MEDICAL REFORM

Newsletter of the Medical Reform Group of Ontario

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Drug benefit reform – Another view

Drug benefit changes have consequences for low-income patients

By Mimi Divinsky

In the last issue of *Medical Reform* (*Vol. 12, No. 5, December 1992*), there was an article by Dr. Mitch Levine on the Drug Benefit Plan reforms. Many of the evaluation criteria of the Drug Quality and Therapeutics Committee have had longstanding support from the MRG - reducing costs without changing benefit or risk and encouraging physicians to amend ill-considered prescribing practices. Nevertheless, as a GP in a downtown Toronto practice I have had a chance to see some of the consequences to patients living on social assistance incomes, since these changes were implemented at the end of August 1992. At the end of December I wrote to the committee requesting "Special authorization" for a patient of mine, age 67, who reports that he cannot afford to have a telephone in his subsidized rental apartment. He suffers from a severe form of neurodermatitis which finally, after skin biopsy, second opinions, numerous emollients, and other antihistamines finally responded to twice daily Atarax (hydroxyzine) 25 mg. A prescription of 200 tablets (this antihistamine is not available OTC) would cost either ODP or the patient approximately $25. What amazed me were the arguments used in the 'refusal' letter I received, dated January 26, 1993:

> "For all products removed as benefits, the primary issue is *not* whether the products are themselves valid therapeutic agents, but rather whether it is a necessary and effective use of public funds to pay for products that are available without a prescription, at modest cost to the consumer for use in self-medication.
>
> "Since the removal of hydroxyzine from the Formulary as of August 25, 1992, the DQTC has received a number of individual requests for coverage of antihistamines under Section 8(1) of the *Ontario Drug Benefit Act*. The committee has given full consideration to requests to redesignate antihistamines as benefits and to individual requests for coverage and it has concluded that hydroxyzine should not be covered under the ODB program."

I know that other physicians are concerned about the deletion of Gravol (dimenhydrinate), alternatives for which Dr. Levine suggests prochlorperazine or metoclopramide (with reservations). I have no 'scientific' proof, only 10 years in practice to confirm that Gravol *is* effective against nausea, with sedation as a common side-effect.

Dr. Levine supports the deletion of multi-vitamin preparations with the valid argument that a well-balanced nutritious diet precludes their necessity: "Thus a more efficient use of resources would be to spend government funds to provide food to the needy rather than paying for prescriptions of vitamin pills."

To quote Tevye, from *Fiddler on the Roof*, "If they would agree, I would agree."

I would appreciate hearing from readers of the newsletter regarding their own experiences and suggestions for 'lobbying' on this issue. I find this contradiction between policy and practice a difficult one to sort out.

Hot line for patients needing de-listed drugs

Earlier this year the Ministry of Health managed to trim its budget substantially by making changes to the Ontario Drug Benefit Plan. One of the effects of these changes was to take some drugs off the list of drugs that the Plan pays for.

Some patients cannot find a suitable substitute for an unlisted drug. People with this problem can ask their doctors to write a note asking for the Plan to cover their special drug needs. Requests from doctors must be medically specific. Criteria may include:

- no alternative drug
- if the drug is needed in combination with other drugs
- if using a substitute drug will lead to toxic or harmful effects
- if the unlisted drug is needed to combat an infectious disease, or
- if the drug is needed to combat a life-threatening condition.

Ministry staff report that the applications process has become bogged down with requests for coverage for drugs of a more elective or less costly nature, such as vitamins. The service is intended for the treatment of serious conditions where drugs are costly and income is a problem.

For information, contact the Ministry's hot-line at 1-800-268-1154.

INSIDE

Science supports case for brand name drugs

The following article supporting the Progressive Conservative government's new patent legislation appeared in the Globe and Mail, 24 December 1992. A response written by the Medical Reform Group's Gord Guyatt (see P. 3) appeared on 14 January 1993.

By John T. Edward

"The destruction of compulsory licensing in Canada," consumer advocate Ralph Nader told a news conference in Ottawa, "is the first wedge toward undermining and bringing down the universal medicare system as you know it..."

Mr. Nader was brought to Ottawa by the Canadian Consumers Association, which has been campaigning against Bill C-91, (on patent protection for drug companies), for obvious reasons. He is the consumers' Mother Theresa. It seem sacrilegious to contradict him, but on this issue he's wrong.

Bill C-91, now before Parliament, would extend patent protection for new drugs to 20 years, bringing Canadian patent law into line with that of other industrialized countries. It is supported by the brand-name pharmaceutical companies and opposed by their generic competitors. The legislation has been endorsed by almost every professional scientific association in Canada concerned in the health sciences: chemists, biochemists, physiologists, pharmacologists, clinical investigators and others.

The arguments of scientific experts might be expected to carry some weight. But in casual conversations I have found that none of these arguments, technical or ethical, seems to have reached thoughtful Canadians. They have heard only the shrill contentions of consumer advocate groups, endlessly repeated by radio and TV commentators calling for cheap drugs for the people, not big profits for the multinational drug companies.

Can the scientists be wrong? Let's look at the arguments.

They point out that since 1940, medical practice has been revolutionized by new drugs, starting with antibiotics such as penicillin and streptomycin. Such drugs and vaccines have almost eliminated polio and tuberculosis; pneumonia is now rarely fatal, and a range of other killer diseases has been brought under control.

The drugs that made this possible have come from about 30 big pharmaceutical firms based mostly in the United States, Switzerland, Germany, France and Britain. These multinationals make large profits, and are the villains in the demonology of Ralph Nader, NDP Leader Audrey McLaughlin et al.

