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'Beating' The Tribal Drum: Rejecting disability stereotypes and preventing self-discrimination

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The "Tribal Drum." It beats in all societies, warning members of the tribe against the dangers of "the others," those who are not members of the tribe, even those who are different within a society. The Drum's messages result in different tribal behaviors, from religious warfare in Northern Ireland and the Middle East, ethnic cleansing in Yugoslavia and Rwanda, to Neo-Nazi racial purification in Germany and America.

But The Tribal Drum's messages can also be subtle, permeating a society, and producing non-violent -- although no less destructive -- behaviors. The Drum's most subtly destructive effect may be when negative messages about "the others" are accepted by those who are supposed to be immune from such prejudice, those who are supposed to actually help "the others."

One of The Tribal Drum's most ardent, if unconscious, listeners was a physiatrist named Steve. I wish I were as sure of anything as Steve was of everything. He had an expert opinion about all topics, from medicine to particle physics, and was eager to tell you just where you had "made your mistake."

On the spinal cord injury unit, Steve was the local tribal king. He would swoop into new patients' rooms, residents in tow, and opine about one patient's neurogenic bladder or another's lack of vaginal lubrication, never actually talking to or even looking at the person in the bed. After the initial evaluation the patient would typically never see Steve again, since all care was given over to the residents. Not that the patients minded being pawned off. "Hell, I'd rather be treated by an orderly than by him," one patient told me.

But absence made Steve's heart grow fonder. The less he saw a patient, the more opinions he offered about where the residents were "making their mistakes with poor Miss Jones" and the more compassion he would voice. "How will she ever manage, a C3 quad alone, on her own," Steve asked, shaking his head sadly? "Who will ever hire her? Who would ever marry her?"

In contrast to his lack of contact with his SCI patients, Steve frequently volunteered to talk to school and community groups about SCI prevention. He would show the most horrific slides of auto wrecks and physical wrecks. He would show a patient using a sip-n-puff power wheelchair, saying, "This is poor Miss Jones; she wasn't wearing a seat belt! You don't want this to happen to you!" Then he would show a patient with tongs buried in his skull saying, "This is careless Mr. Smith; he dove into the shallow end of a pool. Why would you want to live if you were like him?"

Interestingly, Steve developed a converse alter-ego. As much as he avoided SCI patients, Steve eagerly sought out patients with back pain. A dock worker, who had tried to lift a Land Rover by himself and blew out five discs in his back, came to see Steve. The patient hobbled in, bent at the waist, leaning heavily on a cane.

"What do you think you're doing," Steve yelled as he entered the room? "You don't need that," he said, yanking the cane out of the patient's hand. "Only people who really need canes should use them!"

On another occasion a young man with a ten year history of back pain rolled into Steve's office in a wheelchair. I am told that the sight of the chair so infuriated Steve that his screaming was heard two floors away and that a nurse had to physically remove Steve from the exam room.

"I can't stand these pain patients, limping around looking like helpless cripples," Steve once told me, spraying spittle all over my tie. "Do they expect me to pity them!?! Do they think they deserve the same care that I give my patients who are really disabled."

The same care he gave patients who were really disabled? Steve gave no care to his patients who were "really" disabled. He talked at them or about them and avoided them like the plague. Finally, I saw the problem: Steve could not tolerate disability at all. He couldn't deal with not being able to cure his "poor" SCI patients so he stayed away from them. But in public he heaped pity on them and lectured avidly to prevent others from "making the mistake" of becoming disabled. At the same time, he both hated and sought out back pain patients because he was able to "cure" them by removing the assistive devices that made them look disabled.

Although Steve is an extreme example, he demonstrates the double standard that pervades medicine. How many physiatrists shower new SCI patients with encouragement, even telling some "you will walk again," only to withdraw their attention and become irritated when their skill as healers is insufficient to cure the spinal cord injury? How many physical therapists tell polio survivors to "get rid of that brace" and "start pumping iron" to strengthen weakening muscles, only to become angry when polio survivors actually get weaker with exercise?

Doctors -- even rehabilitation doctors -- are merely products of our society, having grown up listening to The Tribal Drum. "Doctors are Gods, omniscient and omnipotent," is one of The Drum's messages. Despite rehabilitation's focus on quality of life, independent living centers and new assistive technologies are just stop-gaps for the present, until "helpless cripples" are cured by the "Great Healers of Medicine" and are able to stand up and walk. Of course, the message that a life with a disability is a life not worth living had been transmitted for eons by The Tribal Drum. The drum says people with disabilities are helpless cripples who will find neither employers nor spouses, that a life with a disability but is, as one disability insurance company states in their advertisements, "a living death."

But those of us with disabilities have had our own attitudes shaped by The Tribal Drum. Our notion of how we "should" look, shaped by the messages the media pounds into us about normality, certainly does not include a cane, brace, prosthesis or wheelchair. All of us have had the experience of being discriminated against because of our disabilities. The greatest danger is that we beat ourselves with The Tribal Drum, adopt society's negative stereotypes and discriminate against ourselves because of having a disability.

Christopher Reeve may be the most visible example of self-discrimination. Despising his own disability, Reeve said he is disinterested in architectural access or civil rights, spending his time physically preparing for and raising money to find "The Cure" for spinal cord injury. If Chris will be walking within the decade, why won't we all? Why should we be concerned about making the world wheelchair accessible or dealing emotionally with our own disabilities, let alone stopping rehabilitation practitioners from treating us as "helpless cripples" or "the living dead?" As Mr. Reeve says we are only temporarily disabled. "The Cure" is just around the corner. We won't be "the other" for long!

Both Dr. Steve and Mr. Reeve serve as warnings. We must be assertive, stopping doctors and therapists from beating us with The Tribal Drum, disabling us as people as they treat our physical disabilities. Even more, we must be vigilant to prevent ourselves from accepting The Tribal Drum's negative messages. We must reject society's stereotypes about disability, which rob us of quality of life in the present, even if some of us expect

"The Cure" in the near future. We can -- we must -- "beat" The Tribal Drum.

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