# Submission to the CAHS Autism Assessment Panel From: Campaign Against Phony Autism Cures

May 20, 2021

To The Canadian Academy of Health Sciences:

The Campaign Against Phony Autism Cures (Canada), together with Autistics for Autistics Canada, are submitting the attached paper for your review as you assess autism services in Canada. It describes some of the most common forms of autism pseudoscience and the risks they pose to autistic children and dependent adults.

The attached paper was first written in 2020 following a request to us by a provincial Office of the Public Guardian. The Office contacted us because they receive complaints about parents using phony autism "cures" and it has been seeking resources and information to share with physicians and others involved in guardianship matters around safety of autistic children and dependent adults.

We were not surprised to hear from them. Autistics for Autistics also receives calls and emails from family members of autistic Canadians who are being abused by parents using these treatments, which include MMS, a form of bleach that sellers claim will "heal" autism when fed to a child or dependent adult. As our paper makes clear, the results can be deadly. Thousands of children and dependent adults have experienced adverse events as well as emotional trauma and suffer from PTSD from these phony treatments. Often, there is little protection for the victims.

The Government of Canada's newly-formed Standing Committee on Science and Research must make it a priority to document and combat autism pseudoscience in Canada. For direction, the Committee can contact UK MP Barry Sheerman and the Westminster Autism Commission who have done excellent work on this issue (See their report here). It can also connect with the UK's National Health Service (and the UK's National Institute for Care and Excellence) and the US Food and Drug Administration, both of whom are active in creating standards around autism care and banning phony autism treatments. The US Department of Justice has also been prosecuting some of the scammers.

Canada lags behind both the US and the UK in regulation and enforcement efforts. Health Canada lacks the capacity to adequately enforce existing regulations or even to communicate whether they have acted on or resolved a complaint. There is not a clear path for criminal enforcement. And as yet, there doesn't seem to be political will in Canada to improve the situation. In early 2019, I reached out to a Canadian politician to build on the UK's report and was told that "we're really more focused on getting people to overcome vaccine hesitancy right now." I assured him--as I am assuring you now--that the antivaccine movement is deeply informed by misinformation about autism. In fact, when it comes to health misinformation, all roads lead to autism.

The experience of the past 18 months has made clear that health misinformation is a serious threat to public health. Social media has been flooded with misinformation about fake "immune boosts" and "treatments"--including claims that bleach can ward off Covid-19 symptoms. Along with being ensnared by purveyors of heath misinformation, some Canadians have become entangled in the radical right wing movements that have used the crisis (and health disinformation) as an opportunity to recruit. Health disinformation has also made its way into some governments during the pandemic. Several governments and politicians in <a href="South America">South America</a> and, briefly, in the US, even embraced pseudoscientific approaches to Covid-19. When US President Donald Trump touted bleach as a Covid-19 treatment, I co-wrote this in the <a href="New York Times">New York Times</a>:

From monitoring [social media] groups, we've watched as the marketing of the "biomedical cure" industry has become increasingly linked with a distrust of social institutions in general. Much of it is based around the autism-vaccine myth, first made popular by <a href="Andrew Wakefield">Andrew Wakefield</a> and later perpetuated by <a href="Jenny McCarthy">Jenny McCarthy</a>, <a href="Robert Kennedy Jr.">Robert Kennedy Jr.</a> and others.

One reason that autism is an epicentre of health misinformation is that there is no one clear standard of care for autism. Despite years of awareness about autism, we are really at the beginning of understanding and providing appropriate services, access and inclusion for autistic children and adults. Our country will be going down the wrong path if it continues with antiquated approaches, like focusing research dollars on searching for the needle in the haystack (autism gene) with the assumption that finding it will "solve" autism. The real problem to solve is that autistic Canadians don't have the quality of life they deserve.

Our government must meaningfully consult with autistic Canadians and autistic researchers from throughout the world to understand how to build a model that addresses the key issues that matter to autistic people and improves their inclusion and quality of life. Seeking vainly to prevent, cure or destroy autism only encourages hatred and propagates health misinformation.

It is also not a safe position to fall back on traditional therapeutic methods that are not based in science. Applied Behaviour Analysis (ABA) was disregarded by the field of psychology more than 40 years ago: why are provincial governments continuing to fund it and present it as an appropriate standard of care for autistic children? Please see this paper on the many research reviews debunking the claims of the ABA field and consider this: the founder of ABA is also the founder of a popular form of gay conversion therapy. Many autistic adults vehemently oppose it, including those who experienced it. There is also a new generation of occupational therapists who oppose the practice. ABA is not broadly funded in the UK (or anywhere in Europe) and funding for ABA is being reviewed and contested in several US states (see the current example of Texas) as well as by one of the US's largest insurers (The US Department of Defense). (See Appendix 1.) With these conflicts in mind—and considering the weak, generally biased evidence that attempts to support ABA, it is time to ask how sustainable ABA really is.

So, where does Canada go from here in terms of science-based autism services? The answer is: forward. Our leaders should be looking to new science-based programs, research and scholarship in this quickly evolving field. They should be calling on the most creative minds in the sciences who are active and aware around the shifts happening in autism research and services. Policymakers should be consulting with and attending International Society of Autism Researchers conferences and actively engaging the neurodiversity movement, including autistic researchers and autistic-led support and advocacy groups in the development of policy.