Their profits need to be large, because the costs of discovering and testing a new drug are astronomical. When a company sets out to find a new drug for a specific disease, it can expect to have to synthesize and test about 10,000 new compounds in its laboratories. Most of these will prove inactive; of the few found active, many will turn out (after large-scale animal testing and then clinical testing on humans) to have undesirable side-effects. The final successful candidate then has to be cleared by Ottawa's Department of Health and Welfare before it can go on the market.

About 10 years will elapse from the time the chemist starts work in the laboratory until the product reaches the drugstore. A small army of chemists, biochemists, toxicologists and clinical physicians is involved, and on average the total cost is more than $200 million.

Only a large and wealthy company can afford to invest $200 million before it sells a single pill. But if it has patent protection for a reasonable length of time, it can sell the drug at a price that covers not only the cost of making, packaging and distributing it, but also the much greater costs of discovering, testing and developing it.

After the patent expires, the drug can be copied by a generic manufacturer, which conducts essentially no research and development, its costs need cover only production. Since these costs are much lower than those of the brand-name manufacturer, generic drugs will always be cheaper.

That's why adequate patent protection is important: no protection, no new drugs. And while the multinationals have had many successes, they face many unsolved problems: Alzheimer's disease, AIDS, most forms of cancer, asthma, even the common cold.

Bill C-91 will bring Canada into line with other industrialized countries in giving drug companies 20-year patent protection, which all other manufacturers in Canada enjoy for their invented products. It will remove the discrimination that started with the Trudeau government's Bill C-102 in 1969, which provided only four years of patent protection. That bill let a generic manufacturer market a drug if it paid a 4-per-cent royalty to the company that had invented it – an absurdly low amount in view of the huge expenses of research and development.

Had other governments followed Canada's eNxample and abolished adequate patent protection, they would have had the cheap drugs that Canada's Liberal government was so proud of, but the multinationals would have collapsed and the discovery and development of new drugs would have stopped.

One of these would have been cimetidine or tagamet, introduced in the mid-1970s, which cures gastric ulcers without the need for surgery. Since it costs $800 a day to keep a patient in hospital, and more to pay the fees of surgeons, anesthetists and others involved in surgery, it is obvious that the introduction of even expensive cimetidine represents an immense saving for a government health scheme.

This example could be multiplied many times. The new drugs introduced by Western multinationals have largely eliminated tuberculosis and other diseases that filled whole hospitals 50 years ago. In 1988, hospitals and institutions accounted for $26 billion of the more than $50 billion total cost of the Canadian health care system. Professional, medical and dental services accounted for $12 billion. Prescription medicines accounted for $2.8 billion.

Drug costs are high, but they are a small fraction of the costs of running hospitals — and hospital costs would be $10 billion to $20 billion higher if the multinationals' new drugs had not appeared in the past 40 years.

As for Mr. Nader's point about undermining medicare, it should be noted that Germany, France, Britain, Sweden and other European countries all have 20-year patent protection for new drugs *and* universal health-care services like those in Canada. It is possible both to protect intellectual property by patents and to have comprehensive health care.

John T. Edward is an emeritus professor of chemistry at McGill University. Several students trained by him have gone on to research careers in the drug industry; he himself has never had any financial connection with the industry.

Higher costs for health care, higher profit for industry

By Gordon Guyatt

It is ironic that John Edward, in his attempt to justify the extension of patent protection for the multinational pharmaceuticals industry, dons the cloak of science [*see P. 2, Science Supports the Case For Brand-Name Drugs*]. His arguments in favour of Bill C-91 ignore the principles and findings from two branches of scientific research, epidemiology and health economics.

Prof. Edward maintains that scientists attribute the elimination of polio and tuberculosis, and the control of pneumonia and other diseases, to new drugs and vaccines. While drugs have had a substantial impact on decreasing morbidity and mortality, their contribution is best seen in a wider context. Scientists have shown that most of the reduction in illness and death in this century is due to improvements in nutrition, sanitation and housing.

By the time drugs and vaccines were introduced, mortality rates were already dropping sharply. The death rate from tuberculosis, 1,400 per million in 1900, had dropped to 500 per million by the time the first anti-tuberculosis drug was introduced. Approximately half the reduction in mortality from pneumonia between 1931 and 1965 preceded the introduction of antibiotics into clinical practice.

Vaccines have also had a limited role in decreasing mortality. By the time the vaccine for pertussis or whooping cough was introduced in 1950, the death rates had dropped from their 1900 level of 1,000 per million to 50 per million.

Given the sharply falling death rates at the time antibiotics and vaccines were introduced, how much of the subsequent drop was due to drugs and vaccines? A clue comes from measles vaccine, which was introduced relatively late. The death rate from measles in children under 15 was approximately 1,000 per million in 1900, and had dropped to less than 10 per million when the first vaccine was introduced in 1965. Clearly, drugs and vaccines have not been the major factor in increased longevity.

Prof. Edward's article goes on to cite drug development costs of more than $200 million per compound. This figure is misleading.

This $200-million estimate excludes drugs that are developed in co-operation with governments and universities, and new drugs that are modifications of existing compounds. In both these instances, costs may be substantially lower. In addition, the article does not mention that $117 million of $200-million-plus in development expenses is the "opportunity cost," the lost earnings that could be achieved if the money were invested where it would achieve a quicker return.

The article uses the example of cimetidine, used to treat ulcers, to claim that new pharmaceutical agents save money. It says the drug "cures" ulcers and avoids surgery, and there is an overall net cost saving. Cimetidine is no cure, and many ulcers recur when the drug is withdrawn.

