

**POST-POLIO SEQUELAE AND THE PARADIGMS
OF THE 50's:
Newtie, Ozzie and Harriet versus Paradigms of Caring
and a Future for Rehabilitation in America.**

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We find ourselves at an extremely interesting and extremely extreme point in our nation's history. The pendulum of what Americans believe government should do has swung all the way from FDR's New Deal, gaining momentum as it flew past LBJ's Great Society to hit Bill Clinton squarely between the eyes. In listening to the political rhetoric since last year's Republican coup, I believe that not only have the times changed but also that time itself has changed. I have the feeling it is not June 24, 1995. It feels to me as if the clock has been turned back exactly forty years. So, put on your

poodle skirts, slick back your D.A. and let's return to those thrilling days of yesteryear so we can view the childhood and adolescence of rehabilitation through the eyes of those who have grown up with it: the survivors of America's polio epidemics. Let's see what lessons have been learned, now that both the polio poster children and rehabilitation have reached mid-life, and ask this most important question: Given the current ideological timewarp, will polio survivors - will rehabilitation itself - have any future at all, let alone enjoy their golden years?

FRIDAY, JUNE 24, 1955.

So it's Friday, June 24, 1955, and everyone likes Ike in these 48 United States. To date, only a California politician named Douglas and the victims of Joe McCarthy hate our Vice-President. Bob Dole is a practicing lawyer in Russell, Kansas ten years after his spinal cord was damaged during a mortar attack in Italy. Little Newtie Gingrich turned twelve just last Friday. I see him praying fervently in his sixth grade classroom that God make Congress understand that U.S. troops should not be keeping the peace in Korea.

In 1955, polio has been at the forefront of our nation's consciousness for more than twenty years. Rehabilitation professionals are intimate with the literature on polio, its symptoms, pathophysiology and treatment. Two years ago, they read in J.A.M.A. that at least 39 percent of those having had non-paralytic polio showed measurable weakness in at least one muscle group, and 43 percent reported "increased fatiguability," as much as six years after their acute polio [[1](#),[2](#)]

These findings were not surprising. As early as 1940, David Bodian concluded that at least 60 percent of motor neurons had to be killed by the poliovirus for there to be any symptoms of weakness. But, even more important, Bodian found that poliomyelitis was an afterthought of the poliovirus. He concluded that an encephalitis exists whenever the poliovirus enters the CNS "whether symptoms (of paralysis) are present or not." [[3](#)] This polioencephalitis was found to consistently and often severely damage specific brain regions: the reticular formation, hypothalamus - even the basal ganglia. [[4](#)] This damage was invoked by Bodian and others to explain the "fatiguability and fleeting attention" that were seen to persist for months after the acute poliovirus infection. [[5](#)]

Unfortunately, these important facts about polio, along with many others, are about to be erased from the consciousness of rehabilitation professionals. Why?

- Because it's 1955 and we believe in The Paradigm of Cure. Americans believe we have 'cured' polio by finding an effective preventative. Seven million Americans have thus far been inoculated with the new Salk vaccine. Last week, only 266 cases of polio were reported, the lowest weekly total since 1951. 43,000 cases of polio will be reported this year, down from the record high of 80,000 in 1952. Still, it will take until 1960 for the annual number of polio cases to dip below 10,000.
- It's 1955, and we act according to The Us versus Them Paradigm. Today the House of Representatives unanimously passed a resolution condemning "colonialism and Soviet imperialism." The man on the street will angrily tell you that Americans are superior to 'those Godless Commies' and that it is better to be 'dead than red.'

And, the ubiquitous symbol of 'them,' the adorably pitiful poster children of the National Foundation for Infantile Paralysis, have done their job well. Clad in heavy metal braces, leaning tenuously on their crutches, they called down from their posters to America's mothers and fathers, saying: "Give money to find the polio vaccine. Don't let your child become crippled, like me!" But, it's 1955 and the vaccine has been found. The poster children are needed no more.

