

family

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Abstract

A collection of articles which criticise an annual telethon held by the Muscular Dystrophy Association and relates the experiences of several critics of the MDA who have been discredited and silenced. Also gives a very articulate critique of the telethon mentality and presents the argument that this strategy serves to undermine the gains of activists in the disability area. **Keyword: Attitudes**

THE MDA LABOR DAY TELETHON

by **Steve Taylor**

Director, Center on Human Policy, Syracuse University

For years I've tried to ignore the MDA Jerry Lewis Labor Day Telethon. The Telethon portrays people with disabilities as objects of pity and ridicule and perpetuates public stereotypes and negative attitudes, but there are many other important issues in the world worthy of our attention. The enclosed editorial, which was published in the Syracuse Post Standard, describes why I finally decided to speak out on the Telethon and what happened when I did. The issue here is not simply the MDA Telethon - as offensive as it is - but how a fund-raising giant tries to use its political muscle and well-oiled public relations machine to silence the legitimate criticisms of the disability community. This goes against everything TASH stands for.

Last year I wrote an opinion piece on the Muscular Dystrophy Association's Labor Day Telethon. I had read about the controversy surrounding the telethon and wanted to add my opinion to the discussion. One article described the efforts of MDA to silence the criticisms of the telethon by then-chairman of the federal Equal Employment Opportunity Commission **Evan Kemp**, who has a neuromuscular disease himself.

It seems unfair for a fund-raising giant like MDA to exercise its political muscle to squelch an opinion by many members of the disability community. This prompted me to write my commentary, but I did not send it to the paper until some time after the telethon and it never appeared in print.

So I put the editorial away and forgot about it until earlier this year when I sent it, along with materials developed by my Center on Human Policy at Syracuse University, to **Dianne Piastro**, who writes the column, "Living with a Disability". This set into motion a series of events that has given me a slight taste of what Kemp experienced when he dared to question the fund-raising methods of MDA.

My tongue-in-cheek commentary reflected common complaints about the telethon made by many disability groups and critiques of stereotypes of people with disabilities found in the professional literature.

Jerry Lewis may be committed to the MDA cause, but he sends the wrong message about people with disabilities. In his movie roles and comedy routines, he has poked fun at people by acting "retarded", "crazy" or "spastic".

As recently as last year's telethon he got a laugh in a stuttering skit that offended many people who stutter and their families -- MDA had singer **Mel Tillis**, who stutters and is a friend of Lewis', to respond to complaints. Lewis has been quoted in print as using "moron" and "mongoloid" as general epithets.

In the conclusion of my brief commentary, I wrote, "For those who contribute money out of pity for 'victims', please direct your pity elsewhere. For those, perhaps the majority, who participate in the telethon out of goodwill and a concern for the wellbeing of fellow citizens, please channel your efforts to help make this a society in which all members are accorded dignity and respect."

Piastro, who has written critical articles on MDA, asked if I would be willing to have my paper appear in her column. With a few revisions worked out between us, it appeared in the *Post-Standard* that Monday.

The Long Beach Press-Telegram was the first paper to carry Piastro's column on August 24th. On the previous day, I saw an article, "Jerry vs. the Kids" in the September issue of the magazine *Vanity Fair*. The article alleges that MDA arranged for a spy to follow Kemp in the early 1980s and describes MDA's attempts to discredit Kemp, Piastro and former poster children who have founded a group called Jerry's Orphans to oppose the telethon.

First came the flurry of calls from MDA headquarters - six in two days - including one at my home. Reached by MDA Executive Director **Robert Ross** and their public relations on August 25th, I confirmed that Piastro's column fairly and accurately reflected my opinions.

In a phone conversation that resembled an interrogation, I answered their questions honestly and openly and subsequently sent them a copy of the only typed draft of my paper.

Then came the FAX attacks challenging me and my opinions, with copies forwarded to my chancellor and dean.

