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Polio Survivors Abroad: Canadian Roulette, Rue Britannia

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Over the past few years much heat has been generated by suggested solutions to the difficult problem of reforming the American health care system. A solution promoted by the Clintons', but despised by their free-market Republican opponents, is a single-payer health care system very much like the ones in Canada and Great Britain. Such systems, where treatment is paid for by the government, provide medical care to all citizens regardless of their ability to pay. Or do they?

from the point of view of one disability group in desperate need of rehabilitation services: the survivors of the polio epidemics of 40 years ago. What I discovered made me question whether socialized medicine is really too unsocialized to help people with disabilities.

Northern Exposure:

In Canada medical care is available to everyone without charge. So I didn't anticipate the problems Canadian polio survivors have in obtaining treatment for their Post-Polio Sequelae (PPS), the new and sometimes disabling fatigue, muscle weakness and pain that occur about 40 years after polio.

One problem confirmed the warning I had heard so often during the our own health care reform debate: Canadians can pick their own general practitioner (GP), but cannot chose their own specialists such as physiatrists and orthopedists. The matter of choice may not be an issue when you have a common problem like a broken leg. But

health care can become virtually unavailable when you have a newly discovered condition like PPS that most physicians don't know how to treat.

"Many GPs have never heard of PPS or do not believe PPS is real," explains Judith Lytle, post-polio services coordinator for Ontario March of Dimes. "So polio survivors are forced to play 'doctor roulette,' going from GP to GP until they find one who is informed about PPS and willing to refer to a specialist."

"Many specialists are also uninformed about PPS," warns polio survivor Jeannette Shannon, president of Ontario March of Dimes. "So, referral does not ensure treatment."

Nearly a dozen polio survivors told me similar stories of diagnosis deferred and treatment ultimately denied: Through trial and error a polio survivor finds a GP who has heard of PPS, but knows nothing about diagnosis. She is referred to an orthopedist, but it takes six months to get an appointment. She sees the orthopedist, who believes the condition is real, but is ignorant of the treatment. She is then referred to a neurologist. It then takes six more months to see the neurologist, who does not believe in the reality of PPS, and who sends her back to the GP with the diagnosis "Nothing physically wrong." It took polio survivors about a year to complete this circuit of doctors and still receive no treatment.

"Our goal is to stop 'doctor roulette' by creating PPS support groups throughout Canada that will educate polio survivors, their GPs and specialists about the cause and treatment of PPS," said Lytle. Until this education process is completed, too many Canadian polio survivors will remain stuck suck on this medical carousel, feeling frustrated and desperate as they continue to lose function.

Yet with the help of an enlightened GP, polio survivors in some parts of Canada can receive outstanding care for PPS. Quebec's polio survivors can be treated at the Montreal Neurological Institute (MNI), one of the world's preeminent PPS research and treatment centers. Unfortunately, even MNI is in jeopardy because the Canadian health care system has another problem: It's broke. There are too many people in need of health care and not enough tax revenue to pay for it.

"Deep federal budget cuts last year caused the MNI to eliminate the therapist in the PPS clinic," says Sally Aitken, president of Polio Quebec Association. "The PPS clinic's director was forced to send letters to his patients asking them to mail in contributions to pay the therapist's salary," says Aitken. "Thanks to the members of Polio Quebec, the PPS Clinic is open--for the moment."

The Canadian national health care system hemorrhaging green, and polio survivors are not the only ones in jeopardy. The government has decided to stop paying for surgery to unblock coronary arteries in heart attack survivors disabled by chest pain because such surgery is no longer "worth the additional cost to society." The result? Thousands of Canadians will be left in pain, non-functional and unemployable. Said Canadian Medical Association president Jack Armstrong, the health care system is becoming a "hollow shell of its former self."

Cutting treatment to trim the budget is a terrifying aspect of government-run health care. A federal committee can just decide that rehabilitation for a disabling condition--or even curing that condition--is simply not "worth the additional cost to society." It's the usual short-term thinking. Long term, thousands of citizens will remain disabled, unemployed and consigned to a life at home waiting for their disability check--until there is no money left in the disability budget, either.