The old method of doing autism policy (policymakers relying on flawed data from charities to <u>award hundreds of millions</u> in sole-source contracts that do not serve the needs of autistic Canadians) has to stop. It was easy, but it was wrong. The right way forward involves critical thinking, hard work and new professional relationships. Canada can lag behind or it can be a frontrunner in building (for the first time) federal autism policy that values science and centres autistic people as the subjects—not the objects—of research, services and policy. It's time for a paradigm shift.

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Please see our papers on autism pseudoscience in Canada, next page



# Autism treatments: What the science says

In this paper, we present evidence on autism treatments and services.

In Part 1, we define autism pseudoscience, discuss why and how it has become so common and advise on how professionals and regulators can intervene.

In Part 2, we describe and debunk the most common scam products/services, along with their regulatory history and status in Canada, the UK and the US.

# 1. Understanding Autism: Science and pseudoscience

## **Definitions**

<u>Science</u>. Knowledge, or a system of knowledge, covering general truths or the operation of general laws especially as obtained and tested through the scientific method.

<u>Autism pseudoscience</u>. Any product, service or research study that promotes health misinformation about autism.

<u>Cure creep</u>. When, after going onto social media to learn about one form of treatment, people get pulled into multiple scam "treatments", sometimes escalating into extremely abusive forms.

When it comes to autism, there are some things we know and some things we don't know.

## What we know about autism:

- Autism is a condition that influences communication, movement and sensory perception, among other aspects of life.
- People with autistic traits have existed throughout history.
  - The reason more people are being diagnosed as autistic today is that the diagnostic criteria has broadened.
  - Autistic people are more visible in society because we are now included in ordinary life, since most segregated institutions have been closed down.

- 20-30 percent of autistic people are either non-speaking or partially speaking.
- Some autistic people have developmental disabilities; others do not.
- The most effective way to support autistic children and adults is to accept that we are autistic, understand our differences and include us.

## What we don't know about autism:

- We do not know what causes autism.
- We do not know if there are any correlated conditions, other than a correlation with epilepsy.

# When "help" is harm

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.

Action must be taken to protect victim, whose rights are protected under the law. We must also work on prevention, educating parents away from these abusive treatments.

Right now, there is not enough action being taken to protect children. Sometimes, this is because authorities lack the information to understand and identify the problem. Other times, it is because they lack a clear legal precedent to act.

# Red flags for autism pseudoscience

The Westminster Committee on Autism (UK) identifies 7 red flags for autism pseudoscience. They are:

- 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 of autism pseudoscience.

Common terms used by people selling autism pseudoscience:

- "recovery from autism"
- "detoxification"
- "biomedical approach"
- "parasite removal"
- "methylation"
- "neuro-inflammation"
- "healing protocol"

# Sources

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# Who is harmed by autism pseudoscience?

Most of the victims of harmful autism treatments are highly vulnerable persons, usually children or adults who are dependent on their parents and unable to escape the site of their victimization, which is typically their own home.

Most often, parents play a direct role in the abusive treatments, either directly by force/coercion to make the victim take the treatments, or by transporting the victim to a provider who engages in the abusive treatment.

**Motive:** Sometimes, abusive autism treatments are part of a broader pattern of child abuse. Other times, parents have been misled to believe they are *helping* their child. In more complex cases, parents are part of a broader network with extremist ideologies about autism rooted in health misinformation (see "Social Media," below). In the latter case, parents will often be using multiple abusive treatments simultaneously.

#### Source

<u>Autistic boy hospitalised after receiving a mix of 12 alternative medicines, including camel milk and silver</u>. Siobhan Fenton. The Independent. 2016.

#### How common are abusive autism treatments?

There are no recent statistics for how often abusive autism treatments are used generally. A 2007 study in the US <u>found that</u> 74 percent of autistic children were being forced to take phony autism treatments. 66 percent of the parents were not sharing the information with doctors. There has been newer research on specific forms as well as phenomena (such as medical tourism for treatments that are illegal in the US and Canada). We provide data on that in section 2.

As the 2007 study suggests, many treatments are done in secret and are only discovered when there is an adverse event, an abuse complaint by a third party or if the sellers of the product are arrested and their selling lists are examined. This may be especially true for treatments that are known to be illegal, such as MMS.

Because so much of the abuse happens in private, we need to think outside the box in studying and combating it. Some autistic advocates intervene by visiting social media pages devoted to the treatments and reporting the clinics and individuals involved to law enforcement. Their anecdotal evidence (including screen shots from the pages) has been useful both to researchers and the courts. Ideally our law enforcement and regulators will begin to use their resources and legal expertise more often to proactively address the problem of abusive autism treatments.

#### Sources

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Clinic 'Advises Bleach to Cure Autism". Harry Shukman. The Times of London. 2020.
Secret Facebook group reveals how parents use bleach enemas on autistic children. Sophie Norris. The Mirror. 2017

<u>"Everyone Can Do Something to Stop Autism Pseudoscience"</u>: Interview with Melissa Eaton. Noncompliant podcast. 2020.

# What is the impact on the victims?

Some children and adults have died as a result of so-called "autism treatments" (see examples in Part 2, below).

Autistic people are often also denied useful therapies and services when parents choose pseudoscience. For example, a patient may not be able to progress in psychotherapy if they and their parents have been taught to believe their meltdowns can be "fixed with detoxes."