Drug therapy for ulcers is costly, and patients require monitoring. As a result, it is far from certain that, for the individual patient, long-term drug therapy for ulcers is any cheaper than curative surgery.

In addition, cimetidine and other drugs in its class are used inappropriately 50 per cent of the time, generating cost but no benefit, and possibly harm. Dealing with side effects from drug therapy also adds to costs.

The article states that "it is obvious that the introduction of even expensive cimetidine represents an immense saving for a government health scheme." In fact, the best available study indicates that direct medical costs have increased as a result of cimetidine.

How many new drugs really improve health? The Patented Medicine Prices Review Board tells us that of 162 new drug products introduced into Canada from January, 1988, to December, 1990, only eight represented substantial improvements.

Prof. Edward's estimate of $10 billion to $20 billion cost savings as a result of new drugs is pulled from the air. This estimate might be plausible if most drugs cured chronic conditions that otherwise require much continuing health care.

This is not the case. Few drugs are curative, and many require expensive, long-term administration. Drugs that prolong life do not save money for the health-care system. When people are dead, they cost nothing. Survivors with chronic illnesses consume large amounts of health-care resources. Further, there are many widely prescribed and costly drugs with very limited benefits.

Finally, there are costs of drug side effects. The best estimate is that 10 per cent to 20 per cent of hospital admissions in Canada in those over 65 are a result of adverse drug reactions.

Thus, while the net impact of the introductions of drugs on health-care costs is speculative, it is extremely unlikely that they have generated the huge cost savings that the article suggests.

All this is not to say that development of new drugs isn't important. It is. The real issue is, how much profit do multinational drug companies need to continue developing new agents?

When considering the development costs of drug companies, it is worth keeping in mind that at the break-even point, all their costs have been covered. How much profit beyond that point is fair and just?

Do the multinational drug companies really need an annual after-tax profit of more than 25 per cent on their capital, as they have achieved in recent years in Canada? Do they really need a return on share-holders' equity more than 50 per cent higher than the median of the Fortune Top 500 companies, as they have achieved in the United States?

The answer is no. They could develop new drugs without such exorbitant profits.

Bill C-91, the government's legislation that will further lengthen patent life for the pharmaceutical industry, will significantly increase costs to the government and to health-care consumers. This is a major threat to an already burdened system.

If the legislation is passed, the provincial governments must raise their taxes further or cut back on non-drug health-care expenditures, all to ensure the huge profits of the giant drug companies. The legislation is another example of the federal government selling out Canadian interests in favour of those of multinational corporations.

Gordon Guyatt is a professor of clinical epidemiology and biostatistics and of medicine at McMaster University.

This article appeared in the 14 January 1993 issue of The Globe and Mail.

USA Today: Organizing for health care

By Rosana Pellizzari

After Bill Clinton's victory in the U.S. elections in November 1992, health activists from all parts of the United States converged in Little Rock, Arkansas to deliver their message to the President-elect: "We represent the demand of the American people for a health care system that resolves the cruel obstacles, shameful waste, and profiteering that can no longer be tolerated".

The 1000 activists represented the first national organizing effort of a fledgling network. UHCAN!, Universal Health Care Action Network, based in Cleveland, Ohio, had been conceived at the Universal Health Care Strategies Conference which took place in Washington, D.C. just five weeks prior to the demonstration in Little Rock. The conference, attended by over 2500 people from 34 states, served as a catalyst for the formation of the network which acts as a clearinghouse and coordinating centre for the hundreds of state coalitions and health reform groups. Currently housed in the offices of Northeast Ohio Coalition for National Health Care, UHCAN! will facilitate communications and organization of a stronger, more cohesive, national lobby for a single-payer, universal coverage health care program. This represents a significant step forward in the growing movement for more just and equitable access to health care.

Dr. Ken Frisoff, a family physician working at the Clements Center in inner-city Cleveland, is the interim convenor of UHCAN! and President of the Northeast Ohio Coalition for National Health Care. He writes, "The parallels between the civil rights movement and today's universal health care activism are striking. In both, activists are motivated not by narrow self-interest, but by a vision of social justice and human rights. Second, while united in principle, they are diverse in background, skills and interests. Third, they recognize that in order to succeed, they must focus their efforts on the political process."

I had the pleasure of speaking in Cleveland recently about the strengths of the single payer model. At Family Practice Grand Rounds, we contrasted and discussed the financial barriers to health care access experienced by Americans, to the cultural, linguistic, class, and administrative barriers experienced by people living in Ontario. They were eager to learn about the progress being made in Ontario in shifting away from the health care = health paradigm, to the conceptual framework which includes the broader determinants of health.

The Medical Reform Group continues to support the efforts of groups and coalitions like UHCAN! through the provision of speakers and the exchange of information. Stay tuned for the upcoming presentation of the documentary, "Doctor to Doctor", a project funded by Physicians for a National Health Plan, which will include interviews with several MRG members.

Medical Reform

Medical Reform is the newsletter of the Medical Reform Group of Ontario. Subscriptions are included with membership, or may be purchased separately at $25/year. Arrangements to purchase multiple copies of individual newsletters or of annual subscriptions at reduced rates can be made.

Articles and letters on health-related issues are welcomed. Submissions should be typed (preferably double-spaced), or submitted on IBM-compatible computer disks (any program, but tell us which program you used.)

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The Medical Reform Group of Ontario is an organization of physicians, medical students, and others concerned with the health care system. The Medical Reform Group was founded in 1979 on the basis of the following principles:

1. Health Care is a Right
The Universal access of every person to high quality, appropriate health care must be guaranteed. The health care system must be administered in a manner which precludes any monetary or other deterrent to equal care.

