



Autism Pseudoscience: A Physician's Guide

by A4A Ontario
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A4A Ontario is an autistic self-advocacy group, founded in 2017. We are autistic adults from a range of professions and backgrounds, advocating for the rights of all autistics in our province. We became involved in the fight against autism pseudoscience in early 2018, authoring a report that outlined the scope of the problem in Ontario. We also gathered more data and reported on health care access and human rights issues for autistics in a presentation to the United Nations Rapporteur on Health in late 2018. (Reports available free upon request).

Introduction

When a parent tries to "cure" their autistic child with pseudoscience, they are physically and psychologically harming their child. Regardless of the parents' intentions, that is the result.

We are reaching out to you, as physicians, to help protect autistic children. You are often one of the first points of contact for families in crisis. You have influence and can take action to protect the health and safety of children.

In this paper, we discuss:

1. the impact of autism pseudoscience;
2. how to detect it;
3. how you can respond in your practice; and
4. other actions to protect children.

The Lifelong Impact of Autism Pseudoscience

Autism pseudoscience is very common. It is everywhere -- and it is big business. Parents have spent millions on unproven autism treatments such as gene therapy, hyperbaric oxygen therapy, chelation for autism, MMS, DAN/MAPS diets and off-label CBD and medical marijuana. The supplement industry promotes hundreds of supplements "for autism" and some providers sell them out of their offices, taking a commission from manufacturers. Other times, parents buy phony products online or may travel as medical tourists for so-called treatments.

Let's be clear: No autistic child or adult wants to undergo a phony autism treatment. These treatments are frightening, painful and emotionally devastating. They are also often physically

risky or harmful. Some children have died from treatments such as [MMS](#) and [chelation-for-autism](#).

At A4A, some of us are survivors of these treatment scams, enduring years of our parents' senseless rituals around food, "biomedicine," drugs and other bogus treatments to supposedly cure us --of being ourselves.

Far from being positive, the results were: PTSD; fear of medical providers; eating disorders; low self-esteem; inability to trust; identity issues; broken family relationships and more. Some of us had to walk on eggshells at home for fear of more painful treatments.

When parents choose pseudoscience, it also often replaces crucial, legitimate therapy for their kids. For example, a psychotherapist recently told A4A that her client's family discontinued essential therapy services because their alternative to psychotherapy was to take their son chelation therapy.

Survivors' lived experiences show that adults who spoke up against a parent's use of autism pseudoscience sent an important message to the child that *this is not okay*. By contrast, when adults/providers were silent about it, survivors received the message that *other adults think this is fine* and *no one will help me*.

If you encounter families who are using autism pseudoscience, it is important to say something. There are also other steps you can take to intervene.

Recognizing Autism Pseudoscience

Terminology. Autism pseudoscience sellers aren't allowed to use the word *cure* in their marketing materials, so they've developed euphemisms for the cure promise. Parents pick up on these terms. Be aware if parents are using terms like:

- "recovery from autism"
- "detoxification"
- "addressing the core symptoms of autism"
- "biomedical approach"
- "parasite removal"
- "methylation"
- "healing protocol"
- "restoring neuroimmune function"

Other Signs. The Westminster Commission on Autism has authored a [report on autism pseudoscience](#) that outlines the problem and identifies some signs of a practitioner selling pseudoscience, including:

- Relying on anecdotal evidence/testimonials;
- Dismissing scientific views on the condition;
- Offering one cure for a broad range of conditions;

- Inventing new conditions;
- Telling patients they “have to believe” for it to work;
- The product is expensive and therapist gets financial gain from each product sold; and
- The therapy can be administered by someone with no medical qualifications.

Off-label use of prescription products is another warning sign.

Parents may:

- present with a completely healthy child, but insist their child needs medicine;
- attribute developmentally-normal behaviours (such as excitement, fears, rebellion or night waking) to an imagined illness;
- perceive autism itself as an illness or a toxin;
- have a pattern of provider-shopping;
- claim their child has other conditions such as "PANDAS" or "chronic Lyme";
- refer to their child’s personality traits/interests as "behaviours";
- claim that there is a cure for autism.

