

adults. Once society's view of children changes, more options can be considered.

Finally, for Morgan and Cohen to conclude that general hospitals need to learn to harness some of the appeal that comes naturally to children's hospitals undermines what children's hospitals do and discounts the fact that appeal comes naturally to children, not hospitals.

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I am profoundly disturbed by the article by Dr. Morgan and Lynne Cohen, who seemed prepared to sound the death knell of children's hospitals. This ill-conceived, badly constructed and largely anecdotal presentation is to be deprecated.

All parties would agree that it is unnecessary, expensive and inefficient to have freestanding children's hospitals in small- to medium-sized communities. However, a comprehensive pediatric facility in a larger, metropolitan centre is, in my opinion and experience, essential. Children are not small adults and do not receive optimal care in adult institutions. Pediatric illness, pathology, investigation and treatment are, for the most part, completely different from their adult counterparts.

Like CHEO, British Columbia's Children's Hospital, in Vancouver, is, practically speaking, "the only show in town." None the less, it has developed into and widely held to be a centre of excellence. In the overwhelming number of parents' opinions, access to this hospital completely negates any inconvenience in travelling to it. Indeed, there is an increasing insistence — nay, demand — that children be treated "in the children's hospital." In British Columbia it is the stated wish of politicians and some administrators that there be "repatriation" and a "closer-to-home" policy that allows and in fact forces children in surrounding areas to remain in these

sites for treatment. This makes the tacit assumption that the facilities and standards in these communities are equal to those in a comprehensive children's hospital. I question this assumption, as do many parents of children I see.

Morgan and Cohen quote the late Dr. Lionel McLeod, of University Hospital, Vancouver, who "grudgingly" admitted that ill children get better support in a children's hospital." With great respect to McLeod, I do not agree with his statement that the need for such care was the result of administrative mismanagement. It is my feeling that in any walk of life a person who performs a function and task exclusively and continually, like a physician in a children's hospital, is likely to provide a better service and have a higher degree of skill and commitment than one who might perform the same duties part-time.

Some of the sources quoted in the article infer that children's hospitals are built to attract pediatric specialists and public donations. This is arrant and arrogant nonsense. Rather, it is perceived that when such a centre exists the standard of care and reputation does indeed encourage ongoing improvement, and, speaking personally, donations are usually made on a basis of the donor's best assessment of where his or her contribution would do the most good. Certainly, children's hospitals do attract numerous generous donations — and so they should, because the public and the parents of children feel that they deserve their fullest support. Setting aside the opinions of the politicians and some of the money managers, I suspect that the medical profession feels the same.

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*CMAJ* appropriately questioned the

need for children's hospitals in the modern Canadian health care system. Regrettably, the opinions expressed lack substance and insight.

Children's hospitals have arisen across North America and elsewhere in the developed world in an attempt to assure high-quality care for ill children. The creation of these separate hospitals was a tangible manifestation of the concern for young people by professionals and communities. In general, children's hospitals have earned respect because they deliver the goods.

Some new health care issues and priorities require interventions extending well beyond the walls of a conventional hospital (e.g., the appalling incidence of child abuse and suicide in our communities); others lie at the interface between pediatric and adult care (e.g., the care of the high-risk fetus). Children's hospitals have been strong advocates for pushing these issues to the top of our health care agenda.

The current (overdue) attention given to preventive strategies and facilities that permit ill patients to remain out of hospital does not diminish the continuing essential role for inpatient facilities. New approaches must evolve, but we must maintain the capacity to deal with children who have illnesses such as cancer and congenital defects requiring hospital care of increased intensity and complexity. The crushing cost of modern technology alone demands that we examine new ways to align children's hospital facilities with other segments of the hospital sector. Because they are small, because they are immature physically, emotionally and intellectually and because they are so dependent children require special hospital facilities and resources, both physical and human.

Marion Dewar is out of touch with the plight of children in contemporary society, in which poverty, violence and broken homes threaten so many young people. To a degree, public education and social services have abandoned our children over

the past two decades. Fortunately, children's hospitals and the dedicated professionals associated with them have not done so; they have earned the right to be heard in any debate dealing with the care of our most important resource, our children.

It is timely to examine the way in which hospital care is provided to children in Canada. Such care must be special, superb and distinct.

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Subspecialists should work in their area of expertise, and a critical mass of them occurs in pediatric medicine only when complicated cases are concentrated. A children's hospital should be exclusively limited to that type of care.

Ruth Derrick, of CHEO, says that the intensity of pediatric care is increasing, and yet children have shorter lengths of stay in hospital for minor surgery and as outpatients. The Hospital for Sick Children claims it has 250 000 outpatients a year (*The Toronto Star*, May 27, 1993: 1). Therapy for cancer, cystic fibrosis, thalassemia and other chronic diseases could be handled in the community, probably more cost effectively. The children's hospital would therefore become a network, not a place or a building.

A children's hospital need not provide emergency or ambulatory care, or walk-in or outpatient clinics. The capital outlay, maintenance and other expenditures could be left to a peripheral hospital or the community. This would ensure appropriate care at the primary, secondary and tertiary care level in the location closest to the need.

Patients of any age or with any problem and their families should be made comfortable. As well, a continuity of care for a chronic illness extending into adulthood requires the cross training of pediatricians with physicians who treat adults. Special-

ists require more extensive training so that they can provide care for patients of all ages. Children are special but no more so than any other segment of the population.

A minority of illnesses require a level of expertise not easily found. Patients with these illnesses can be treated centrally or flown hundreds of miles if necessary. Canada might do well with only a couple of children's hospitals. This would be possible if the existing children's hospitals and their university backers cooperated with the community. More children's hospitals would further inhibit the development of better primary and secondary care.

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[*The authors respond:*]

Throughout our article we focused on whether children's hospitals were needed. The letter-writers seem to associate the best pediatric care with such hospitals and see our article as denouncing such care. We and the many people we interviewed never questioned the need for expert, multi-tiered pediatric care. But we still aren't convinced that tertiary pediatric care cannot be delivered as well in the wing of a general hospital as in an isolated, and much more expensive, landmark building.

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## Confidentiality and research

**A**lthough we concur with the recommendation made in this editor's page (*Can Med Assoc J* 1992; 147: 1299), by Dr. Bruce P. Squires, about the need for explicit guidelines on access to patients and their records we also agree

with the researchers and editors mentioned that "rigid interpretation of the guidelines would effectively stifle certain types of useful clinical research." Clinical research was specifically addressed, but the same ethical issues are germane to epidemiologic research.

As guidelines are developed we urge due consideration of the issue of balance: between an individual's right to privacy and a researcher's need for access to health care records and between the potential risk to individuals and the potential benefit of high-quality scientific research to society and public health. In addition, if restrictive ethical guidelines adversely affect research validity or prevent research from being conducted we would face the ethical dilemma of not being able to answer important research questions.

Ethical guidelines that ensure a "correct" balance are needed now. Recent international guidelines pertaining to epidemiologic research recognize this need for balance.<sup>1</sup> Our society must ultimately decide what is the appropriate balance; we doubt, however, that the consensus would preclude the judicious use of confidential information, if the full impact of a restrictive approach on epidemiologic research and public health were understood. Perhaps it is time to include the public, along with the academic, legal and medical communities, in the development of ethical guidelines, thus permitting consideration of the full range of perspectives. Guidelines developed by consensus among concerned parties have the greatest chance of achieving the necessary balance.

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