

## FOR THE RECORD

## Inadequate surveillance

The Public Health Agency of Canada's capacity to detect, monitor and control infectious disease threats remains sorely lacking even though 4 years have elapsed since it was established, says Auditor-General of Canada Sheila Fraser.

Fraser cast the agency's surveillance as largely ad hoc and piecemeal, because of fractured jurisdiction over health, growing pains, and managerial flaws, including a "failure to apply certain management principles, such as setting priorities, tracking performance, and periodically evaluating progress."

The agency is now essentially incapable of meeting Canada's international obligations to report disease outbreaks, said Fraser, whose audit examined the Infectious Disease and Emergency Preparedness Branch's \$139.4 million budget in fiscal 2006/07. According to agency figures, the branch will consume \$282.5 million of its overall \$669.8 million budget in fiscal 2007/08.

The public health agency "has not done enough to assess and document the information needs of users, to establish common surveillance standards, to implement a data quality framework, to evaluate its surveillance systems, and to obtain data-sharing agreements with the provinces and territories," Fraser states in the report, tabled in Parliament on May 6, 2008. "We are concerned that a nationally standardized approach to disease reporting remains years away."

A follow up to 1999 and 2002 audits of Health Canada surveillance programs, the report says little progress has been made in ensuring that reliable information is obtained from provinces. What data is shared is often incomplete or inadequate as comprehensive standards have not yet been developed governing such factors as the diseases reported, definitions used, information to be provided, reporting timelines, mode of submission and parties responsible for reporting,

An information sharing agreement was recently reached with Ontario to obtain routine surveillance data (after 2 years of non-sharing). But there are no similar agreements with the remaining provinces or territories. "This limits its [the Public Health Agency of Canada's] ability to provide Canadians with a complete and consistent national picture of infectious diseases as a basis for public health actions."

Ministerial approval has not yet been given to a similar intergovernmental agreement for sharing information in public health emergencies like the 2003 SARS outbreak. But even if approved, it's missing such "critical" elements as "procedures for notifying other parties, and protocols affecting the collection, use, and disclosure of personal information."

Lacking such data, the Public Health Agency of Canada will be unable to meet Canadian obligations for notifying the World Health Organization of outbreaks within the deadlines specified by International Health Regulations.

The Public Health Agency of Canada has also failed to reach an agreement with the Canadian Food Inspection Agency as to which zoonotic diseases — such as West Nile Virus, bird flu, Lyme disease or bovine spongiform encephalopathy — they will respectively monitor. "Responsibilities for surveillance of wildlife and pets, 2 potentially important sources of human disease, have not been sorted out."

The agency has also been slow to develop a framework for determining surveillance objectives and priorities, or for evaluating the effectiveness of its surveillance activities. The agency's Canadian Network for Public Health Intelligence is highly limited, while the federal government hasn't given the organization adequate legislative authority to conduct its surveillance activities.

In response, the Public Health Agency of Canada essentially disputed none of Fraser's conclusions and vowed measures to address the deficiencies. — Wayne Kondro, *CMAJ*

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## Whatever happened to Jordan's principle?

Thirty-seven special needs children living on a remote Manitoba First Nation reserve are going without a variety of medical and social services because the federal and provincial governments cannot decide who should cover the costs.

Advocates for the community claim the prolonged dispute stands in stark defiance of Jordan's Principle, a resolution passed in the House of Commons in 2007 that stipulates that government's must adopt a "child first" principle in resolving jurisdictional disputes involving First Nations children (*CMAJ* 2008;178[3]:277).

"We were very hopeful Jordan's Principle would end these kinds of disputes," says Cindy Blackstock, executive director of the First Nations Child and Family Caring Society. "But once again, we have children in need and neither government is stepping forward to provide the services."

The dispute appeared resolved in early May, 2008, when federal Health Minister Tony Clement promised that the government would ante its share of the bill. But Health Canada spokesman Paul Spendlove later clarified that Clement's promise applied to existing services now being provided on the Norway House Indian Reserve, located 800 km north of Winnipeg. The provision of new services will be considered on a case-by-case basis, Spendlove said,



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The Norway House Cree Nation has proposed to establish a new facility for special needs children, but the federal government has been mum on funding a share of the costs.

adding that a needs assessment of each child will be undertaken to determine what services may be required.

