

## Consumer health information

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### Interactive prose literacy map

[www.ccl-cca.ca/literacy](http://www.ccl-cca.ca/literacy)

What part of your district would benefit most from a family literacy program? What's the average literacy level in the area surrounding your library? This kind of granular data on literacy levels across different communities is now available, for free.

The Canadian Council on Learning has launched an interactive online map that shows adult prose literacy levels in 52 200 cities, towns, and communities across the country. The map allows you to zoom in and get data on a particular neighbourhood or zoom out and see the patchwork of different literacy levels within a city, town, or region.

The map uses data from the 2003 International Adult Literacy and Life Skills Survey (IALSS), which was conducted by Statistics Canada and the Organisation for Economic Co-operation and Development (OECD), and combines it with 2006 Census data. It displays levels of prose literacy — that is, the knowledge and skills needed to understand and use information from text, such as news stories, editorials, poems, and fiction.

The map drives home a sobering point. According to the 2003 data, *nearly half of all Canadian adults have low literacy levels (level 2 or below)*, meaning they are ill prepared for the current demands of society. As many of you know, adult literacy is often measured on a prose literacy scale of 1 to 5. Level 3 is widely considered to be the minimum threshold for coping with the demands of the global knowledge-based economy. That nearly half the population can't cope with today's literacy demands should be a wake-up call, especially for those of us concerned with health.

### Book reviews

**Autism's False Prophets: Bad Science, Risky Medicine, and the Search for a Cure.** By Paul A. Offit. New York: Columbia University Press, 2008.

Those who cannot learn from history are doomed to repeat it. That's why librarians, parents, public health officials, medical publishers, and journalists should read this cautionary tale that chronicles and discredits the movement to blame autism on routine childhood vaccinations.

Paediatric vaccinologist Paul Offit situates his discussion of the autism–vaccine controversy in the context of alternative therapies that gained and then lost favour among autism advocates, including secretin and facilitated communication.

Where mainstream medicine admits an incomplete understanding of autism's aetiology and treatment, alternative practitioners offering definitive answers, "recovery", and "cures" have drawn support from a segment of parents who are desperate, willing to spend money, and able to suspend disbelief in the hopes of seeing their children recover. Offit also describes the struggles of parents who have kids with autism. He points to cases where parents killed their kids with autism as a rare criminal response to challenges that are all too common: limited access to diagnosis and treatment, little financial support for expensive therapy, and the daily grind of taking care of demanding children in an uncompassionate society.

In Offit's telling, the lack of simple answers on autism and the extreme difficulties faced by families both helped prepare the ground for the favourable reception of a new theory about what causes autism and how to cure it. At a February 1998 press conference, London gastroenterologist Andrew Wakefield asserted that the measles-mumps-rubella vaccine (MMR) causes autism in children. His assertion was based on a poorly conducted study he led, published in *Lancet*, whose key finding was ostensibly the presence of measles virus in the spinal fluid and gut of eight children with autism. Wakefield's study didn't come close to proving causality according to any scientific standards, but to a popular media hungry for sensational news and parents eager for definitive answers, it was enough to unleash rage — and plenty of lawsuits against vaccine makers. Parents were angry at Big Pharma who created the vaccines, government and medical agencies who licensed and recommended them, and anyone — other parents, politicians, or scientists — who dared question the validity of the flimsy research. (In fact, many of the researchers who tried to counter the autism–vaccine myth received death threats, including the author of this book.)

Some parents in the US and a few fringe scientists took up the vaccines-cause-autism theory and elaborated on it: they said that thimerosal, the preservative used in some vaccines (though never the MMR), contained dangerous levels of mercury and that autism symptoms were really symptoms of mercury poisoning. This new explanation for autism's aetiology set the stage for a number of risky, expensive, and unproven "treatments", including chelation therapy, purported to remove mercury from the body. Many of these alternative treatments were practiced by fringe doctors, some of whom had been subject to disciplinary action for professional and ethical violations. A five-year-old boy died sud-

denly of a heart attack as a result of a “chelation treatment” injection. Countless other children endured difficult and unproven therapies (chemical castration being one example) and submitted to thousands of sham diagnostic tests that cost their parents millions.

Offit follows the trajectory of the vaccine–autism myth as it made its way into senate hearings in the US, CDC vaccine policy meetings, parent advocacy groups, and the offices of fringe medical practitioners and big law firms. He explains how the investigative work of a dogged British journalist, an American librarian, and other “heros” helped uncover connections and significant undisclosed financial incentives among the proponents of the vaccine–autism myth. Dr. Wakefield did not disclose payments of \$800 000 he received from a lawyer representing parents who wanted to sue vaccine makers. He himself had a patent for an alternative measles vaccine, whose success was presumably contingent on proving there was something wrong with the existing vaccine. Wakefield also failed to secure proper ethics approval for his research. Five of the eight children in his study were recruited from families launching a class-action lawsuit against vaccine makers. The lab assistant who handled and tested the samples of spinal fluid and intestinal tissue for Wakefield’s 1998 study testified that all samples tested were in fact negative for measles virus, though Wakefield’s study asserted the opposite. After learning of his lack of ethics approval and source of funding, most of Wakefield’s coauthors retracted the *Lancet* study. Wakefield was asked to resign from the hospital where he worked and was banned from practicing medicine in Britain. He fled to the US to practice in an alternative clinic that treats children with autism.