2. Health is Political and Social in Nature
Health care workers, including physicians, should seek out and recognize the social, economic, occupational, and environmental causes of disease, and be directly involved in their eradication.

3. The Institutions of the Health System Must Be Changed
The health care system should be structured in a manner in which the equally valuable contributions of all health care workers in recognized. Both the public and health care workers should have a direct say in resource allocation and in determining the setting in which health care is provided.

National health care gets boost

By JOAN M. MAZZOLINI
PLAIN DEALER REPORTER

CLEVELAND

Canadian doctor Rosana Pellizzari was in Cleveland last night to dispel some myths about her country's national health care program.

"There's a pervading myth and exaggeration in the U.S. about waiting times in Canada for health services," Pellizzari, a family practitioner, said in an interview before her talk last night to local doctors involved in the U.S. organization, Physicians for a National Health Program. The program was at Case Western Reserve University.

"There are no waiting lines for urgent surgery," she said. "There are waiting periods for elective surgery like hip or knee replacement."

Pellizzari said that Americans might view a six- or eight-week wait for a hip replacement in Canada as a weakness of that system because insured Americans might be able to get that same surgery done within a week after diagnosis.

But, she said, the poorest Canadians get the same amount of heart bypass surgery as the richest Canadians, proving that residents have equal access to the medical care they need.

"That's the compromise," Pellizzari said. "My aunt might have to wait for her knee surgery, but everyone's aunt has equal access to the surgery."

Pellizzari, president of the Association of Ontario Health Centres, works at a community health center in Toronto.

She said another misconception Americans had was that Canadians were coming across the border in droves for medical care. She said studies done at the border areas, such as Buffalo, showed less than 1% of the services in those American hospitals went to Canadians.

But Pellizzari said that in some instances the government would rather fly someone to the United States than buy a $5 million piece of equipment needed by one patient a year.

While the Canadian system is a national program, it actually is made up of 12 systems that operate in the two territories and 10 provinces.

Each province's program operates slightly differently, but they all get money from the national government.

For example, Ontario received $17 billion in 1992. About $5 billion was for the doctors, $8 billion for the hospitals and the rest divided among areas such as mental health, public health and emergency services.

In some provinces, all prescription drugs are covered. In Ontario, drugs are covered only for senior citizens, welfare recipients and those with catastrophic illnesses such as AIDS or cystic fibrosis. Private insurance has taken up the slack, and many Ontario residents buy it to cover medications.

There have been many changes over the years to make the program more efficient and equitable, Pellizzari said. For instance, the national government passed the Canadian Health Act in 1985 making it illegal for doctors to charge fees above what the government had agreed to pay.

FIDGUS CHAN

ROSANA PELLIZZARI: "There's a pervading myth and exaggeration in the U.S. about waiting times in Canada for health services."

Some doctors had tried to get around the system by charging patients extra.

The government also has instituted a salary cap for all doctors. Pellizzari said the most a doctor can earn in Ontario is $400,000, with the salary cap varying for different specialties in different provinces. She said most family physicians earn about $120,000 a year, similar to what a family practitioner makes in the United States.

To keep and entice doctors into the underserved remote areas, the government has established a higher salary cap.

Remuneration of physicians: Another opinion

By J. V. Frei
Professor of Pathology

I am writing in response to the December Newsletter which asks for input from members about remuneration of physicians. This is something all of us must have been thinking about for some time. I find it difficult to consider that point without considering the entire financial structure of the Health Service, which we, I think, all agree is one of the best in the world. A point immediately emerges: we must not kill it!

One of the major psychological problems with the Welfare State is that it engenders the feeling that we have rights to its benefits without having corresponding responsibilities. I think the era of rights without responsibilities has come to an end. I therefore think that the Health Insurance system must become exactly what the term, hidden in an acronym such as OHIP, means: we get what we pay for. The nationwide system should, in my view, be independent of all other government moneys financially and administratively. It should not get money from general revenue but from specific monthly deductions from pay or contributions from self-employment income. The contributions would be the same for everyone who pays taxes and everyone should get the same quality of service, as need arises. Decreasing contributions could be assessed at the low income end of taxable income. It could be debated whether the contribution should continue, possibly at a reduced rate, after retirement at whatever age it occurs. Each province's scheme should be, as at present, committed to the principle of universality of service in Canada with complete reciprocity. Each provincial system should be governed by a small body (say 12 people) representing government, the health service professions, and the general public in equal proportions and each should send a delegate to a 12 member (remember the territories) National Board responsible for interprovincial coordination.

The problem of remuneration is a very complex one. On the one hand we do not wish to pay for unnecessary services, but on the other hand we must maintain incentives which would reward initiative and hard work - without these the system would be fatally weakened in time. I think that salary or capitation have the potential not the satisfy the preconditions I just outlined. Furthermore, the fee-for-service system is traditional, has worked well for a long time, and allows for rewards for hard work under certain conditions.

I submit that it will be more effective to examine the conditions for an improved and effective fee-for-service system. I believe that physicians and other health professionals could be paid for each procedure they perform for a patient. I define for the purpose of this discussion "Procedure" as any contact of a health professional with a person seeking advice or treatment. There would, however, have to be specific definitions of all procedures on a Canada-wide basis. Specifically, for each procedure there would be written conditions: indications, methodology considered adequate for performing it, the required facilities, the appropriate qualifications of the health professional performing them, the required follow-up, the time the procedure is deemed to take, and the fee. These conditions in lay terms should be given to the patient in printed form.

A number of desirable consequences would result. Only procedures deemed effective (see below) would be paid for, industry would be rewarded provided the time billed for would not exceed something like 70 hours a week, and procedures would be performed by qualified practitioners in appropriate facilities. The fees could be adjusted upward by a set percentage in under-serviced areas, say by 15% in Northern Ontario north of the French River.

