

Stopping Chelation-Autism Therapy in Canada: An FAQ and Action Plan

by Anne Borden, Campaign Against Phony Autism Cures

On Monday, the *Globe and Mail* [reported](#) that Ontario regulators had declined to take action on my complaint about an Ontario doctor administering chelation drugs to children as an autism treatment (a practice that is banned in both the US and the UK). I've written an FAQ about it, including next steps, which you can read [here](#).

Background: In November of 2017, I filed a complaint with the College of Physicians and Surgeons of Ontario (CPSO, a professional self-regulating body) that one of their members had been advertising and offering chelation as an autism treatment. After 8 months, the CPSO dismissed my complaint and endorsed chelation-autism therapy as, in their words, “valuable and evidence-based”. I appealed their decision to a Government of Ontario oversight body (HPARB) and last week—more than 2 years after my original complaint—they also endorsed chelation-autism therapy, despite clear evidence it can cause grave harm and has no benefit.

This is not the end of this case. We will take it to the next level of legislation/regulation and are currently weighing our legal options.

What is chelation?

Chelation is the removal of metals and minerals from the blood (including calcium, essential for heart health). It is traditionally done in a hospital setting in cases like industrial accidents.

Chelating agents are injected or given orally; they latch on to metals in the body and minerals and metals are carried out through urine or feces. Chelation-autism therapy is an off-label use of these chelating drugs: a phony “treatment” that causes harm without benefit.

Is chelation for autism legal in Canada?

There are no regulations against chelation-autism therapy in Canada. This is in contrast to the [UK](#) and the [US](#), where chelation for autism is **not** allowed. The US Food and Drug Administration has banned it and the National Health Service in the UK has included chelation-autism therapy on its [list](#) of “fake and harmful autism “treatments”.

Why is chelation being sold as a phony autism treatment?

Chelation-autism therapy is based around the belief (made popular by disgraced British MD Andrew Wakefield) that thimerosal, an ingredient in MMR vaccines, becomes lodged in the brain and causes autism in children. Wakefield was forced to retract his paper on thimerosal, and scores studies have since proven beyond a shadow of a doubt that there is no connection between vaccines and autism... and although thimerosal isn't even included in contemporary MMR vaccine the myth still remains.

What are the risks of chelation-for-autism?

Children have died during chelation-autism therapy. One of the youngest victims was Abubakar Tariq Nadama, who was 5 years old when his parents brought him from the UK to a doctor in

The HPARB appeal board said the complaint didn't show large enough random control trials debunking chelation-autism therapy. Is that valid?

There are no large RCTs of chelation for autism for the same reason that there are also no large, random control trials about whether staring at the sun for 3 hours cures diabetes...because it's a terrible idea and no one wants to bother to study it. Chelation for autism has no credibility even as a theory, so the giant RCTs aren't happening.

Lack of giant RCTs doesn't validate a pseudoscience in any circumstance, ever.

Would it even be ethical to do a large RCT on chelation-autism therapy?

No. By US standards, any study of chelation-autism therapy would contravene ethical guidelines according to the National Commission for the Protection of Human Subjects. According to it, individuals can only be involved in research studies if the study poses minimal risk and has a strong benefit directly to the individual. Guidelines in Canada are similar. So we will not have any large scale studies on chelation for autism because there is no way to justify the study.

The HPARB stated that CAM is acceptable per the CPSO if there is no "evidence the therapy is riskier than the traditional medical approach."

That argument is nonsensical because chelation *is* more dangerous than standard (traditional) medical approaches to autism. One can't possibly say that removing calcium from a young child's blood is safer than taking them to a speech pathologist for help with eating and speaking, or discussing their feelings with a psychotherapist.

As well, this type of CAM also often replaces useful services. For example, a psychotherapist told me that the parents of one of her clients began taking him for chelation every month. They began to believe that his anxiety and meltdowns were related to metals deep within his brain that a doctor could remove. The parents lost faith in psychotherapy and withdrew their son from this crucial service.

The HPARB stated that the complaint was not actionable because there was "no evidence his use of chelation therapy directly resulted in injury or other harm to a child." What do they mean?

A large portion of the HPARB and CPSO's responses centred around what I call the "wrong limb proviso," their assertion that if you're not personally a victim of malpractice, such as a patient who got the wrong limb amputated, you have no business filing a complaint, ever. This in my view is an argument of intimidation that marginalizes patient rights groups and advocates. There are many compelling reasons to file a complaint about a practice that is not science-based and carries risk for vulnerable patients such as children. (And by the way, the CPSO, currently, is the ONLY means through which to even file such a complaint.)

As a self-regulating college, the CPSO should proactively be reviewing the practices of its members, especially around CAM, to ensure the safety of patients. The idea that we need to wait for someone to lose the wrong limb or die or suffer PTSD before taking action to regulate or ban a CAM practice reveals a lot about how the college is running its affairs.

In its response, the HPARB states that the CPSO's CAM policy allows CAM "if that is what patients desire." What's wrong with that argument?

What's wrong is that the patients, who are mostly young children, **don't** desire chelation for autism--at all. Find me a 5 year old who wishes that they weren't playing on a Saturday morning but longs instead to be sitting in a dingy clinic being chelated. No child wants that and it is not in the best interest of any child.

