charity would have to stop using "the archaic and degrading word 'patient' to describe those it serves" and replace it with "something more dignified, like 'client' or 'consumer'"; it would have to provide services for its clients' "more immediate needs, including advocating for their rights" and it would have to put people with disabilities into "meaningful positions of power" within the organization. This included putting disability rights advocates onto its board.

"We are not necessarily out to put the Telethon — or MDA — out of business," he wrote, "but we are definitely out to put Jerry Lewis out of the disability business."

Whether putting Lewis "out of the disability business" would cause the demise of the Telethon or MDA, Ervin told Ross, "is totally up to MDA. We wish to avoid it as much as you do, but we will do our battle on whatever field you choose.

"As long as you cling to Jerry and your charity-laden fashion of depicting the disability struggle, the fight will continue," Ervin wrote.

Though Kemp had fired the first fusillade, now the battle would start in earnest. It was a battle that "would continue to grow," Ervin warned Ross. "We will challenge you in greater numbers; we will protest in your local offices. We will pressure your corporate sponsors to pressure you. We will make Jerry Lewis and the pity pitch as much a liability for you as he is for the rest of the community of disability," Ervin warned.

"You can choose to doubt our ability to win this fight," Ervin continued; "but we have been in bigger fights than this."

Matthews, as it happened, was on the list to receive a motorized wheelchair from MDA. That fact would be publicized relentlessly by MDA to smear her reputation; Matthews says MDA got information from medical records of a Chicago-area

physician with neither her knowledge nor her consent.

The Muscular Dystrophy Association is one of the nation's largest charities — and considered one of the best-run (last December, *Money* magazine cited it as one of the ten best-managed large charities in the U.S.). Since its start in 1950, its focus has been on medical research, its goal the cure of neuro-muscular diseases. Criticism of its fundraising tactics by Kemp a decade ago irritated the group, but it's safe to say its management has never truly understood the reasons for Kemp's criticism. The new criticisms also took them unawares.

In Denver, former MDA poster child Laura Hershey organized a protest of the 1991 Labor Day Telethon, using the name "Tune Jerry Out." Her protests, and those of groups in Los Angeles and Las Vegas, garnered national publicity. Hershey was invited onto the nationally syndicated Gil Gross radio talk show originating on WOR radio in New York City.

The show aired on September 3. Callers branded Hershey "ungrateful" and a dissident." MDA circulated a transcript of the talk show and urged that letters be written to Hershey. Hershey says she received over 50 hate letters.

"Your entire interview was a bitter, negative slam against MDA and the Jerry Lewis Telethon," wrote David A. Sheffield, an assistant district attorney from Kountze, TX, who has muscular dystrophy and who would later serve on MDA's Task Force on Public Awareness, a group set up to counter the demonstrators. Sheffield accused Hershey of perpetuating "the false, age-old stereotype of disabled people as angry, deeply embittered, negative persons."

"The MDA has not been founded for the purpose of making you look good," wrote Shelley C. Obrand, who signed herself "one of 'Jerry's Kids.'" It is not Jerry Lewis's or MDA's responsibility to fight for disabled rights. . . . You are a selfish, negative person," she wrote.

Hershey began dutifully replying to the letters. "My basic objection to the telethon is that it encourages us to mourn again and again; that it reinforces the message that being disabled is not okay; that it implies that disabled people should get what they need through charity, not as a matter of right; and that it discourages us as a society from accepting disability and seeking to accommodate it permanently into our social fabric," she wrote.

"The disability rights approach views disability as a natural phenomenon which occurs in every generation, and always will," Hershey wrote to her critics. "It recognizes people with disabilities as a distinct minority group, subject at times to discrimination and segregation . . . but also capable of taking our rightful place in society. From this perspective, people with disabilities have rights, which society must guarantee . . . the right to health care, full integration and opportunities for . . . non-institutional living. Instead of begging, we are expected to participate fully in the community."

By this time, the Association had moved on to other methods of discrediting protestors.

In October, MDA Director of Research and Patient Services Administration, Ronald J. Schenkenberger, put out the word to selected people associated with MDA in and around the Chicago area that "developments relating to initiatives undertaken by Chicago-area residents Cris Matthews and Mike Ervin . . . have sufficiently hurt our fundraising programs in your area" that the Association would "regretfully" have to "enforce a regulation of many years' standing" to limit admissions to MDA camps.

Lest anyone believe this was simply following policy, Schenkenberger made it clear that this cutback was all Matthews' and Ervin's fault. "Action of the nature undertaken by Cris and Mike can only serve to impair our ability to raise funds and thus have a negative impact on the Association's ability to provide a full range of services."