Some autistics develop psychological problems, such as PTSD; fear of medical providers; eating disorders; low self-esteem; inability to trust; identity issues; broken family relationships and more. Some families using abusive autism treatments become increasingly isolated, which is devastating for autistic children and adults in the care of their parents. This is especially true when parents are affected by "cure creep"; after going onto social media for information and support for one form of treatment, they get pulled into multiple forms of treatment, sometimes escalating into extremely abusive forms, all marketed by scammers via social media "support groups".

There has been very little quantitative research into the mental health risks to autistic children who have gone through rigorous pseudoscientific procedures in attempts to treat autism. But the online autistic community is filled with testimonies by autistic adults about this topic. Many

take issue with what is known as the *grief mindset*, where parents try to "recover" the child they'd imagined they would have through various unproven treatments. "Having a grief mindset instilled into my parents was the single most devastating thing that has happened in my entire life," wrote one blogger. "I learned at a very young age that my parents would have preferred a version of me that did not have a disability, rather than the only version of me that will ever exist—the actual me."

#### The role of social media

Over the past several years, health misinformation has accelerated on social media. In the case of autism, scammers have been recruiting more parents to purchase phony and harmful autism cures.

Companies that sell scam products create autism "support" groups for parents on Facebook as stealth marketing campaigns for their brand. Parents join for support and are quickly drawn into online communities that act as an echo chamber, reinforcing false information and selling products that harm.

Typically, these pages are a marketplace for multiple forms of pseudoscience, drawing parents into multiple phony products and services. Business Insider reporter Tom Porter <u>reported</u> on a group promoting MMS and GcMAF as phony autism cures; it had more than 7,000 members, each of whom had requested to join. Inside the groups — largely invisible to moderators and regulators — anyone can falsely portray themselves as a medical expert. In many groups, parents and even group moderators share information and links to multiple scam products, which leads to cure creep.

Much like QAnon and other phenomena, users begin to consume more unscientific information across a broad ideological spectrum, including antivax beliefs. While some parents only dip a toe into social media groups that promote phony autism cures, others become part of the community. As their engagement deepens, they begin to give their children multiple types of "treatment" as part of the accelerationist nature of these groups. For example, a parent may join a group to learn about one thing (such as special diets for autism) and within months be trying measures vastly more extreme, such as MMS bleach, which might have been unthinkable to them previously.

The more engaged a parent is in social media groups, the harder it is to get them to change. Authorities will need to understand how involved a parent is in social media to determine the level and type of intervention and enforcement they will need to use.

Since social media platform are not externally regulated for content (as television and radio are), it is up to each social media platform to self-regulate according to their preferences. None of the platforms are doing a good job of this. As advocate Melissa Eaton, who documents and reports MMS and other illegal products on social media, <u>notes</u>: "Most of the time, when these things are reported we get a blanket response back. Facebook generally sends you back one

rather quickly that says 'this has not violated our community standards'. On Twitter, it's 30 days before generally we get a response. More needs to be done as far as content management for things that are harmful to children. They wouldn't allow child trafficking and pornography of children on their site, but they allow this." (See section 4 of this paper for more discussion).

# The overall impact of health misinformation about autism

Health misinformation has a devastating impact on autistic individuals. One of the most pervasive myth is the false link between vaccines and autism, promoted by disgraced pathologist and expert witness Andrew Wakefield in a <a href="now-retracted paper">now-retracted paper</a> that drew the attention of a <a href="co-founder of Autism Speaks">co-founder of Autism Speaks</a>. Unfortunately, Autism Speaks then perpetuated the antivax myth for years as they funded research into "whether vaccines and autism are linked". This amplified antivaccine beliefs and sowed doubts in parents for years. Autism Speaks finally distanced itself from Wakefield's theory in 2015.

The impact of the autism-vaccine myth on autistic people was threefold.

- Those of us whose parents believed the autism-vaccine myth were often made to feel as
  if our natural ways of being were the result of a terrible "toxic insult" and that we
  ourselves were toxic.
- Some parents have taken their autistic children to dangerous "chelation clinics" that claim they can detoxify children from their vaccines. (See Part 2 of this report.)
- The association of autism with toxicity created hateful stereotypes about us within the broader society.
  - Instead of being accepted and included, too many saw us as the objects of pity or revulsion.

More broadly, health misinformation has a negative impact on public health; one example is the current movement against the coronavirus vaccine and the plethora of phony Covid cures. Health misinformation also undermines faith in public institutions, as QAnon and other conspiracy groups have infiltrated alternative health spaces. As Dalmayne, et. al <a href="write">write</a>: "From monitoring [social media] groups, we've watched as the marketing of the 'biomedical cure' industry has become increasingly linked with a distrust of social institutions in general."

According to <u>Science Up First</u> (a consortium of health providers and scientists) "Throughout the COVID-19 pandemic there has been a marked rise in misinformation and conspiracy theories related to health information.... The WHO has classified this as a global infodemic. According to experts conspiracy, misinformation and conspiracy theories are rapidly spreading on social media and represent a threat to health and safety."

Research <u>conducted by Press Gazette</u> in July 2020 found that 4,094 of 7,295 misleading claims about Covid originated on Facebook. In comparison, 1,066 false claims were traced to Twitter,

999 on WhatsApp, 265 on YouTube and 90 on Instagram. Unlike radio and television, social media remains a largely self-regulating platform. As <u>one study noted</u>: "Each social media platform is effectively its own universe ... a commercially independent entity (that) can at best only control content in its universe." For fearful people in a pandemic, as for parents who are ignorant about autism, social media can become a trap.

