



Post-Polio Sequelae and the Paradigms of the 50's: Newt, 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 American's believe government should do has swung all the way from FDR's New Deal, gained 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 time warp, will polio survivors - will rehabilitation itself - have any future at all, let alone enjoy their golden years?

1955.

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 fatigability," 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 "fatigability 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. 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 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 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 rooms, 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 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 their 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. They are hard driving, overachieving perfectionists who become the leaders of their communities, their professions, the chief executives of the largest corporations. Normal? Polio survivors transcend mere normalcy to become America's best and brightest as our country's clock runs forward.

FORGETTING POLIO

During the next decades America - along with its more than 1 million polio survivors - happily forget about polio as we experience wonderful advances in rehabilitation and violent changes in our society:

- The Soviet empire was dissolved;
- Wooden legs become polypropylene prostheses;
- Wheelchairs, once wicker and wood, become carbon composite;
- The Cold War "heated up" in a country called Vietnam;
- Paternalistic institutions become independent living centers;
- 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.](#) in 1990
- In 1980, Americans were “glued” to “The Adventures of Ozzie and Harriet.” A TV show that took us back in time to a “better” era.

For America’s polio survivors, the clock had already been running backward. They were being reminded of a 1955 that at was definitely not happy. Forty years after polio, their bodies were beginning to break down as a direct result of the paradigms of the 50’s. Societies’ Paradigm of Normalcy, applied so successfully by polio survivors, was now extracting its price in disabling fatigue, muscle weakness and pain. 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.”

Today, the plight of polio survivors is of no interest to America. Why? Because it’s 1955, again. Polio has been conquered and the posters with photos of Polio afflicted 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. “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?”

Of course, the “few remaining polio survivors” conservatively number an estimated one million in the US (at the time of this article’s publication). Polio is still the second most frequent cause of paralysis, after stroke. And, polio survivors are hardly moribund; our typical patient at the Post-Polio Clinic, is a working mother age 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 1950’s have returned.

It is vital that we all remember that it is not 1955. The clock has not been turned back that far...at least not yet.

- As we go forward, will polio survivors and rehabilitation have any future, let alone their golden years? It is up to us as individuals, as rehabilitation professionals, to insure the future by not allowing the pendulum to swing back, by not allowing America to revert 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 it’s 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 the patients and for our 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.
- 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 physical disability as “a living death.”
- 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 physical disability. We must end society’s view of people with disabilities as “them.” 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 re-dedicate ourselves to self-advocacy, self-determination and independent living - to Roberts Rules if you will - in memory of polio survivor and voc rehab 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 rehab professionals must be the voice of caring in society.

Today, 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 “Roseanne” and “Melrose Place;” 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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