I found that section of the HPARB decision to be quite chilling, actually. It's like the HPARB and CPSO committees do not see autistic children as patients at all. In their responses, the CPSO and HPARB consistently position the parents (paying clients) as the only relevant party and erase the children (the actual patients). This contradicts the principle of patient rights and is shocking to see from a health care regulator.

Since autistic children do not consent to chelation-autism therapy, who is consenting?

Parents are proxy consenting to the procedure as guardians of their children.

Is it appropriate for a parent to consent to chelation-autism therapy, for their child?

It is never appropriate for a parent to consent to chelation-autism therapy, which is a phony autism cure with no evidence of benefit and clear evidence of harm.

Chelation for autism does not fall under any of the three justifications for medical proxy consent according to medical ethicists. Those are: the right to an open future, substituted judgment, and the best interest standard. Chelation-autism therapy causes needless suffering, carries significant risk and has no benefit--meeting none of the criteria for ethical proxy consent.

Is there a precedent for stopping a parent from proxy consenting to a dangerous procedure?

There is ample precedent, legally, for the province to intervene and stop parents from engaging in procedures that compromise the welfare of their children. In fact, it happens every day when Child Protective Services investigates families for neglect or abuse based on the principle that the state has a responsibility to ensure health and safety of children.

What legal repercussions could a parent face for using chelation for autism?

If a judge decides that the chelation treatments comprised medical abuse or neglect, the parent could serve jail time. In Canada in the past year, two sets of parents have been jailed for medical neglect that resulted in the death of their children. In the UK, parents have had their children removed from their homes after the parents were found to administer a phony bleach cure for autism on them.

But aren't these parents just desperate?

While the emotional state of a parent is at times used for leniency in sentencing, "desperation" is not legally an excuse for neglect or abuse which, on their face (regardless of intention) cause harm. Many parents' emotions and belief systems allow for corporal punishment, for example. However, since that is banned under law, they are not allowed to beat their children no matter

what their emotional state or belief systems are. The state has a responsibility to ensure the health and safety of children if their parents put them in danger.

When is it ethical for a parent to proxy consent to a medical treatment?

When the treatment is actually medical--as in the case of an experimental cancer drug--it undergoes trials (e.g., with animals and adults) then goes through ethics boards before released for use on children, after which participants undergo a rigorous process of informed proxy consent.

We don't see the same rigour--or indeed any rigour--for complementary and alternative medicine (CAM) in Ontario. The self-regulating board here (the College of Physicians and Surgeons of Ontario, CPSO) does not identify children as being patients, *or even as entities of any sort*, in its guiding documents on CAM. The document never even references proxy consent, despite a body of literature on the complexities of medical proxy consent.

Why do parents fall for this snake oil?

The pseudoscience industry is taking advantage of existing attitudes that autism should be "fixed" rather than accepted. That attitude is fairly pervasive. For example, some autism charities and services also promote pseudoscience. Until last year, Autism Speaks listed numerous pseudoscientific resources on its website (and it promoted the vaccine myth for years as well) and Autism Canada still has pseudoscience listed on its "resources" webpage. When the disability is described as something to "fight" or "battle," as it is in much fundraising material, autism gets reified as though it can be removed from a child.

Parents may believe a certain product or approach can remove autism from their child. Processes like MMS and chelation are extreme versions of the idea that autism can be removed; in a way they are like quasi-exorcisms. But autism can't be exorcised or removed from a person; all it does is destroy the child's self-esteem and their connection with their family and community. It makes everything worse, for everyone.

What is the alternative?

The social model of disability, embraced by inclusion advocates, moves towards considering the desires and needs of disabled children and taking action to improve their environment; for example, removing access barriers and incorporating inclusive design at school. The neurodiversity movement (which follows the social model of disability) promotes autistic acceptance, where parents learn about autism and appreciate their kids on mutual terms, rather than focusing on trying to "fix" them at any cost.

The evidence is clear that inclusive design and acceptance allow children to flourish in ways that segregation and stigma never can. We can see this in the current new generation of Downs syndrome children who were mainstreamed and who outpace every expectation in terms of positive life outcomes in contrast to previous, segregated generations.

Why has it been so hard to get chelation banned in Ontario?

The simplest answer is that professional self-regulation is the problem: that it's a fraught concept because professional relationships can cloud the self-regulatory process and that rather than having peers regulating their peers we need an outside regulator.

A more nuanced view is that the regulatory boards are also coloured by existing bias about disability and about children, as outlined above.

What's next?

There are no further review processes easily available in Ontario, but there is the option of a judicial review which I'm currently discussing with my lawyer. At the same time, advocates need to approach the Government of Canada/Health Canada to regulate, as was done in the US and UK. The UK has an excellent [report](#) on the subject as well as guiding documents from the NHS that our government could use as a model.

Action plan for stopping autism pseudoscience

I will be blogging here about the case and sharing information on [Twitter](#) as we take it to the next level, with community campaigns that everyone can take part in.

There is definitely hope for change. Autistic self-advocates, physicians, parents and allies worldwide are doing powerful activism around the issue of autism pseudoscience. We should all keep doing this work and not get discouraged. We have a lot of momentum and an amazing community working on this. Thank you for your support!!