- In 1955 rehabilitation is provided according to The Institutional Paradigm. To house and treat the thousands who contract polio each year, special hospitals have been built. Children are ripped away from their families and admitted for months, sometimes years. Huge wards provide assembly-line care as scores of scores of polio survivors are fed, bathed and treated. Parental visits, which always disrupt the hospital routine, are allowed rarely, briefly or not at all. Patients are slapped or beaten with rubber truncheons by therapists to 'motivate' them to stand up and walk. Patient's tears or an angry word - triggered by pain, fright, homesickness, or even a nightmare - not infrequently result in the application of a straight jacket or being locked in a dark closet for the night.
- It's 1955, and we also practice The Paradigm of Shame and Shunning. Much is shameful in 1955 and many are shunned. Young, pregnant women are regularly sent away to homes for wayward girls or to back alleys. A 'Gentleman's Agreement' is still in effect, and many Americans remain in the closet while others are allowed to ride only in the back of the bus.

So it is not surprising that merely having had polio, let alone not recovering completely from paralysis, are cause for both shame and shunning. Polio survivors and their entire families are often shunned for having been tainted by the 'dreaded disease.' Braces and crutches are certainly cause for shunning, repulsive reminders of our own physical vulnerability and of the medical profession's shame at its failure to actually cure polio.

- Finally, and most distressing, in 1955 we believe in The Paradigm of Normalcy. Tonight, at 8:00 on A.B.C, a cardigan-clad Ozzie Nelson will sit in his (and our) living room while wife Harriet waxes the kitchen floor wearing high-heels and pearls. Sons Rickie and David will come running in from a sock hop. Needless to say, no character on "The Adventures of Ozzie and Harriet" will be seen to have had polio or to have any other disability.

Thus polio survivors are taught that if they are to be accepted back into society, they must become 'normal' again. They must work hard and then harder in physical therapy to rid themselves of the wooden and steel stigmata of the terror that is polio. If they are to function in a totally inaccessible world, even paraplegic polio survivors must be able to walk.

So, polio survivors do work hard, harder than anyone ever has. They discard their braces and crutches. Then they go even further. They go to college, when other Americans only finish high school. They marry and have children. They work more hours of overtime and take fewer sick days than non-disabled workers. [6] They are hard-driving, overachieving perfectionists who become the leaders of their communities, their professions, the chief executives of the largest corporations. [7,8]

Normal? Polio survivors transcend mere normalcy to become America's best and brightest as our country's clock runs forward.

THE CLOCK RUNS FORWARD . . .

During the next decades America - along with its 1.63 million polio survivors - happily forget about polio as we experience wonderful advances in rehabilitation and violent changes in our society:

- The domino theory is displaced by detent and followed by dissolution of the Soviet empire;
- Wooden legs become polypropylene prostheses;
- Our leaders and our innocence are assassinated again, and again, and again;
- Wheelchairs once wicker and wood become carbon composite;
- The War Against Poverty is overshadowed by the Cold War become hot in Vietnam;
- Paternalistic institutions become independent living centers;
- Richard Nixon, Vice-President, becomes President, unindicted co-conspirator, pariah and finally, inexplicably, elder statesman;
- Charity appeals for 'those poor, pitiful cripples' are finally made unacceptable by the demands of people with disabilities for their civil rights;
- Multidisciplinary, becomes interdisciplinary becomes managed care;
- The Voting Rights Act is followed by Section 504 and finally by the A.D.A.

. . . AND THEN THE CLOCK RUNS BACKWARD

But, in 1980 America's clock stopped moving forward and began to actually run backward. An old rhetorical cold warrior became President by asking us to remember how happy we were in 1955 watching - and he believed living - "The Adventures of Ozzie and Harriet."

But, for America's polio survivors, the clock had already been running backward. They were being reminded of a 1955 that was not happy. Forty years after polio, their bodies were beginning to break down as a direct result of the paradigms of the 50's. Society's Paradigm of Normalcy, applied so successfully by polio survivors, was now extracting its price in disabling fatigue, muscle weakness and pain. [9] Polio survivors were losing the very abilities that allowed them to appear normal, that prevented shame and shunning, that freed them from institutions and allowed them to pass for normal, to become one of 'us.'