He urged writing to Matthews and Ervin directly, and provided addresses. He also pointed out that Matthews "will shortly be the recipient of an MDA-purchased power wheelchair costing over \$8,600."

MDA disputed Matthews's and Ervin's claims that they themselves had been MDA poster children. When columnist Dianne Piastro referred to the brother and sister as former MDA poster children, she received a swift letter from MDA Director of Field Operations Gerald Weinberg insisting that Piastro verify the fact. Other letterwriters, both to Piastro and Matthews, disputed the claim also. Only when Matthews was able to dig up a February 1962 newsletter of the Greater Chicago MDA chapters proclaiming the smiling brother and sister "muscular dystrophy poster children for 1961," did the questioning stop.

Even more direct was the attack on Hershey from Mike

Gault, MDA's Director of Community Services. "This Association has received a considerable amount of negative publicity as a result of your Tune Jerry Out campaign," he wrote Hershey late last October. "Your campaign is a factor in what appears to be a serious financial drop in Association income this year. As a result, it will be necessary to curtail — or eliminate entirely — certain of MDA's programs."

Gault enclosed a newspaper clipping about Rhondi Geist, "a 38-year-old Friedreich's ataxia patient [sic]" in a Colorado nursing home who had recently been the recipient of a wheelchair from MDA. Gault told Hershey that a thank-you note from the man (which Gault also enclosed) had "started me wondering how much longer MDA will be able to provide the kind of help this young patient received. The thought struck me that this is a matter you'd like to think about."

Hershey says she was "shocked by both the content and the tone" of Gault's letter. "If your attitude is representative of the Muscular Dystrophy Association as a whole," she wrote him, "then I must conclude that the Association's problems go much deeper than just the offensiveness of the Telethon." Hershey told Gault she thought he might be exaggerating the drop in funds to make her feel guilty, but said she was even more disturbed by MDA's response to the drop. "You seem very willing — even eager — to cut client programs. . . Has the Association considered administrative salary cuts instead? Or is this part of the budget considered sacred?" she asked.

In 1990, MDA had spent \$34.6 million on salaries and benefits; its executive Robert Ross received nearly \$285,000, making him one of the top paid of all the nation's charity executives.

As to Geist's situation, Hershey wrote to Gault, "It seems to me that MDA has condoned, and even participated in, the widespread institutionalization of people with disabilities in this nation. . . MDA, with its medical-model approach, has done little to provide independent living services and supports or to free its clients from the confinement of nursing homes.

"I do not want my views or actions to punish Rhondi Geist and other disabled people," Hershey told Gault, "but the fact is that if Mr. Geist were living independently, outside of a nursing home, he would most likely be eligible for Medicaid — which, in Colorado, would enable him to obtain not only the high-tech

wheelchair he needed, but also home health care services and other equipment he required to stay independent and healthy."

If Gault intended his letter to make Hershey back off, it did not work. "Protests against the Jerry Lewis Telethon will continue, and probably increase, until the Muscular Dystrophy Association changes its approach to fund-raising, as well as its attitudes toward clients," she wrote. "As long as MDA's organizational and service philosophy values charity over independence, it will continue to be in conflict with the goals of equality and empowerment of people with disabilities."

If MDA's threats last fall were efforts to instill guilt, by early 1992 they had become more serious. Matthews began to be harassed by MDA officials demanding copies of Jerry's Orphan's nonprofit status and tax exemption, evidently not realizing at first was that Jerry's Orphans was merely a name, not an organization. Later, they began hassling Matthew's about AccessAbility Associates, which was a non-profit corporation — which Ervin reports they were continuing as this story went to press.

A January 14 registered letter from attorney Bruce S. Wolff of the law firm McDermott, Will & Embry warned Matthews that MDA had hired his firm to "advise the Association on an ongoing basis concerning its rights to hold you legally accountable for any damages it may incur as a result of your efforts.

"Our firm intends to monitor — from our offices in Chicago, New York, Washington, DC, Boston, Miami and Los Angeles — the activities which you . . . may engage in." Any activities "which have the effect of disrupting or interfering with, or which are intended to disrupt or damage, the Association's relations with existing and prospective sponsors and/or Telethon stations will provoke a swift and substantial reaction."

"I don't know what they could do to us," Matthews laughed. "We have no money; we have nothing to lose."

Matthews says she thinks MDA targeted Evan Kemp because they realized they could win nothing by fighting Jerry's Orphans. Kemp was a bigger target; his dismissal from the Bush Administration would be a win for MDA. But they lost that gamble, too. He was renominated by the White House in June.