It is my understanding that in Ontario the Joint Committee is working towards definitions of this type. Ideally, and in time, each procedure would be defined on the basis of clinical trials reported in the world literature or performed under contracts put out for competitive bidding by the Health Insurance boards from their finances. Initially, financial contributions by government would be needed to get the system under way. Initially also, many procedures would be defined on softer grounds than clinical trials, i.e. accepted under "grandfather" clauses. Once the system is functioning, a regular review of all procedures would be needed at variable intervals suggested by those initially defining them, or as need arises.

Room must be made for the development of new procedures. New procedures would be accepted by the health insurance system only if developed under peer-reviewed grants with appropriate ethics approval under such auspices as the MRC, NCI, or other similar agencies, including provincial health grants.

In order to reward initiative and inventiveness, both the contracts for defining procedures and the grants to develop new ones should, unlike present practice, provide a significant contribution to the investigators' income.

This proposed system would be labour-intensive in the definition and development areas, but for a very good and logical purpose: to provide the best appropriate health services. At the same time it would provide employment in the "service" sector of our economy, the one that economists seem to consider as the most suitable for expansion at the current state of our highly automatized agriculture and manufacturing industry. It seems we will be spending more of our income in the future on serving others than on growing food and producing machines.

Perhaps these thoughts will be of interest in the current deliberations about money and health care.

De-institutionalization

A noble concept that is often abused

For provincial governments stung by cutbacks in federal transfer payments and looking for ways to cut health care costs, the term "de-institutionalization" is coming back into fashion. The word may be difficult to pronounce but the concept is simple. de-institutionalization means taking people out of large institutions and relocating them in smaller facilities in the community, or providing them with home-based services. In theory, this one move provides a dual benefit. De-institutionalization is, on the one hand, enlightened social policy: it's all about taking people with special needs out of a segregated, confined environment and putting them back into the mainstream of society. And at the same time, in the long-term, it's a cheaper model that allows government to cuts its expenses.

Here are The Facts:

While trade unionists and citizen advocates generally agree that the concept of de-institutionalization is a good one, there are major qualms about it's execution. In the past, government concern with cost-cutting has short circuited the concept's social goals. Poorly-financed and poorly-planned processes of de-institutionalization have been disastrous.

As provincial governments across Canada contemplate a new round of de-institutionalization in the health services sector, there are signposts from the past that clearly show the need for caution and proper planning. Input from all concerned parties is essential for the success of any move from institution to community. So is sufficient funding. Unfortunately, the issue is often framed in a way that cuts off critical debate.

"De-institutionalization has motherhood and apple pie written all over it," says Steve Sanderson, president of CUPE local 1521 in Ottawa and a front-line worker in developmental services. "So it becomes very difficult to criticize." Sanderson makes it clear that he's not critical of the objectives of de-institutionalization. "I know of people who ten years ago were in institutions who now live independent lives. It was a tragedy for them and we're glad they're out." But he also says that by underfunding community-based alternatives, governments have created situations where difficult, disruptive clients have been placed in group homes without adequate supervision, where the range of services have been cut-back, and where it's difficult to accept new clients into programs from the community.

Critics potrayed as enemies

A lot of this sounds familiar to Harry Beatty, staff lawyer at the Advocacy Resource Centre for the Handicapped (ARCH) in Toronto. About a decade ago, when Beatty worked for the Association for Community Living, the Ontario government started moving people with developmental handicaps out of institutions and into communities. Beatty believes the

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government deliberately created an adversarial climate to distract attention to the fact that "beneath all the rhetoric of a great social advance, there was a hidden cutback." Anyone who criticized the government's pre-arranged blueprint for de-institutionalization was labelled an enemy of community living.

"It became seen as 'we and they'," says Beatty. "Everyone got into a big fight, and the people who's interests were supposed to be first — the residents — were often lost."

Beatty says that while many people moved successfully into the community, others were put into worse situations because their wishes weren't taken into account. Some were simply shifted from one institution to another, to suit the government's plans for economic rationalization. Others wound up in foster homes or other settings where they were separated from old friends and familiar ways of life. Some of the people who were unhappy left their new homes. "Frankly, we don't know where a lot of those people are now," says Beatty. There was no provision for follow-up or monitoring to chart the progress of de-institutionalized people.

But by far the most dramatic examples of de-institutionalization gone awry are in the mental health area. Canada had advanced warning of what could happen, given the experience south of the border. While Saskatchewan put in place an extensive network of community service to replace most institutional psychiatric care in the mid-1960s, Ontario chose to follow the American model...with the same, disastrous results. In the United States, President John Kennedy's plans for a community alternative to state mental hospitals, degenerated into the practice of simply dumping patients onto the streets. Between 1955 and 1975, the resident population of state mental hospitals dropped by 65 per cent. But emergency admissions nearly doubled between 1955 and 1972, due largely to the "revolving door" syndrome: ex-patients who had wound up in nursing homes, cheap hotels, and on the streets, were commonly re-admitted several times a year at times of crisis.