The child may:

- seem afraid to express/speak;
- be unwilling to contradict the parent;
- repeat the same jargon as the parent;
- not have his or her AAC device available because the parent did not bring it;
- show a trauma response when the topic of the treatment is brought up.

Taking Action in the Clinical Setting

Two types of consent. When you meet an adult patient using pseudoscience to treat *their own conditions*, you may decide to step back because the patient is **consenting** to their own treatment even if it may not be in their best interest.

With autism pseudoscience, a different approach is needed because the child cannot give informed consent. Parents are **proxy-consenting** for children who do not want to undergo these treatments--treatments which have no evidence of benefit and clear evidence of harm. It is important to step forward in these cases.

Here are some strategies:

Define the patient

Let parents know that you value and acknowledge the needs of your patient.

- Speak directly to your patient by name (even if it seems like they aren’t paying attention);
- If your patient is non-speaking, ask the parents to bring along their AAC communication so that your patient can communicate directly;
- Let parents know that you value and care for your patient;

- Always assume your patient is listening. Even if they are missing some of the details, they are perceiving the tone around these subjects;
- Redirect from talking *about* your patient. Example: if parent complains to you about their child having trouble sleeping, turn and ask your patient, “How are you feeling at bedtime these days?”;
- If a parent mentions a pseudoscience treatment, let them know about any potential harm associated with the treatment and that you’re concerned about its impact on your patient.

Stay connected

- Keep track of any missed appointments and ensure that the patient sees you regularly. Children whose families have dropped out of the system are more vulnerable to medical abuse.
- Consider referring the patient to an expert such as a speech language pathologist or psychotherapist who can monitor and forward notes to you.
- Stay calm about autism. Many parents report that they were frightened when providers talked about a “narrow window for early intervention” and felt like they had to try *everything* on their autistic child (including pseudoscience) before it was too late.
- People make bad decisions when they panic. If you sense that a parent is panicking, provide resources on autism acceptance and autism throughout the life span. Provide written information and links. Don’t let them walk away empty-handed.
- Use the EGRIP strategy. [This article](#) by Gleb Tsipursky for *Scientific American* is a great starting point in applying the EGRIP strategy in practice.

Reporting

There is Canadian precedent for adults to step forward and protect the health rights of children. Medical neglect is included in reporting requirements for suspected child abuse. There are also mandatory reporting requirements of teachers and providers who become aware that a child is going to be sent abroad to undergo procedures illegal in Canada, such as “gene therapy” for autism.

If you are unsure whether or how to report suspected medical abuse, ask a social worker or other professional at your clinic. If you do not know who to consult, contact us and we can connect you.

The Situation in Ontario

Autism pseudoscience impacts autistic people across Ontario. We have identified 14 Ontario clinics promising to treat autism through a range of [protocols](#) including [chelation](#); vitamin injections; off-label prescription drugs such as long-term antibiotics; bleach enemas (MMS Miracle Solution); chemical castration; herbal and vitamin supplements; hyperbaric [oxygen tanks](#); severely restrictive diets; and other protocols.

In Ontario, there are currently no Provincial regulatory measures to stop practitioners from continuing to market pseudoscience to new customers. A group of MDs in Ontario is working independently for better regulation. They are seeking to collaborate with the federal government

on a report addressing gaps in regulation and enforcement, to establish a clear path for policy around health claims for CAM and autism in Canada.

There is precedent for making these changes. In the UK, the Westminster Commission on Autism has written a comprehensive report that identifies such gaps in their current regulation and are working to address this problem so that complaints no longer fall through the cracks. The UK working group are helping to ensure that its government is more proactive in regulation and enforcement. We hope to see the same in Canada in 2019.

Contact Us

Thank you for reading this report and for caring about the health and safety of autistic patients! Please follow us on Facebook or Twitter @a4aontario to keep informed. If you would like any other information, please send us an email at a4aontario@gmail.com.