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# How health professionals, regulators and protective bodies can help

- Professionals have the power and responsibility to intervene if they become aware that parents are using an abusive autism treatment.
  - o Physicians are often a first point of contact and seen as an authority by families.
- Teachers, carers and health providers have an obligation to report abuse to law enforcement or other authorities.
- Law enforcement and other protective bodies have the power and responsibility to remove children and dependents from dangerous situations and to prosecute providers or parents for abuse.
- Regulators have the responsibility to hold sellers and promoters of health misinformation responsible for violating any health regulations in their marketing claims and services.

There is a pressing need for regulatory reform in most Canadian provinces and territories, as well as in the UK. (See discussion in section 3.) Efforts are underway in the UK and Canada to

rectify gaps in regulation and to remediate flaws in the self-regulatory college system. Advocates are also working to educate law enforcement about how to identify abusive autism treatments.

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<u>Autism Case Highlights Urgent Need to Reform Ontario's Regulatory Colleges.</u> Anne Borden King. Healthy Debate. 2020.

<u>Advertising Watchdog Rules Fake Autism 'Cure' Adverts Must Stop</u>. Samantha Fenwick. BBC News. 2019. Science Up First: Why (The Goal of Science Up First). 2021.

# 2. Types of autism pseudoscience

## **Definitions**

ARFID. Avoidant/restrictive food intake disorder (ARFID): An eating or feeding disturbance that is characterized by a persistent failure to meet appropriate nutritional and/or energy needs.

<u>Medical child abuse (MCA):</u> A child or other dependent receiving unnecessary and harmful (or potentially harmful) medical care at the instigation of a parent or other caregiver.

Medical consent by proxy (Legally authorized representative): A legal authorization for a representative (parent or other guardian) to consent to medical care and procedures on behalf of a person in their care.

Off-label drug use: The use of pharmaceutical drugs for an unapproved indication or in an unapproved age group, dosage or route of administration.

Off-label procedure: The use of a medical procedure for an unapproved indication.

# Chelation (off-label drug/procedure)

**What it is:** Prescription chelating drugs remove metals and minerals from the blood. They are indicated for lead poisoning, industrial accidents and other similar incidents—**NOT INDICATED for autism**.

In the clinical chelation scam, an MD will prescribe and infuse chelating agents, off-label, for conditions not indicated by the drug maker (such as autism, diabetes, fatigue or heart disease),

charging roughly \$700 per infusion and telling patients they need repeat infusions.

In the case of oral, "DIY" chelation, substances are sold to parents by naturopathic MDs or sold online. Eaton: "Oral chelation products can be purchased on Amazon. There's plenty of moms that have YouTube channels where they're showing you how to cut up these doses, how to divide them out, how to put them in the syringes and medical droppers. Some of these parents...their children are sleeping and they just squirt these doses in their mouth while they're asleep."

**Regulatory Status:** Chelation it is not approved as an autism treatment in the US or the UK. Unfortunately, it has not been reviewed by Health Canada.

**Marketers' claim:** Off-label use of chelating products detoxify autistic children of their vaccines and thus treat/cure their autism.

What the science says: Autism is not caused by vaccines. There is no evidence of benefit and clear evidence of harm, including death, from chelation as an autism treatment. There is no plausible mechanism for researching chelation as an autism treatment.

A <u>research review</u> by Dr. Yashwant Sinha et al. concluded "The potential for vulnerable families to seek this as a promised miracle cure raises ethical and professional practice questions that need international consideration."

"Chelation is a treatment for which we have no evidence of benefit and we have evidence of harm," <u>says Dr. Evdokia Anagnostou</u>, a pediatric neurologist and senior autism researcher at Holland Bloorview Kids Rehabilitation Hospital in Toronto. Anagnostou notes that it can damage the heart and kidneys, and even result in death. There are at least two cases of children dying from chelation therapy for autism which have been reported in the scientific literature, according to Anagnostou.

#### **Product Risks and Adverse Events**

Death, dehydration, hypocalcaemia, kidney injury, liver enzyme elevations, hypotension, cardiac arrest, allergic reactions, essential mineral deficiencies, neurodevelopmental toxicity and teratogenicity are all <u>risks of chelation</u>.

In 2005, <u>Abubakar Tariq Nadama</u>, age 5, died of cardiac arrest in the office of Pennsylvania doctor Dr. Roy E. Kerry after receiving chelation-autism therapy.

## **Regulatory Action**

- Chelation for autism is banned by the US Food and Drug Administration.
- Chelation is on the UK's Do Not Use list, per its National Institute for Health and Care Excellence (NICE).