Few reporters have had the interest — or the guts, maybe — to take on the Muscular Dystrophy Association. One who tried

was Dianne Piastro, disability columnist of the syndicated "Living with a Disability" column. Piastro wrote a six-column series on the issue, starting by outlining the protest, giving readers the opportunity to contact Matthews and Ervin, and ending with an unflattering look at MDA finances. MDA stonewalled when Piastro sought financial information from them. "In light of the obvious bias that so extensively characterizes your apparent ongoing assault upon MDA, I believe it would be decidedly counter-productive to the interests of those served by the Association to participate in any interview with you," wrote MDA Director of Finance Robert Linder in response to Piastro's verbal, then written, questions about expenditures on the group's IRS annual tax forms. Piastro finally obtained the forms from the Illinois Attorney General; she had to file a complaint with the IRS about MDA's refusal to release them.

Despite their refusal to set the record straight before her article ran, MDA seemed outraged when her column hit the papers. They had the accounting firm Ernst and Young scrutinize every financial allegation in her column, and used it to send a four-page, typeset point-by-point rebuttal to newspapers that had run her column, characterizing her facts as "uninformed and misleading," "out of context" and "grossly incomplete," which seems particularly unfair given MDA's refusal to answer questions she had asked.

Miami Herald reporter Marjorie Valbrun was contacted by MDA folks to do a story on Jerry when he came to Miami. When they learned Valbrun had contacted Kemp for his side of the story, MDA's offer of an interview with Jerry dried up. Valbrun told MDA she couldn't do a story with just one side — and the story was never done.

Jerry's Orphans vowed to Ross to "pressure your corporate sponsors." ADAPT's Mike Auberger, with the allusion to South Africa not unintended, calls it pressure for "a divestment plan."

The divestment plan is simple: Don't give money on the Telethon. That was what Matthews began asking major Telethon contributors last year. With ADAPT behind it, the campaign has picked up this summer. Protesters targeted United Airlines, Southland Corporation, which runs the 7-Eleven convenience stores, Gannett Outdoor Advertising, Service Merchandise and TCI, the nation's largest cable TV operator.

Protesters did not ask corporations to reduce their contributions to MDA. They merely asked that the contributions not be made to the Telethon itself, and that contributors not appear at the Labor Day event. "This way, the Telethon is neutralized," says Auberger, "while MDA's fundraising efforts are unharmed."

ADAPT and others point out that the bulk of money shown as being raised during the Telethon is actually raised months before. As major corporations' gifts are announced on the Telethon, the amount on the tote board rises; but that money has in reality been raised in preceding months. The appearances by corporation heads like Service Merchandise's Raymond Zimmerman are a form of free advertising for the corporate giants, and, in a way, their contributions can be seen as advertising fees — because they believe the good publicity generated by appearing on a Telethon for a worthy cause that isn't controversial can only help them in the eyes of customers.

ADAPT's Diane Coleman calls it "advertising at our expense." She was among the activists who met with Zimmerman earlier this summer to ask him to stay off the Telethon; he refused. Activists from Denver reported better results with TCI.

As Telethon time rolls around again, MDA's Task Force and Telethon officials appear to be making attempts to defuse what they fear may be mass protests in Las Vegas, where the Telethon takes place. In May, MDA officials traveled to Denver to meet with ADAPT; in July, members of the Task Force tried to arrange a meeting with ADAPT activists in Texas in an effort ADAPT says they characterized as "building bridges."

ADAPT's Bob Kafka said a Task Force member had called him to try to set up a meeting with Regional MDA folks; the conversation, with a man Kafka had known in disability circles years ago, he said, brought home to him why he had always been "anti-MDA."

It was two things, he said: "The Jerry's Kids image — that's paternalism — and their 'patient services' approach — that's the medical model.

"Those are the two things the Muscular Dystrophy Association has interjected into Americana," he continued. "They are the two things which are the antithesis of what we stand for."

Though MDA tries to convince the public that its detractors are simply jealous of the fundraising group's success, says

Kafka, activists' real anger, he thinks, is at the group's success in projecting images into mainstream America — images activists hate.

Lewis told the *Los Angeles Times's* Charles Champlin in 1990 that his telethon pulled in 120 million viewers, a figure he claims is just below the Super Bowl and the Miss America Pageant in audience size.

It's precisely because they have such an impact on public perception, says Kafka, that the MDA is the target of activist criticism. "MDA is Americana," says Kafka. Because they have made such a pervasive image, he says, "they have a higher responsibility to project an image of disability that is real."

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