The 37 children range in age from less than 1 to 18 years. Many are in wheelchairs and require a wide variety of services including speech therapy, occupational therapy, physiotherapy and respite care for their families. To date, the Norway House Cree Nation has been unable to secure any of these services because the federal and provincial governments cannot agree on who should pay.

Band Councillor Mike Muswagon says the community is angry that the 2 governments would dare compromise the care of these children in the wake of Jordan's Principle. "The fact is that both levels of government have to provide for these kids, period," he adds.

Jordan's Principle was drafted in response to the death of Jordan River Anderson, another Norway House child who died in 2003 of a rare muscular disorder after years of medical treatment in a Winnipeg hospital. There was a plan to discharge Jordan in 2001 so he could be with his family in his home community but no agreement could be reached between Ottawa and Manitoba about which level of government would pay for his special medical needs. The House of Commons resolution stipulated that in the event of a jurisdictional dispute over funding for a First Nation child, the government of first contact would pay for any services and seek cost-sharing after the services had been provided.

However, for Jordan's Principle to be effective, Ottawa and the provinces had to reach intergovernmental agreements to implement the policy. Manitoba hopes to become the first province to reach such an agreement with the federal government but negotiations have not yet proved fruitful. Muswagon says federal and provincial officials visited Norway House on Apr. 23, 2008, to assess capital needs on the reserve and review case files on each of the 37 children. He also says the band has proposed to establish a new facility to provide a variety of therapies for the children.

Manitoba has verbally offered to pay one third of the cost of those additional services. Ottawa would be on the hook for the remainder. Indian and Northern Affairs Canada declined comment other

than to say that a proposal from the First Nation is under consideration. — Dan Lett, Winnipeg, Man.

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## Ontario and Manitoba to reimburse expenses for living organ donors

**L**iving organ donors in Ontario and Manitoba are now eligible to receive reimbursements for out-of-pocket expenses and income lost during surgery recovery. British Columbia is the only other province with such a program.

In Manitoba, the government is partnering with that province's branch of the Kidney Foundation of Canada, each contributing \$25 000, to provide up to \$5000 to donors to cover things such as travel expenses, hotel stays, meals and child care. Manitoba Health Minister Theresa Oswald made the announcement on Apr. 18, 2008.

Ontario's program began on Apr. 1, 2008, and will be run by the Trillium Gift of Life Network, a government agency. Donors will be eligible for up to \$5500 in reimbursements. The program was officially announced as part of National Organ and Tissue Donation Week (Apr. 20–27, 2008) but is retroactive to August 2007, when Ontario Premier Dalton McGuinty promised to reimburse living donors as part of his election campaign.

"Our society values organ donation enormously," says Frank Markel, president and chief executive officer of the network. "It is one of the most generous acts anyone can perform, to give an organ to another human being. People should not suffer financial loss because they do this."

The British Columbia reimbursement program, a 36-month pilot project, has given money to 145 donors and potential donors, \$154 000 in total, since its inception in July 2006. Of those, 106 were British Columbia residents, 20 were from other provinces and 19 were international donors. As long as the organ recipient is from British Columbia, the

residence of the donor is irrelevant.

The program benefits both recipient and donor, says Lorraine Gerard, executive-director of the British Columbia branch of the Kidney Foundation of Canada. Although it's unlikely the program has resulted in more donors, it does accelerate the transplantation process, as donors no longer need to schedule their surgeries to minimize financial losses (waiting until their holidays, for example). It also provides peace of mind to donors during recovery.

"They can concentrate on recuperation rather than on how those bills will be paid," says Gerard.



Trillium Gift of Life Network

Trillium Gift of Life Network President Frank Markel.

In addition to being reimbursed for expenses, the families of Ontario residents waiting for an organ will now receive financial aid if forced to relocate to be near a hospital that can provide the operation should an organ become available. Ontario Health Minister George Smitherman announced the creation of the \$500 000 annual fund on Apr. 21, 2008.

The 3 provinces are among few jurisdictions offering incentives for donation, (*CMAJ* 2006;175[9]:1043-5). The United Kingdom reimburses costs ranging from travel and accommodation to lost wages. France covers travel and accommodation, while the United States is examining a range of options, including reimbursing donor's funeral expenses. — Roger Collier, *CMAJ*

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