One came on the letterhead of Utah's attorney general signed by an assistant attorney general identified in the *Vanity Fair* article as a person with a disability who is a defender and close associate of Jerry Lewis and MDA.

MDA's Ross wrote me to accuse me of being Piastro's "mouthpiece" and suggest that I am a "mindless zealot".

And then came another FAX from Ross quoting from an "analysis" by a philosophy professor at Syracuse University. The professor, who has never met

me, never contacted me to obtain all of the facts of the situation and has an opinion about telethons and MDA that is different than my own, "analysed" Piastro's column, my draft editorial and my and my centre's reputation.

The most recent FAX came from a 32-year old woman who is proud to be one of "Jerry's Kids" and accuses me of violating her right to life. So I am wondering whom MDA will next find to attempt to discredit me.

Perhaps I have been naive about the hard-ball politics of big-time charitable fundraising, but I have been surprised by MDA's attacks on people for expressing views that are widely published in disability newsletters or the professional literature. I think I now understand when MDA chooses to attack its critics.

Evan Kemp was a federal appointee who also wrote an opinion piece for *The New York Times* in 1981; Dianne Piastro writes a column that appears in the "mainstream media"; former poster children are taking their concerns about the telethon to the media; and I am an academic -- or, if one prefers, a "researcher/activist" -- who threatens to confirm publicly that the MDA telethon is indeed controversial within the disability community.

Why am I taking the time and energy to express my views on the MDA telethon and opening myself to attacks on my credibility and integrity, when I could be writing academic articles and doing other things?

I am a tenured professor and have a credible record of publications. I work at a university that has never attempted to interfere with my expressions of ideas in scholarly works or opinions on controversial issues in public forums. If people like me, who can be attacked but not silenced, do not speak out on this issue, who will?

THE TELETHON

by Chris Matthews

One of the many difficulties presented by Jerry's Telethon is the image that it gives to an unwitting public. It mocks the notion that children with neuromuscular diseases, or any disability can, and do, grow into happy, fulfilled adults. If they don't die soon, children can expect to be excluded from social activities, as one father explained to viewers. He guaranteed that his beautiful pre-teen daughter would never be asked to the prom or out for pizza with friends on a Friday night. Jobs are out because Jerry informed the country his "Kids" can't work. Might as well forget planning anything resembling a life. Characterised as a mistake, that child's life can't amount to much.

The solution posited by Jerry and his MDA pals is to cure us. It is not in-home care or assistive technology, providing an environment conducive to independent living. To them, the answer lies not in accessible transportation or non-discriminatory employment practices. The only possible option a person with a disability has in the world according to Jerry is not to have a disability! Problem solved.

This business of a cure is distressing. Besides placing the onus for change on our community, it exempts the American public from addressing the barriers to successful independent living. Why provide personal services when Jerry's gonna cure 'em? Assistive technology looks like a death sentence, next to a cure. There is no apparent reason to employ a person with a disability when a cure is on the horizon. People incarcerated in nursing homes can be ignored until they can walk out: problem solved.

Worse, almost, than this is how many willingly surrender to this mentality. Our nastiest letters come from parents whose children have received much attention from MDA and adults with MD in a similar position. The theme is universal: This life of mine is pointless in its present form. It doesn't matter that I completed medical or law school or that I have a beautiful, intelligent child with a head full of ideas to offer the world. I am half a person until Jerry cures me. I owe all that I am to him. Problem solved.

That is the problem - or one small part of it. Jerry gets and takes a lot of credit for things he doesn't do. I doubt Jerry will volunteer to do personal care when an assistant doesn't show up. I'll bet Jerry can't be called on when one of his "Kids" is forced into a nursing home because there aren't enough support services available. I'll bet Jerry didn't pay for law school or convince transit agencies to buy buses with lifts, or fight Medicaid single-handedly for a ventilator his own organisation refuses to provide.