- In the US, medical Boards of professional conduct have conducted hundreds of <u>investigations</u> and disciplinary actions involving practitioners of off-label chelation.
- This <u>case</u> of a physician using off-label chelation involved action by two Boards of Medical Examiners as well as three civil suits. After ten years of suspensions and other disciplinary actions, the Boards revoked the physician's license. (The lawsuits were settled for undisclosed amounts.)
- In 2014, the FDA issued a <u>warning</u> that companies are making false claims about products or therapies that claim to treat or cure autism. The FDA stated in its warning that chelation therapy or mineral treatments, carry "serious and life- threatening outcomes."
- In 2016, the FDA again issued warning letters to companies marketing OTC chelation for autism products, writing in its <u>press release</u>: "Consumers who use OTC chelation products for detoxification are exposed to all the risks associated with chelation. These risks are not acceptable, given that there is no proof that 'detoxification' using these products is effective to prevent or treat any condition or disease."
- In 2012 and 2014, the US Advertising Standards Authority (ASA) investigated complaints about false advertising by chelation-for-autism <u>providers</u>. In <u>both cases</u>, the ASA concluded that the ads were misleading and could not be run again.
- The UK's National Institute for Health and Clinical Excellence (NICE) recently published A guideline on the diagnosis and management of autism in adults and a guideline on the management and support of children and young people on the autism spectrum. Both documents address the health risks of a number of biomedical interventions for autism including chelation, stating: "Do not use chelation to manage autism in any context in children and young people."
- In a widely-publicized case, in August 2017 Dr. David O'Connell of Chelsea (UK) was restricted from treating autistic patients by the Medical Practitioners Tribunal Service while an investigation takes place for so-called autism treatments he has used on children, including animal hormone injections and chelation.
- As the US Poison Control Center <u>states</u>: "The National Center for Health Statistics reported that 111,000 adults said they used chelation therapy, along with 72,000 children under the age of 18. It is highly unlikely that 183,000 US residents required chelation therapy for the limited number of approved indications. It is much more likely that therapies were received for conditions attributed to heavy metals without scientific validation."
- Health Canada has not reviewed chelation-for-autism.

- In Canada, there has been one publicised <u>complaint</u> against an MD (2018-2021) for using chelation to treat autistic children's "vaccine injury." *The MD also served on complaint review boards with his medical regulating college, the College of Physicians and Surgeons of Ontario (CPSO).* 
  - The CPSO refused to review the 2018-19 complaint or consult with autism experts on the antivax claims of the MD, on the grounds that the complainant had submitted hyperlinks in her electronically-submitted complaint which would have been "onerous" for reviewers to click and read.
  - The case <u>casts doubt</u> as to the competency of the CPSO as a health regulating body and raises the question of whether the competency of Ontario health regulatory bodies should be reviewed as per recent reviews and reforms in British Columbia.
  - The case is on the public record in CanLII (Health Professionals Arbitration Review Board, see Sources).

#### Discussion

It is difficult to stop clinical chelation for autism because it is performed in some cases by MDs, lending it a false air of credibility. MDs may have the support of their regulating college if the college chooses to close ranks and refuse to even review the evidence of a complaint against an MD. (See above.)

Oral (DIY) chelation is also difficult to stop, because the products are sold on multiple platforms with multiple names and regulators do not have the resources to proactively search and issue orders for companies who, even after being censured, pop up again with new names in new platforms.

To address this problem, it would be best for governments to take a systematic approach by 1. Reforming their health regulating colleges to actually do their job and protect the public; and 2. Developing a comprehensive strategy for regulating online sales and promotion of health products. In the meantime, authorities and other professionals must intervene when they become aware of a family doing chelation-for-autism, through a combination of law enforcement and education efforts.

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# Fecal Transplants/FTM (off-label procedure)

**What it is:** Fecal transplant (FMT) is a procedure for several diseases. To perform fecal transplants (FMTs), doctors transfer fecal matter from donors into a patient's bowels, either through capsules or a colonoscopy. **NOT INDICATED for autism**.

**Regulatory Status:** While FMT is approved in Canada and the US for specific conditions such as recurrent *Clostridium difficile* infections, it is not approved as an autism treatment.

**Marketers' claim:** Autistic children need fecal transplants to heal autism, which is caused by intestinal issues.

What the science says: Autism is not caused by intestinal issues. There is no evidence of benefit and clear evidence of harm for FMT as an autism treatment. Like chelation, FMT is marketed based on a false causation theory. Thus, there is no plausible mechanism to justify researching FMT as an autism treatment.

The only study on FMT as an autism treatment was biased, used very small sample sizes, had no control groups and had no controls for the placebo effect.

#### Product risks and adverse events

In recent years, there has been a series of injuries and deaths in the US following FMT. FMT carries risk of infection transmission such as HIV, hepatitis and retrovirus as well as transmission of intestinal parasites.

Autistic children are required to fast, have their bowels chemically cleansed and undergo anaesthetic and surgical procedures, multiple times, during the FMT-for-autism protocol. Some suffer from severe psychological trauma as a result.

Since it is illegal in Canada, the children are transported to unregulated clinics abroad for this procedure, adding to trauma and furthering other risks.

## **Regulatory actions**

• In 2020, Health Canada investigated Naturopath Jason Klop after learning that he was transporting autistic children to Mexico for fecal transplants. Their warning letter stated

that his business was not compliant with federal law, telling CBC News: "Selling unauthorized health products or making false or misleading claims to prevent, treat or cure illnesses is illegal in Canada. The department takes this matter very seriously and will continue to take action to stop this activity."

- The College of Naturopathic Physicians of British Columbia suspended Klop's license after the CBC reported the story.
- In 2019, the FDA warned providers and patients of the potential life-threatening risks of fecal microbiota transplants (FMT), after a patient who received an FMT was infected with a drug-resistant bacteria and died.