An Ontario tragedy

A similar tragedy was to be played out in Ontario. Plans for de-institutionalization drawn up in the 1960s gave rise to a major social crisis which had become front page news by the early 1980s. With the closure of institutions like the Lakeshore Psychiatric Hospital, Toronto's Parkdale neighbourhood became a "ghetto" for ex-psychiatric patients who were thrown into the community without proper accommodation or support services in place. Community organizer and author Pat Caponi, herself an ex-psychiatric patient, told the Canadian Council on Social Development's 1984 symposium on de-institutionalization that, while life in psychiatric institutions had been dehumanizing, the government's alternative was worse:

"As near as I can understand, once the professionals had twigged to the fact that hospitalization creates its own problems and difficulties, the government and the doctors reacted as though bubonic plague had been discovered. Haste was deemed necessary to prevent further infection. It did not seem to matter that most of the people had long since experienced the worst the disease could do to them. Radical and instant surgery was performed in hospitals all over the country. With a bus ticket and the address of a boarding home, a hostel or the Sally Ann, thousands were supposedly saved from the dreaded onslaught of the institutional bug. The first truly criminal act performed by both the government and the professionals was that little or no attempt was made to prepare the patients for their departure, or to get them used to the idea of living in the real world again. People who had been in hospital 10, 15 or 20 years were shown to the front door where a special kind of hell awaited them."

Part of that hell was falling prey to unscrupulous landlords who charged extortionate rates for space in broken down, dangerous boarding houses. Often, between 30 and 70 people were crammed into a house, where they received inadequate meals and often experienced violence. Although some appropriate housing has been created for ex-psychiatric patients since the early 1980s, many of the worst effects of de-institutionalization — such as homelessness — remain. In May, 1990, a publication of the Ontario Public Service Employees Union (OPSEU) reported that 10 per cent of the clients of a Toronto recreation centre for ex-patients are homeless, living either in shelters or on the streets. Fifty per cent of the centre's clients were jailed during the 1988 G-7 economic summit, part of a police "clean up" of the streets. And it's estimated that 25 to 30 per cent of inmates of Toronto's overcrowded remand centres have psychiatric disorders.

Worrying Stories

Since that fiasco in mental health services, de-institutionalization has not produced any disasters on the same scale. But across the country, there are worrying stories about government penny-pinching undermining the promise of community living and creating new problems and dangers. A common complaint is that specialized services once available in institutions have been lost, with the result that clients with specific needs often wind up in places where they can't be properly cared for. Here are some examples:

- In Portage LaPrairie, Manitoba, the province's "welcome home" program has moved developmentally handicapped people from a large institution into foster homes and group homes. But as some of the older clients developed physical problems, the group homes found themselves ill-equipped to meet their needs. The clients can't go back to institutional beds that have been eliminated, or move into nursing homes that are also understaffed. So they've been transferred to active hospitals.

- Marge Archer, a hospital workers and vice-president of CUPE Local 1390, says that an acute-care hospital ward is no place for these clients. "Nurses with acutely ill patients don't have time to watch over them," she says. "Some of them are wanderers. They don't realize they shouldn't walk off the ward or into the operating room, which has happened." In addition, these patients receive inadequate attention: they are unable to be with their friends or to participate in the activity programs that are available in more appropriate surroundings.

- A recent CUPE report on violence against staff in Nova Scotia's nursing homes attributes part of the problem to clients with special needs being sent to places without the staffing or resources to deal with them. The report advises that nursing home residents with severe emotional or psychological problems should be placed in more specialized centres where they are not a threat to staff or other residents. It also recommends special care for Alzheimer's patients, and new funding for the assessment of residents' needs.

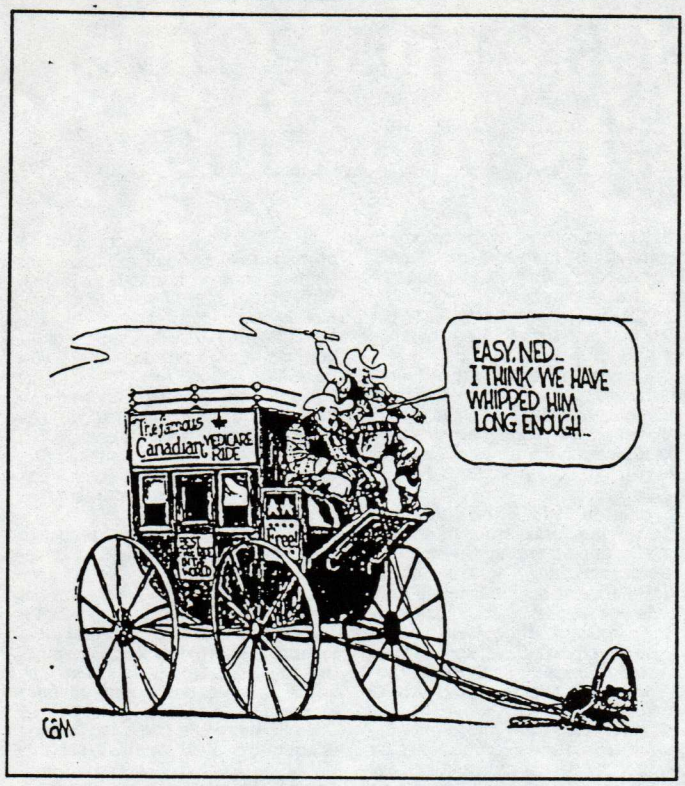
- In Ottawa, the last clients coming out of institutions for the developmentally handicapped are those with physical disabilities or behavioral problems. But this new demand on community services corresponds with a decline in funding. When de-institutionalization began, there was the expectation of funding increases of 5,6 or 7 per cent per year. Now, increases of 1 per cent or less mean that community services can't even keep up with inflation — let alone provide the staffing required for clients needing extra physical care or supervision. Temporary funding for one-to-one situations is sometimes available but can just as easily disappear. Clients who are violent towards fellow residents have been difficult to control, but administrative considerations make it difficult to send violent clients back to institutions. "People come out of institutions with dollars attached to them," explains Steve Sanderson. "So the organizations don't want to let them go."