But today, in 1995, the plight of polio survivors is of no interest to America. Why? Because it's 1955 again. Polio has been conquered and the poster children are gone. "Forget about polio," says our society. The National Foundation for Infantile Paralysis, now the March of Dimes Birth Defects Foundation, was asked to fund research on Post-Polio Sequelae (PPS). "No," said the March of Dimes, "Polio is gone. We're curing birth defects now. If we help polio survivors, our donors will become confused. Why don't you ask Congress for help with this orphan disease?"

So, every year since 1985 Congress has been asked to set aside funds for research on PPS, just one dollar for each polio survivor. And every year Congress says, "No. There will be no set aside. The few remaining polio survivors will be dead soon anyway. Why don't you study an important disease or ask a private foundation for research funding?"

Of course, the 'few remaining polio survivors' conservatively number more than one and a half million. Polio is still the second most frequent cause of paralysis, after stroke. [10] And, polio survivors are hardly moribund; our typical patient is a working mother of 48. Polio survivors are still America's best and brightest, both the foundation and the leaders of our society. But these facts are of no importance. The clock has been turned back and the paradigms of the 50's have returned:

- In 1995, The Paradigm of Normalcy has returned. Conservative Christian, two-parent families are normal. Anything else, to quote House Speaker Gingrich, is "corrupt and bizarre."

The senior Senator from Kansas is running for President, again. Why? Because of his vision to lead our country forward into the new millennium? No. And not even because he wants to lead America back to the glorious 50's. According to Senator Dole's niece, Nancy Poche, "He still has this one thing he needs to do. He's still proving that he's not handicapped." [11] Bob Dole is clearly following the Paradigm of Normalcy: Crippled is unacceptable, normal is necessary and only achievements above and beyond normal can make 'the handicapped' acceptable to society. As we have seen once before in this century, only being elected President of the United States can convince a disabled man that he is normal again. [12]

- In 1995, The Paradigm of Shame has also returned. Americans should be shamed into changing their circumstances, or at least their behavior. The homeless are prostitutes, alcoholics and drug addicts who should be ashamed of their lives and 'pull themselves up by their boot straps.' Irresponsible single women should be shamed into abstaining from sex so as not to become pregnant out of wedlock and end up on the dole.
- But if shame doesn't change behavior The Institutional Paradigm should again be applied. The Poor House should be rebuilt; children should be removed from their shameful single mothers and raised in orphanages.
- The Institutional Paradigm can also be used as an adjunct to the 1950's tried and true Paradigm of Cure. Those having a disease whose effects leave them unable to contribute meaningfully to the economy should not be allowed to place a drain on the free market. All forms of "compassionate excess," to use the House Speaker's phrase, should be eliminated : i.e., Medicaid, Medicare, SSI, SSDI, and especially funds for rehabilitation. Even today, Medicare will only cover outpatient rehabilitation if an individual is 'falling or unsafe,' the maxim being don't let them die, but don't help them regain function, either. This current policy is tragic for those whose PPS have forced them to go out on disability but who want to regain function and return to work.

But, you know, it would be much less expensive to forgo rehabilitation completely and simply institutionalize all of those too disabled to work. This will be an about-face from current policy, where the only people who shouldn't

be institutionalized are the homeless and the recently reinstitutionalized mentally ill. But, such a policy reversal could be a deficit busting bonanza if we heed the advice of New York's Governor and require that residents of homeless shelters pay rent. Imagine the tremendous cost savings to society if the government stops paying for rehabilitation and actually makes money by collecting rent from those it institutionalizes.

- Finally, in 1995, The Us versus Them Paradigm has returned. In a remarkable echo from the 1950's, House majority leader Dick Armey published a letter last May black-balling left-leaning charities. Principle among these communist organizations was the American Cancer Society, tarred as an enemy of the free-market because it opposes the sale of cigarettes.

Representative Armey and his troops have also stated that everyone who is not 'us' - that is white, working, born-again, non-disabled males - is not a 'true' American and should be regulated - that is shamed, cured or institutionalized - into normalcy. However, all regulation of 'us' - that is white, business-owning, non-disabled males - should be removed. Clean air and water statutes, safe food regulations, and especially OSHA (including its new repetitive motion disorder guidelines) should be eliminated because they constrain the operation of the free market. Can repeal of workers' compensation, child labor laws and the spendthrift A.D.A. be far behind?