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Reactions Due to Transmission of Multi-Drug Resistant Organisms. US Food and Drug Administration. 2019.
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#### **GcMAF**

What it is: Gc protein-derived macrophage activating factor (GcMAF) is an injectable product made from human blood with a protein by modification of vitamin D binding.

GcMAF is sold illegally for around \$600 a vial, with no verifiable guarantee that it's been screened for transmissible diseases. One company that marketed GcMAF (Immuno Biotech) earned £7.9m between 2011 and 2015. It was raided and shut down by UK government regulators in 2015.

"GcMAF blood product is injected by parents...they take hypodermic needles and inject this into their autistic children. Sometimes they squirt it under the tongue," says Eaton.

**Regulatory Status:** GcMAF is not approved in the UK, US or Canada. According to the FDA, "GcMAF treatments have not been subject to the rigorous approval process and manufacturing scrutiny required for FDA-approved products, and are therefore not being legally marketed."

**Marketers' claims:** In a well-known case, a company in the UK claimed GcMAF is "the body's way of becoming cancer free", that 85 percent of people with autism "respond", and "15% make full recoveries". Another high-profile GcMAF marketer, Amanda Mary Jewell, sells GcMAF products online from social media groups as a cure for cancer and autism.

What the science says: There is no evidence of benefit and clear evidence of harm in GcMAF as

an autism treatment. There is also no plausible mechanism for studying it as a potential treatment.

**Product Risks:** Toxic shock; headaches; nausea; abdominal pain; disease and/or death from tainted blood products; emotional trauma from procedures.

## **Regulatory Action**

UK government regulators have cracked down on one of the chief sellers of GcMAF, David Noakes and his company, Immuno Biotech. In 2015, more than 10,000 vials of GcMAF were seized by the UK government. Noakes was sentenced to 15 months in prison for practicing unlicensed medicine and money laundering; in 2020 his assets were seized by the government. Two Immuno Biotech scientists were also sentenced to 8 months each.

At the trial, Judge Lorraine-Smith told Noakes the evidence pointed "very strongly to personal gain becoming a motive as your business developed," noting that Noakes marketed his products to "extremely vulnerable people".

The UK's National Autistic Society (NAS), which has <u>repeatedly warned</u> about GcMAF, is running a Google advertising campaign that directs anyone searching for GcMAF online to its own accurate information. "Not only is there no verified scientific evidence for these so-called cures, but any autistic adult or child using them risks serious harm," says Sarah Lambert, NAS's head of policy.

#### Sources

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The Fake Cures for Autism That Prove Deadly. Frances Ryan. The Guardian. 2016.

A woman promoting an unlicensed drug as a miracle cure for autism and cancer made it back onto Facebook despite being banned. Rob Byrne. Business Insider. August 2020.

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Cancer "Cure" Boss David Noakes jailed for 15 months. BBC News. 2018.

Quackery Exposed: GcMAF. Fierce Autie.2020.

Paper about widely-touted "cure" for autism, cancer, retracted. Adam Marcus. Retraction Watch. 2007.

## Gluten Free Casein Free Diet

What it is: Under the GFCF, parents prohibit their child from eating products containing gluten as well as products containing casein and most other dairy products.

The diet surged in popularity between 2005 and 2015. Out of 1,200 families <u>surveyed</u> by the University of Rochester in 2014, about 1/3 of parents had tried the GFCF diet on their children. A larger <u>review</u> by Reissmann et al. (2014) found that close to 25% of families had tried the GFCF diet.

**Regulatory Status:** The National Institute for Care and Excellence, a standards agency of the National Health Service (UK) has listed GFCF on its <u>"Do Not Use for Autism" list</u>. GFCF is not banned in any jurisdiction.

## Marketers' claims

- 1. That gluten and casein can leak out of the gut and enter the brain, having an opioid effect and leading to autism "symptoms and behaviours".
- 2. That avoiding these proteins (and buying the books, programs and dietary supplements they are selling) can heal, cure or treat autism.

Marketers wanting to pivot away from cure claims will often make false claims that autistic children are more likely to have celiac or other digestive conditions and that a main driver of autistic stereotypies and other behaviours is digestive discomfort rather than stress responses to their emotional environment.

Marketers will also falsely claim the diet is without risk. As one <u>marketer</u> writes "While there is no guarantee you will see positive changes in your child, the good news is the diet does not have major risks or side effects, so it is a relatively safe change to make - and for many, it's worth a try."

# What the science says

There is no evidence that wheat or casein have an "opioid effect" on autistic people. There is no evidence the diet benefits autistic people and there is clear evidence of harm. There is no plausible mechanism for studying it as a potential treatment.

In a 2015 double-blind study, Hyman et al. <u>found</u> "no significant effects on measures of physiologic functioning, behavior problems, or autism symptoms."

In their <u>research literature review</u>, Reissmann et al. concluded: "The majority of identified studies evaluating GFCF diet outcomes failed to meet basic methodological standards....

Comparison of study results did not show any clear-cut results, with a substantial proportion of studies failing to show any positive dietary effect.... These and other negative results related to the opioid excess theory weaken the underlying rationale for GFCF diet use."

#### **Risks**

- 1. Social isolation. GFCF removes two foods that are shared among children at school and at celebrations. Having to bring and eat special foods further separates the child from family and peers.
- 2. Eating disorders. Autistic children are more prone to eating disorders such as ARFID, the fear of eating certain foods. Adding parental anxiety that certain foods will make them "sick" (more autistic) can escalate ARFID.

