

nous investigators, says Episkenew. She recalls one project grinding to halt when the children involved became fixated on what were meant to be warm-up games. Ultimately, the research team changed their study to focus on the games. “We realized they had parents for whom playing with the imagination is a foreign concept because

“You need to take a wide lens approach,” explains Makokis. “It’s taken hundreds of years for our health disparities to get where they are and it’s not going to take a five-year research project for you to start seeing immediate changes.”

But that sort of approach can bring financial issues, says Kevin Willison, a

In Nova Scotia, for example, a community-driven data linkage project revealed surprising disparities in oral health. Previously, it was impossible to get a clear picture of First Nations health in the province because surveillance was fragmented across various agencies, says Sharon Rudderham, health director at the Eskasoni Community Health Centre, which serves Nova Scotia’s largest Mi’kmaq community.

Gathering First Nations data under a single registry governed by the communities revealed that 42% of ambulatory care admissions were related to dental issues. “We were extremely shocked,” says Rudderham. “We knew about the issues with diabetes, obesity and addictions in our communities, but no one knew about this.”

Ultimately, though, Rudderham says the process of negotiating better partnerships may be more important for the long-term health of communities than any immediate outcomes. For example, people are more likely to sustain health interventions they helped design. “It goes back to our ability to take ownership and control,” she says. “When you and your family have a say, then it has more of an impact.” — Lauren Vogel, *CMAJ*

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## “If researchers don’t treat them with respect... then the communities will say no.”

they grew up institutionalized,” says Episkenew. “We could have cherry-picked the kids that did what we wanted ... but what we actually did was more valuable.”

In some cases, however, that value won’t be easily or immediately measurable — particularly if Western-style empiricism isn’t a community’s research method of choice.

“Sometimes there won’t be an immediate hard outcome, but that doesn’t mean there hasn’t been a positive change in the community,” says Makokis. He cites the example of building a community garden as part of a sexual health project. “People come out and participate, and it creates a safe space to start engaging around those sensitive issues.”

member of Public Health Ontario’s Ethics Review Board and professor of sociology at Lakehead University in Thunder Bay. Funding for indigenous health research seldom takes into account the extra time needed to design and carry out the kind of collaborative projects that communities are demanding. Meaningful evaluation of a community-based participatory approach is also difficult given that these projects are, by definition, unique to one community. “We have nothing really to compare it to,” says Willison.

Proponents of community-based research acknowledge that it can be slow and messy. However, they say it’s worth the effort to generate data that more accurately reflect Aboriginal realities.

## Red tape blocks care for Aboriginal children

**E**ight years after the House of Commons unanimously approved the principle that no First Nations child should be denied health services because of inter-jurisdictional wrangling over costs, Ottawa is engaging in “structural racism” by narrowing the definition of cases so none qualify, says the principal researcher behind a new report.

“The structure of funding and service delivery for First Nations children is much more complicated than the structure of services for other children,” says Vandna Sinha, an assistant professor in the School of Social Work at

McGill University. “I would call that structural racism.”

Sinha leads six researchers from McGill, the University of Manitoba and the University of Michigan, whose Feb 10 report examines the implementation of Jordan’s Principle, which Parliament approved in 2007. The principle is named for Jordan River Anderson, a five-year-old boy from Norway House Cree Nation in Manitoba. Jordan died in the Winnipeg hospital where he had been confined for two years while the federal and provincial governments argued over who should pay for his home-care costs.

Jordan’s principle states that whichever government department or level of government is first contacted about health and welfare services for a First Nations child should supply whatever services would be available to a non-Aboriginal child without delay, and iron out jurisdictional responsibility for payment later.

Working with the Assembly of First Nations, the Canadian Association of Paediatric Health Centres, the Canadian Paediatric Society and UNICEF Canada, the researchers launched an investigation into why the federal government and some provincial govern-

ments have repeatedly said there are no Jordan's Principle cases.

"We're hearing from communities that children are still falling through the cracks," says co-author Josée Lavoie, director of the Manitoba First Nations Centre for Aboriginal Health Research.

The report, *Without denial, delay or disruption: Ensuring First Nations children's access to equitable services through Jordan's Principle* documents how the federal government has narrowed the definition of cases. Only children with multiple disabilities requiring multiple service providers now qualify. Ottawa will not consider cases of intra-departmental disputes, such as those between Health Canada and Aboriginal Affairs and Northern Development Canada. Both the federal and a provincial/territorial government must acknowledge a dispute exists before the federal government will act. This means that if one or both chooses not to recognize a dispute, there is no case.

"What we're seeing are institutionalized delays whenever a dispute occurs," says Marv Bernstein, chief policy advisor for UNICEF Canada.

The 95-page report outlines a lengthy, complex, 12-step process, including assistant deputy minister and deputy minister approval, that families must navigate to access treatment. As a result, "the current govern-



Cindy Blackstock

Children demonstrate on Parliament Hill for equitable access to health care, education and child welfare services for Aboriginal children during Have a Heart Day, Feb. 10, 2015.

children were denied coverage for their medical needs, such as:

- Dewey Pruden, of Pinaymootang First Nation in Manitoba, whose family has been unable to access physiotherapy, occupational or speech therapy for a congenital condition causing seizures, partial paralysis, glaucoma and autism;

eral government to cover his home-care costs.

The report calls on the federal, provincial and territorial governments to seriously discuss the implementation of Jordan's Principle with First Nations representatives, and to identify and address systemic underfunding and jurisdictional problems underlying these cases.

Currently, children on reserves rely on charitable individuals or fundraising for their treatment — a lucky happenstance rather than equitable treatment, says Cindy Blackstock, executive director of the First Nations Child & Family Caring Society of Canada. "I'd characterize the [report's] findings as further evidence of the discrimination that [First Nations] children on reserve face." — Laura Eggertson, Ottawa, Ont.

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## "What we're seeing are institutionalized delays whenever a dispute occurs" — UNICEF

ment response renders those cases that should be called Jordan's Principle cases invisible," Sinha says.

Indeed, in response to the report, Aboriginal Affairs and Northern Development Minister Bernard Valcourt released a statement saying "...there are currently no outstanding jurisdictional disputes involving Jordan's Principle in Canada..." while stating Ottawa's intention to work with provinces, territories and First Nations on implementing the principle.

The report documents what the researchers believe are clear Jordan's Principle cases where First Nations

- a baby with allergies whose special infant formula was not covered;
- a girl on-reserve who couldn't get funding from Health Canada for a \$9000 enclosed hospital crib because of her neurological and mobility issues;
- a paraplegic child for whom Health Canada refused to cover the cost of a wheelchair;
- Jeremy Meawasige, a Mi'kmaq child from the Pictou Landing First Nation in Nova Scotia, with autism, hydrocephalus, cerebral palsy and spinal curvature whose parents had to go to Federal Court to get the fed-

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