MDA even claims that people are alive today because of Jerry. All this time we thought medical science was advancing! Instead of claiming victory for the

staggering strides we've made individually and collectively, Jerry's "Kids" consistently and adoringly lay their lives at his patent-leathered feet. Let me know when he assists in the bathroom. Problem solved.

We've lost four friends to MD so far this year. Jerry didn't know a thing about them or their dreams, or that they wanted to live independent lives. Pictures of two of them were included in Chicago's roll call of death, their faces, names and ages. Who they were was not what mattered, just that they died. And therefore disability-free at last. Problem solved.

Jerry's Orphans confronts the limits of the telethon mentality by asking questions about image and accountability. The first step is removing Jerry Lewis from the organisation. Once he goes, real change can begin. Problem solved.

Chris Matthews and her brother Mike Ervin are the founders of Jerry's Orphans. Chris works for Protection and Advocacy in Chicago.

TELETHON REALITY

by Mike Ervin

During the recent Muscular Dystrophy Association's Telethon, as always, you saw plenty of images of people with neuromuscular disorders suffering silently through their pain. As a person with muscular dystrophy, or "MD", the greatest pain I have silently suffered is the distortions about life with a disability that **Jerry Lewis** and the telethon sells to the world.

This distortion is more than just personally offensive; it is immeasurably harmful. It does more to make my life - and the lives of millions of people with disabilities - unnecessarily difficult than any single other factor.

Jerry Lewis has referred to having MD as a "curse" and to someone who has it as "half a person". If you have amyotrophic lateral sclerosis (Lou Gherig's Disease), he once said on the telethon, "you might as well put a gun in your mouth." The message is loud and clear; life with muscular dystrophy (or any disability) is not worth living.

Jerry's dehumanising stereotypes are a placebo that comforts Americans and enables us to avoid the social complexity of disabilities. How soothing it is to believe that, whatever the obstacle a disabled person faces, giving Jerry \$25 will fix it.

But some telethon sponsors don't even have wheelchair accessible facilities. One shop in my neighbourhood has a coin canister for "**Jerry's Kids**" on the counter and steps at the front door. A local pizzeria took out the wheelchair ramp when it remodelled and put in stairs while its proprietor was giving the telethon big cheques on camera.

This hypocrisy would escape anyone who buys the telethon premise, as millions obviously do. Why go to any lengths to accommodate someone who is cursed? Why go to any lengths to hire half a person? Why don't we just follow Jerry's advice and put guns in our mouths?

The Muscular Dystrophy Association so completely accepts these stereotypes that it will not purchase respirators - equipment many people with MD eventually will need to continue living. For those with MD, there is obviously no higher priority than this piece of equipment. But for those who set MDA policy, it's not a priority at all.

The self-serving stereotypes on which Jerry and the Muscular Dystrophy Association have built their charity empire make them the biggest hypocrites of all. How else could they purport to be the great champions of people they perennially insult and devalue?

Some say that in the final analysis, finding a cure for MD is so important that any means justify the end. If cure and treatment are so vital, why do we allow them to hinge on the success or failure of a Vegas minstrel show? The same approach to the AIDS epidemic would be rightly viewed as horrifying. The very

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existence of the telethon shows how insignificant treatments and services for people with disabilities really are in our national consciousness.

I would not trade my life for anyone's, especially Jerry Lewis'. And I expect a whole lot more than a pat on the head from Jerry and a life of quiet desperation. I refuse to believe that anyone should grovel, sing a pretty song, or even have to explain themselves as the price for living.

When faced with death or life on a respirator, I will absolutely choose life, I will choose life -- and dignity. I never will accept the telethon's proposition that I must choose one or the other.

Mike Ervin was a Muscular Dystrophy Association poster child in 1962. He is a writer and the founder of Jerry's Orphans, a national organisation of people with disabilities opposed to telethons. This article is reprinted with permission of the author; it was originally written for the Progressive Media Project.