But think about it. The elimination of regulation should be a boon to the medical industry in general and rehabilitation in particular. Just think of how much carpal tunnel syndrome we will be treating. However, the people most affected by eliminating regulation will be 'them:' workers with no clout, no voice, no cash to pay for a \$500-a-plate campaign fund raiser for Congressman Armey. Their medical insurance will have been lost along with their jobs and government funding will no longer be available to pay for rehabilitation. There will be nothing left for 'them' to do but beg for spare change to pay rent at the shelter.

SATURDAY JUNE 24, 1995

It is vital that each one of us remembers it is not 1955. No matter how loudly the strident and self-assured voices across the Potomac proclaim that they are restoring the old world order, the clock has not been turned back that far . . . at least not yet. It is still 1995, where we find ourselves at an extremely dangerous point in the life of our nation. The pendulum of what Americans believe government should do and our nation should be is swinging back to a simpler and more simplistic time. Will polio survivors and rehabilitation have any future, let alone their golden years? It is up to us, as individuals, rehabilitation practitioners, and members of this Congress, to insure the future by not allowing the pendulum to swing back and by preventing America from reverting to the paradigms of the 50's.

- We must prevent a return to The Paradigm of Normalcy and instead embrace Paradigms of Quality. Rehabilitation is the one specialty where normalcy - that is the absence of disease or its symptoms - is not the goal. Rehabilitation's focus on function, on nothing less than quality of life is uniquely ours as a specialty.

But, promoting quality is not easy. Recommending that our post-polio patients use new 'abnormal-looking' assistive devices is emotionally painful, both for our patients and for us on the treatment team. However, it is only this departure from 40 years of 'normalcy' that allows our patients to regain function and maintain their quality of life.

Further, promoting Paradigms of Quality will have effects far beyond our clinics. Our philosophy of quality of life places us in the eye of the vitriolic hurricane of debate about life itself. Should an elevated alpha-fetoprotein be an automatic criterion for abortion because no child with spina bifida could possibly have quality of life? Should a C2 quad, like Christopher Reeve, or woman in Wisconsin with CP or the paraplegic director of a post-polio service - be allowed or even assisted to die because having any disability is, as one insurance company describes it, "a living death?" [\[13\]](#)

Our unique experience and philosophy can help this society make reasoned decisions about whether life should end when its quality is gone. In the process, we will begin to eliminate society's notion of disability as "a living death." [\[14,15\]](#)

- Further, if we reject The Paradigm of Normalcy we will also be eliminating The Paradigm of Shame. It must no longer be shameful in America to have a disability. We must end society's view of people with disabilities as 'them.' We must act together to finally end Jerry Lewis' demeaning Labor Day spectacle. We must ask well-meaning A.C.R.M. members to stop injury prevention programs that send former SCI and TBI patients to high schools and Rotary Clubs as a warning to careless drivers and careless divers. The message of these programs is the same as that of the polio poster children forty years ago: "Don't become crippled, like me. Don't become one of the living dead."
- We must also continue to fight The Institutional Paradigm as we have for more than a generation. We must rededicate ourselves to self-advocacy, self-determination and independent living - to Roberts Rules if you will - in memory of polio survivor and vocational rehabilitation pioneer Ed Roberts.
- Finally, we must reject The Paradigm of Cure and replace it with Paradigms of Care and, even more, with Paradigms of Caring. We rehabilitation professionals must be the voice of caring in our society, demanding that Congress set priorities for policy beyond merely cutting the budget deficit. We must state clearly that assuring medical care for all Americans is not the redistribution of wealth, but the redistribution of health; that managed care is not desirable merely because it manages to cut costs. We must demand that the emphasis always be on care that is also carefully managed. We must state unequivocally that medical care is an American's first right, the right that makes possible not only life, but also liberty and the pursuit of happiness.

In 1995, at this extreme point in the life of our nation, we have three choices: We can react, revert and return to "The Adventures of Ozzie and Harriet;" we can remain in the present, recline and retire with "Rosanne" and "ER;" or, we can reject 'us versus them,' normalcy, shame, inhuman institutions and simplistic cures. We can remember our past, remake our present and restore the possibility of a future - and even golden years - for polio survivors and for rehabilitation in America.

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