More investigation revealed that a UK government agency mandated to help fund research for class-action lawsuits had spent \$30 million to pay scientists to try to find a vaccine–autism connection. Many of the scientists and doctors who testified in the US senate hearings and later in class-action lawsuits were found to be paid by the UK litigants’ fund, or operated as “professional expert witnesses” who made a living testifying against vaccines, though they had no expertise in autism, virology, or immunology. Author Paul Offit contends that politicians who supported the autism–vaccine myth had disingenuous motives, noting for example that Robert F. Kennedy Jr., who wrote a *Rolling Stones* article on the topic, did not disclose that he was a senior partner in a law firm specialising in tort law (class-action lawsuits), a potential conflict of interest.

While the autism–vaccine myth wended its way through talk shows, newspapers, and parent groups, science plodded on, propelled by the sincere concern of scientists and parents and the lobby of litigants and politicians. One well-conducted epidemiological study after another (16 in total) concluded that there was no association between the MMR vaccine or thimerosal and autism. In jurisdictions that banned thimerosal as a precaution and thus created a large natural experiment, autism rates didn’t drop over time; in fact, they continued to climb. A few years after Wakefield’s initial announcement, no legitimate scientist had any doubts about the evidence. But the autism–vaccine myth lingers, propelled by celebrities like Jenny McCarthy, former actress and mother of a boy with autism, and by weak journalism

that erroneously believes that balanced reporting means giving a voice to “both sides”, even when one side is overwhelmingly supported by legitimate scientists, and the other is supported by a tiny non-expert fringe.

Apart from the bad medicine and the opportunity cost of pouring hope and money into a false lead, another major result of the autism–vaccine myth is a significant decline in vaccination rates in the UK and elsewhere. This decline in vaccination has led to the deaths of several children from vaccine-preventable illness, the infection and hospitalization of many more, and a lingering and unjustified concern on the part of many parents that childhood vaccines are somehow unsafe.

Offit’s use of transcripts from shows like *Oprah*, court cases against vaccine makers, and senate hearings helped convey the timbre of the popular, legal, and political discussion concerning vaccine safety. He relays this complicated story clearly, introducing the main players, explaining their relationship to one another, and giving a blow-by-blow account of developments on several fronts. This approach means Offit’s narrative has some stops and starts; he sometimes repeats himself, which is a little jarring but ultimately helpful for the reader trying to follow the unfolding events. Generally, Offit’s writing is straightforward, and his reporting is careful and well supported. He quotes from many of the main actors to give a strong sense of what they thought and when.

For consumer health librarians who try to bridge the gap between scholarly and lay understandings of science and medicine, the story of the autism–vaccine myth is thought provoking. If mainstream media is uninterested or ill equipped to explain the scientific method of discovery, reproducibility, and refinement, and unable to critically evaluate theories using scientific criteria, who can take up this task? If a model has a stronger influence on vaccine uptake than a paediatrician, what does that mean for the health of children or the rational development of health policy? What are the necessary conditions for fostering evidence-based health beliefs and behaviours? *Autism’s False Prophets* tells an important story that has broad implications for anyone interested in consumer health, medical reporting, autism, or health policy.

**Strong at the Broken Places.** By Richard M. Cohen. New York: Harper Collins, 2008.

*Strong at the Broken Places* tells the stories of five Americans living with chronic diseases, including an undergraduate student with Duchenne muscular dystrophy, a Bible Belt dad with advanced non-Hodgkin’s lymphoma, and a young social worker with Crohn’s disease. Their stories are told by writer Richard Cohen, who in a previous book recounted his experience with multiple sclerosis and colon cancer. The stories are the result of hours of interviews by phone, e-mail, and in person, in which the author asked personal and sometimes uncomfortable questions: How does sickness affect your relationships? Are you afraid of death? Are you angry? The stories themselves are honest, revealing, and ultimately uplifting, and their authenticity allows readers both sick and well to feel a common humanity with the subjects.

The author's own experience with chronic illness certainly lends credibility to the book, likely helping him earn the trust of his subjects and helping him analyse and formulate questions. However, his authorial hand is at times too heavy for my taste. He tends to use over-stylized turns of phrase

("The H<sub>2</sub>O was sipped through a straw") and sometimes renders speech unnaturally, with the characters always using "it is" rather than the more usual contracted form. But these are fairly minor quibbles in a book that has potential to inspire and inform.