- 3. Nutritional deficits. It is common for autistic children to self-restrict their diet due to sensory issues. Adding a GFCF diet can lead to stunted growth and other poor nutritional outcomes.
- 4. "Cure creep". GFCF can be a gateway to more extreme dietary restrictions and autism cure protocols. When parents seek information about GFCF on the web, especially in social media, they are often drawn into bigger and more dangerous scams. As well, some MDs and NDs who market GFCF programs also promote other autism pseudoscience such as the Nemenchek Protocol and chelation.

#### Discussion

Doctors and other authorities should not mistake GCFC for an elimination diet to determine food intolerance. GFCF is a heavily marketed lifestyle that is associated with products and services that take advantage of families by promising a cure for autism and "autistic behaviour".

If an individual or family is concerned that a type of food is causing physical symptoms, a dietician should be consulted, **not** a "GFCF practitioner".

#### Sources

<u>The GFCH Diet: A Double-blind Challenge Trial in Autistic Children</u>. Susan L. Hyman et al. Journal of Autism and Developmental Disorders. 2015.

<u>Do Not Use Gluten Free Casein Free Diets for the Management of Autism.</u> National Institute for Care and Excellence (UK). Website. Updated 2021.

Gluten-Free Diet Has No Benefit for Children With Autism, Study Finds. Shirley S. Wang. Walle Street Journal. 2015

<u>Gluten-free and casein-free diets in the treatment of autism</u>. Andreas Reissmann et al. Functional Food in Health and Disease. 2014.

# Hyperbaric Oxygen Therapy (off-label procedure)

**What it is:** Hyperbaric oxygen therapy involves breathing pure oxygen in a pressurized environment. It is a well-established treatment for decompression sickness, serious infections, burns, radiation injury, carbon monoxide poisoning and several other conditions—**NOT as an autism treatment.** 

**Regulatory Status:** HBOT is not approved by the FDA and Health Canada for autism. HBOT is on the UK's "Do Not Use as an Autism Treatment" list.

**Marketers' claim:** HBOT can cure autism by "relieving oxidative stress" which also causes autism.

What the science says: Oxidative stress does not cause autism. There is no evidence of benefit and clear evidence of harm in using HBOT as an autism treatment. There is no plausible mechanism to study HBOT as an autism treatment.

A review of studies evaluating HBOT and autism found bias in the small studies whose results that could not be replicated in a scientific setting.

**Risks and Adverse Events:** Serious adverse effects include middle ear injuries, lung collapse, seizures, paralysis and embolisms.

There is also a fire risk which has been involved in about 80 deaths, including a 4-year-old child being treated in a clinic that <u>falsely claimed HBOT could "cure" him of cerebral palsy</u>.

**Regulatory Action:** Health Canada issued a new warning against HBOT for autism in 2020. The FDA has also issued warning letters to clinics making false claims about autism, cerebral palsy and migraine relief.

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FDA Warns Consumers About Common Off-Label Autism Therapy. Emily Willingham. Forbes. 2013. Hyperbaric oxygen therapy for treatment of children with autism: a systematic review of randomized trials Ahmed Ghanizadeh. Med. Gas. Res. 2012.

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<u>Do Not use Hyperbaric Oxygen to Manage Autism in Any Context</u>. NICE (Govt of the UK) Guidelines. Published 2013. Updated 2021.

<u>Unlicensed soft-shell hyperbaric oxygen chambers may pose serious health risks</u>. Health Canada. Health Canada website. Warning identification number: RA-74275. Posted 2020. <u>Hyperbaric Oxygen Therapy</u>. Mayo Clinic. Website. Updated 2020.

## Medical tourism

What it is: The process of traveling outside one's country of residence for the purpose of receiving medical care.

More than 50,000 Canadians engage in medical tourism, according to the Fraser Institute.

While there are a number of motivators for medical tourism, the motivator for parents of autistic children is to access services that are not allowed by regulators.

**Regulatory Status:** Canadians are allowed to travel to other countries for treatments. Due to proxy consent laws, parents are typically allowed to travel abroad to force dangerous and unregulated treatments on their non-consenting children—an exception is Female Genital Mutilation, which is <u>covered</u> under Duty to Report legislation.

What the marketers say: Marketers promise miracle autism cures/treatments not available in Canada and encourage potential clients to engage in crowdfunding for travel and treatment costs.

What the science says: There are very good reasons that Canada has not approved the autism treatments being offered in these other countries. It is because the treatments are neither safe nor evidence-based.

**Risks and adverse events:** There are no uniform measures for tracking adverse events in medical tourism for autism treatments.

#### Discussion

Bioethicists Jeremy Snyder and Leigh Turner have <u>been tracking online crowdfunding</u> activity for medical tourism, including treatments marketed for autism. They note there is a "market-sustaining effect of clinical trials for direct-to-consumer facilities" abroad, giving example of Duke University's pay-to-play trials of stem cell autism treatments. Despite Duke finding no evidence of benefit for stem cells as an autism treatment, the hype around the studies is associated with parents going outside of Canada and the US to have stem cell infusions done to their autistic children.