De-institutionalization has also put pressure on families in the Ottawa area. With no expansion of group homes or day programs - and all new openings being filled by clients from institutions — there are hundreds of people waiting for admission. "There are older parents in their 60s and 70s who maintain their sons and daughters at home," says Sanderson. "But there comes a point when you just can't continue looking after someone; you need someone to look after you. It's not only a terrible burden for the families but a terrible worry: "What's going to happen to my son or daughter if I die? Will they be taken care of?"

Problems With Community Boards

There are also concerns that de-institutionalization has allowed the provinces to abdicate responsibility for quality of care, by handing power to community boards. Lorraine Sigurdson, CUPE staff representative in Manitoba, says that quality of care in the province's group homes varies according to the board's performance. "If you've got a good board that's got lots of smarts, things will go well," she says. "But if not, the money just won't get there. We see community boards — particularly in rural areas — that don't have a lot of expertise in applying for grants, in getting money."

The effectiveness of a community board has also come to the fore in Trail, B.C., where a period of acrimonious relations between workers and management of the Trail Association for Community Living (TACL) culminated in the fire-bombings of two Association employees' cars. One had just won an arbitration for wrongful dismissal; the other had reached a settlement to return to work after she had been involved in "blowing the whistle"



on alleged management wrongdoing. Since the firebombings, the province has taken charge and put the Association's manager on probation.

Wes Hughes, president of CUPE Local 2087 in Trail, believes the situation got out of control because TACL's board didn't have control over the management. With de-institutionalization, he says, "the burden of care has been shifted onto the shoulders of families and good-minded people in the communities, who don't necessarily have any knowledge or experience running an organization." The result in Trail, Hughes believes, is that the board gave free reign to the managers it hired, and became a mere "rubber stamp".

The next frontier

The next frontier for de-institutionalization is hospital services. There has been some experience of this in New Brunswick, where employees are wary of emerging trends. The McKenna government has pledged to rationalize the system by closing beds at small community hospitals and shifting use to larger, regional hospitals. Community health centres known as "extra mural hospitals" would also take up some of the slack. But one problem is that the extra-mural hospitals are only 9 to 5 operations, and emergencies can happen anytime. "If your child is sick in the night, what do you do?", asked Maureen Michaud, CUPE staff representative in Fredericton. "It could be a long way to the regional hospital."

Michaud is also concerned that the community-based alternatives that have been promised, might not materialize. "You don't have the community structures out there," she says. "Part of the community based model is preventative health care. If you don't have any preventative care, you'll wind up in a major institution on your death bed, but there's nothing before then."

Positive Solutions

Positive suggestions are being made about how the snags in de-institutionalization plans can be fixed. In British Columbia, for instance, the B.C. Teachers' Federation has proposed some measures to correct problems with the integration of special needs students into the classroom. There has been widespread complaints that teachers and teachers' aides have not received adequate training, and that the necessary facilities have not been budgeted for. CUPE B.C.'s submission to the province's Royal Commission on Health Care, for instance, notes some cases where, due to the lack of facilities, students have had diapers changed in crowed classrooms.

The B.C. Teachers have taken aim at the training question with a package of five proposals designed to develop resource materials and to share, within the system, knowledge about specific disabilities and effective classroom techniques. The federation is asking the ministry for $178,000 to implement its plans.

Meanwhile, Steve Sanderson in Ottawa says community services can be improved by reallocating funds. "We still see a lot of fat in the bureaucracy," he remarks. Money is still available for purchasing computers and fax machines, and several service organizations in the Ottawa area have recently moved into much more expensive quarters. "But you don't need posh offices to do this kind of work," he says.

Ultimately, it is important that money go into services. The 1991 Vickers report to the Ontario government, stated that the development of comprehensive community services was one of the two essential preconditions for the success of de-institutionalization. Many people believe that costs will need to rise during the transitional phases, not fall. Past experience has shown that, if the investment is not made up front, there will be higher social and financial costs later.

– Stephen Dale

Take two big doses of humanity and call me in the morning

By David South
SPECIAL TO THE STAR

"ANYBODY going into medicine should read a whole bunch of good novels." Dr. Alvin Newman isn't kidding. The head of curriculum renewal at the largest English-speaking medical school in the world, the University of Toronto, feels strongly that doctors have been ill-prepared for their profession's challenges.

How doctors become doctors is being hotly debated as Ontario's five medical schools institute a potpourri of curriculum reforms. After a century of taking a back seat to scientific achievement, bedside manners and the art of medicine are in vogue once again.

"Around the world, medical education is undergoing significant changes," says Newman. "Medical schools must strike a balance between the incredible explosion of scientific knowledge and re-establishing the role of the physician as wise counsel and empathic healer."

It's a role that many feel doctors have ignored. An American Medical Association poll, conducted between 1985 and 1988, found that fewer than 50 per cent of respondents said they thought doctors listened well and half believed doctors no longer care as much about patients as they used to.

In response to these criticisms, current reforms are shifting medical education away from reliance on the turn-of-the-century science-based approach, says Professor Jackie Duffin, a medical historian at Queen's University who helped organize the new curriculum introduced there in 1991.

"In the old days doctors could probably make a diagnosis and tell people what was happening to them, but not do very much for them," says Newman.

"Yet society had more trust and fondness for physicians than they do now. Much of the condemnation of the medical profession is because we have become the custodians of high-tech medicine."

While the Ontario government embarks on the most sweeping reforms to health care since the 1966 introduction of comprehensive health insurance in Ontario and the founding of national medicare in 1968, many doctors feel their profession cannot afford to maintain the status quo.