Pass the Parcel:

Britain, I imagined, would be more hospitable to polio survivors. A national organization for survivors--the British Polio Fellowship--has existed for more than 40 years, and 1996 was publicized by the BPF as "Polio Awareness Year." But the U.K. is even less hospitable to polio survivors than is Canada.

"PPS is a well kept secret in Britain," says Leicestershire polio survivor Helena Edwards. "And the BPF has taken an ultra-conservative position." In 1995, the BPF distributed a questionnaire to all of its members asking about PPS symptoms. "When 77 percent reported new physical deterioration," Edwards says, "the BPF was frightened off." The BPF declared that the questionnaire was "too long" and had its name removed from the report, this even after the findings were published in the BPF "Bulletin."

Polio survivors and even many BPF members disagree with the organization's head-in-the-sand position. As the only organization for polio survivors, the BPF is ideally positioned to educate Britain about PPS and advocate for treatment. Sadly, it has preferred to continue its traditional role of organizing sporting and social events. It is also sad that the British Government views the BPF as the representative of all polio survivors--even though only 7 percent of Britain's polio survivors are members--and has adopted its inclination to ignore PPS. "I suspect the Government's ignoring PPS has more to do with the British disease of 'old-boy networks' than intentional cruelty," says Edwards. "Nevertheless, we are being hurt by their neglect."

One particularly pernicious example of neglect is the decades-long relationship between the BPF and London's government-funded St. Thomas Hospital. "Whenever we ask the BPF or the government for treatment we are told to go to St. Thomas, a centre for treating respiratory polio in the 1950s," says Edwards, who did go all the way to London for an evaluation. "The doctor's only suggestion was that I should have respiratory testing," Edwards reports. "Nothing was said about my progressive leg weakness and loss of mobility, let alone the possibility of therapy." To date, Edwards has had no treatment for any of her advancing symptoms.

That a St. Thomas doctor should identify only respiratory problems may be explained in part by the hospital's own survey of 208 respiratory polio patients of 40 years ago. Seventy-eight percent reported new "progressive functional deterioration" that was deemed to be caused by "respiratory factors." And although 22 percent were found to have "late functional deterioration" unrelated to breathing problems, new symptoms were always attributable to a clearly defined cause such as rotator cuff tears, arthritis or carpal tunnel syndrome. Although the survey made no mention of late-onset fatigue and muscle weakness, the St. Thomas doctors concluded that not one of their patients had PPS.

St. Thomas's findings are in stark contrast to the survey of 1,200 BPF members conducted by polio survivor Peter Field. Sixty-six percent reported late-onset fatigue, 57 percent reported muscle weakness and only 16 percent reported new respiratory problems.

But St. Thomas's position on PPS came as no surprise to those who know the hospital. After all, it originally treated survivors of respiratory polio, who should be reporting more breathing problems than the general post-polio population. And while patients describe St. Thomas's chief physician as "a lovely kind man," they say his focus on respiratory problems has caused him to be "unable to see the wood for the trees."

"But even if St. Thomas' doctor did see "the wood," and provided comprehensive treatment for PPS, a single hospital in London could not treat all 50,000 polio survivors in England, Scotland and Wales. So in 1994, polio survivor Fred Griffin wrote to local newspapers in the British Midlands describing the neglect polio survivors were experiencing at the hands of the BPF, the government and St. Thomas. These letters encouraged Helena Edwards and Internet maven Jim McVay to join Griffin in forming the Leicestershire Polio Network to lobby county health authorities for comprehensive PPS treatment by local doctors. "Why shouldn't we have treatment locally," asks McVay? "The government's own tallies estimate that there are 1,600 polio survivors in this county alone."

The Leicestershire Polio Network conducted its own survey of local polio survivors and found "a complete lack of diagnosis of PPS, much misdiagnosis, and the widespread prescription of inappropriate drugs and use-it-or-lose-it physical therapies," says McVay. British polio survivors were also caught in their own version of "doctor roulette," what Edwards calls the "pass-the-parcel game, with the patient being the parcel."