The consensus at Ontario's five medical schools — U of T, Queen's, University of Western Ontario, University of Ottawa and McMaster University — has gelled around a belief that doctors need to be as comfortable dealing with people as they are with scientific medicine. To this end, revamped curricula supplement basic science and clinical medicine with emphasis on early exposure to patients, communication skills, psychological issues, medical ethics, medical literacy and health promotion.

These schools hope to produce new doctors to fit into a rapidly-changing health care system — one that many believe will rely far less on large hospitals.

Instead, many procedures will take place in the home or in day clinics. Expanding community health care centres will try to tackle extensive social and health problems ignored by hospitals, while nurses and other professionals encroach on the physician's long-protected medical domain. An increasingly diverse and grayer population will make things even more complicated.

Until recently, most of Ontario's medical schools shunned the innovative approach to medical education pioneered by Hamilton's McMaster medical school.

Since its founding in 1967, McMaster has experimented with teaching methods that steer away from mass lectures to concentrate on the individual student. The evolution of McMaster's curriculum has placed greater emphasis on communication skills, psychosocial aspects of medicine, community issues, and disease prevention and health promotion.

How do McMaster students rate against other med students?

Last year they scored above the national average on licensing exams. A higher proportion of McMaster students enter research and academic medicine than their counterparts from other schools. One study comparing them to U of T suggested they were more motivated to be life-long learners.

Dr. Rosanna Pellizzari practises the kind of medicine everyone is talking about these days. Working out of a renovated church, Pellizzari's practice at the Davenport/Perth Community health centre in west-end Toronto serves a working class neighborhood that has been home to generations of recent immigrants.

A member of the Medical Reform Group — which has long advocated significant reforms to health care — and trained at McMaster, Pellizzari can be seen to represent the doctor of the future: Sensitive, salaried and working in community health.

"McMaster's curriculum attracts people with innovative ideas," says Pellizzari, who was active in community health education before going to medical school. "It is a very supportive environment.

"I think the important question is: Who do we choose to be medical students? They should open up medical schools to those who know what it's like to be a parent, a mother or disabled. Doctors should represent the population they serve. We are still getting mostly white, inexperienced young males as physicians. They aren't going to practise the way that is necessary."

In Ontario, many doctors see the 1986 doctors' strike as a watershed for public opinion.

As a result of the negative fallout from the strike and a perceived gap between physicians and the public they serve, a five-year project entitled Educating Future Physicians for Ontario became a major advocate for reform.

Started in 1988, EFPO has examined fundamental issues in designing and implementing new medical school curricula. These issues include defining societal health care needs and expectations, faculty development and student evaluation. While each medical school has adapted reforms to its particular situation, EFPO hopes to prod further reforms.

"This is a unique venture in Canada, and could have implications far beyond Ontario if successful," says Dr. William Seidelman, a key player in EFPO. "It captures the unique sense of the Canadian scene, and will build on the implied contact in the Canadian health system."

Pellizzari sees the attitude of medical schools and teaching hospitals towards medical students as a significant factor in creating insensitive doctors. She recalls the high rate of suicide among medical students and the abusive work environment that forces doctors-in-training to work shifts unthinkable for other workers.

"The way we train doctors is inhumane," she says. "We don't expect other workers to put in 30-hour shifts. It creates in new physicians the attitude that they paid their dues and now society owes them."

Many critics feel that changing training methods isn't enough; the whole ethos and selection process must be changed. If doctors are to better serve the population, they must better reflect it.

"We are getting very close to gender equality and a laudable distribution of ethnic and racial backgrounds," says Newman. "But students still come from a fairly narrow social spectrum, very middle-class kids. Their exposure to the extremes of society, to poverty, to homelessness and related illnesses have been very limited."

Pellizzari found how out-of-date the medical profession was in her first year. One teacher wanted her to work till 10 at night. When told that she needed 24 hours notice for a babysitter, the teacher shot back that motherhood and medicine don't mix.

"I was a mother before I was a physician. When I get a call at night from a mother, I understand this. With 30 per cent of visits to doctors having no biological basis — like depression due to unemployment — you can't do anything unless you have experienced life.

"If we don't address this, you can design the best training in the world, but things won't change."

But Newman also feels many factors outside of medical school discourage a more diverse student body.

"To go through medical school in the United States requires large indebtedness. That's not true in Canada. You can calculate what a year of medical school costs in terms of a finite number of CDs, a leather jacket and a ghetto blaster. So something is dissuading people from pursuing this career, and it isn't money."

While there is a consensus among academics that medical schools haven't prepared doctors well enough, there is little support for a dramatic change in selection criteria. "I can't muster a lot of support from colleagues for serious changes," says Newman.

Dr. Jock Murray, the former dean of Dalhousie medical school in Halifax, recently told an EFPO meeting he doesn't see any significant changes ahead.

"Physicians have a reputation for being conservative and self-serving," says Murray. "If reform is going to be successful we have to be clear that it is about what is good for the people."

Pellizzari believes life experience and empathy with social circumstances just can't be taught.

"I grew up in this neighborhood. I understand their powerlessness, the conditions. Doctors have to see themselves as a member of a team of health professionals, not as the top of the social and medical totem pole."

U of T's experience is a classic example of the hurdles to reform that lie ahead. Newman admits it has come as a shock to students loaded with society's ingrained expectations.

"They spend half a day a week in the community seeing things like drug rehab clinics and community health centres. But being out in the community doesn't make the students feel comfortable. Their image of what they are going to do involves big buildings, chrome and steel, scurrying personnel and banks of computers."

□ David South is a freelance writer and medical reporter for *Today's Seniors*.