Hilary Hallam, secretary of another new polio network in Lincolnshire County, was one of those unfortunate "parcels." A former police officer, lifeguard and occupational therapy aide working with people with disabilities, Hallam developed severe leg pain and progressive leg weakness, then fatigue, pain and weakness in her arms, that forced her to stop working. It took 14 months for her to circulate from GP to orthopedist to neurologist, in the end receiving a tentative diagnosis of nerve root damage and a referral back to her GP. "The neurologist said that I do not have PPS--as it doesn't exist--and that there is nothing he can do," says Hallam. In an attempt to end the parcel passing, Edwards wrote to her county's director of public health about the failure of local neurologists to identify, diagnose and treat PPS. Health department officials spoke

to local neurologists, and replied that the doctors "see only three or four new cases each year of polio patients who develop a form of motor neurone disease. No treatments," it concluded, "are indicated." What's more, the officials were puzzled by the Network's complaints: "You have acknowledged that the service available in Leicestershire does not warrant particular criticism in comparison with others parts of the country."

Edwards was incredulous. "We complain that local neurologists do not recognize PPS," she says. "The health department asks the neurologists if they see cases of PPS and their answer is 'No.' So the health department concludes there is no PPS. We're in a Catch 22."

As for local services not warranting criticism in comparison to the rest of England, Edwards replies, "That's like saying that because there is no food anywhere in the country, no one should feel hungry. Leicestershire is no different from the rest of the U.K. Treatment for PPS doesn't exist anywhere."

Out of frustration, the Network has decided to find other resources, rather than depend on help from the BPF or local authorities. Edwards and McVay have met in Oxford with Hallam, Peter Field and other polio survivors to try to establish Britain's first comprehensive PPS treatment center. Edwards has also met with Britain's Secretary of State for Health and has asked the European Parliament for funding. "It is sad that we have to ask other countries for money to help British citizens," she says. "But Britain has turned a blind eye to its polio survivors." "Understanding the cause and treatment of PPS has progressed in the U.S. by leaps and bounds over the past fifteen years," adds McVay. "Time has been allowed to stand still in the U.K., with terrible physical and emotional consequences. For polio survivors on this side of the pond, the year is still 1980."

America: Dollars or Sense? It may be heartening for America's polio survivors to know that their country is the world vanguard of PPS research and treatment. There are support groups and clinics throughout the U.S. and widespread --though hardly universal-- knowledge about PPS among polio survivors and physicians. Payment for treatment is routine by private insurance, HMOs and even Medicare.

But America's health care system has begun to change and will change even more. Medical care is far too expensive, Medicare and Medicaid are going bankrupt, and there are now 40 million Americans without health insurance.

There is the clear and present danger that politicians, in promising to balance the budget and cut taxes, might just ignore the rights and needs of people with disabilities and create a lean and genuinely mean government-run health care system that denies rehabilitation--or even medical care--to all those they judge not "worth the additional cost to society."

How can health care be provided to all without cleaning out the treasury or neglecting those who most need treatment? I must admit to being an unrepentant liberal. I believe, since our Declaration of Independence guarantees "life, liberty and the pursuit of happiness," that it is the government's responsibility to make "life" possible by providing medical care to all citizens. I had thought that a tax-funded, government-run, single-payer system was the best way to provide that care. But my experience with British and Canadian polio survivors has caused me to re-think my position. Now I just don't know what the solution is.

Whatever the shape of America's health care future, any changes must be made only after considering the failures of both "socialized" and "free-market" medicine, and the rights, needs and input of people with disabilities. Decisions about disabled Americans' life and health should not be made from the government down ... or from the bottom line up. *Dr. Richard L. Bruno is chairperson of the International Post-Polio Task Force and director of The Post-Polio Institute and The International Centre for Post-Polio Education and Research at Englewood (New Jersey) Hospital and Medical Center.*

Resources:

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= Lincolnshire Polio Network, 69 Woodvale Ave., Lincoln, Lincolnshire LN6 3RD; e-mail linpolio@legend.co.uk
= Ontario March of Dimes, Post-Polio Services, 60 Overlea Blvd., Toronto, Ontario M4H 1B6; 416/425-3463, 800/263-3463; e-mail omod@inforamp.net

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