Snyder and Turner's search of GoFundMe Campaigns on May 25, 2020 returned 69 campaigns referencing Duke and 92 referencing the Stem Cell Institute of Panama (SCI). 11 others had destination locations that included facilities in the US, Russia, India and Mexico. "Some campaigns note that members of the philanthropic family supporting Duke University's stem cell research in the area of ASD visited SCI and had stem cell procedures there. In other cases, campaigners referred to first seeking stem cell interventions at Duke."

Crowdfunding platforms do not limit parents from appealing to fund treatments outside of Canada that could be risky to their children. As families continue to travel for these treatments, often spurred on by hype around clinical trials, it is important for physicians and others who become aware of the crowdfunding campaigns to intervene to protect the health and safety of the children. If a patient's parent discloses that they will be traveling for treatments that are not approved by Health Canada or other country authorities, physicians should advise the parent against it.

#### Sources

Leaving Canada for Medical Care 2015. Report by the Fraser Institute. 2016.

<u>Crowdfunding, stem cell interventions and autism spectrum disorder: comparing campaigns related to an international "stem cell clinic" and US academic medical center.</u> Jeremy Snyder and Leigh Turner. Cytotherapy. 2020.

<u>Examining News Media Reports of Deaths Following Travel for Cosmetic Surgery or for Bariatric Surgery</u>. Leigh Turner. The Globalization of Health Care. Legal and Ethical Issues. Oxford UP. 2013

## MMS- Miracle Mineral Solution

What it is: MMS is a bleach product made of chlorine dioxide, sold typically in small dropper-

style bottles. It is marketed by various scammers online, primarily through social media. Customers are encouraged to use MMS to cure a variety of conditions including autism, diabetes, cancer and Covid-19.

"It is 28% Sodium Chlorite, mixed with an activator such as Hydrochloric Acid," <u>says Eaton</u>. "They then mix the solution into water and it's given to children every 45 minutes, up to 24 hours a day sometimes. It's also administered rectally by enema once or twice a day. The mixture is so harsh that the insides of these children's intestines shed. The promoters use this to convince parents that this lining is 'parasites leaving the body', and then autism is going to go away."

**Regulatory status:** MMS is banned in Canada, the UK and US. All 3 countries have had crackdowns on MMS (see Regulatory Action, below). In 2020, US Attorney General William Barr led "Operation Quack Hack," which led to the arrest and indictment of several; MMS sellers.

**Marketers' claim:** MMS can cure/treat autism by removing toxic parasites that cause autism. When victims suffer from side effects, MMS claim it is the "Herxheimer effect," which they say is a positive sign of recovery and discourage people from seeking proper medical care.

What the science says: Autism is not caused by parasites. Ingesting bleach can kill. Forcing children or dependent adults to drink bleach or giving them bleach enemas is child abuse.

## Regulatory action

Health Canada was a leader in early action against MMS peddlers, issuing warnings for years prior to a series of legal actions that resulted in the <u>arrests</u> of Sarah Nowak of Alberta and Stanley Nowak of British Columbia on charges related to marketing and selling MMS bleach as a tonic for a broad range of health conditions.

In the US, efforts to combat MMS have been scattershot. In 2010, the FDA issued a warning letter on its website. Then in 2015, seller Daniel Smith was convicted and sentenced to four years in prison after a woman named Sylvia Nash died from consuming MMS. For reasons unknown, warnings about MMS disappeared from the FDA website for a year, then reappeared.

In 2020, Operation Quack Hack, a project of US government regulators and law enforcement, cracked down on MMS sellers, notably the Genesis II "Church," an originator of the product. The new crackdown was in response to claims by sellers that MMS could cure or prevent the novel coronavirus. In late 2020, three leaders of Genesis 2 were <a href="apprehended">apprehended</a>, one in the US and two by military police while in hiding in Colombia. They are currently in jail awaiting trial on conspiracy and other charges and their MMS products have been ordered destroyed.

## **Discussion: The cult of MMS**

MMS sellers use an aggressive, cult-like marketing strategy that heavily <u>leverages social media</u>. For example, the Genesis 2 group of sellers refer to themselves as a church and the bleach products as a "sacrament". Some sellers, like Kerry Rivera, live in hiding from authorities and

have their followers do their marketing through social media and multi-level marketing. Rivera's online groups have membership in the tens of thousands.

MMS is a lucrative business. According to IRS documents, Genesis 2 earned \$123,000 in one month (March, 2020). The Genesis 2 church also travels worldwide conducting seminars. For every 30 people who attend, the Genesis 2 Church earns \$15,000. The MMS cult has infiltrated 129 nations. Like the ABA industry, it sees the so-called developing world as a previously untapped market for sales and recruiting. MMS scammers have influenced some governments to legalize MMS. For example, in Bolivia, MMS is legal and endorsed by the Health Minister as a Covid treatment. MMS marketers are also connecting with religious groups; for example, recently 1/3 of the Catholic Bishops in Ecuador called upon their government to endorse MMS as a Covid treatment.

If parents are using MMS, it is almost certain that they are involved in the social media pages of the MMS cult, where they have been told that doctors—and indeed any outsiders—are an enemy of the "truth". They are coached in how to hide MMS use, hide signs of abuse and "treat" adverse events without going to hospital or arousing suspicion.

If you are intervening in an MMS case, please take immediate action to remove the child from the household. Then contact us and we can put you in touch with experts on the MMS cult.

#### Sources

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It Took Moms to Hack the Covid Quacks. by Anne Borden King. Healthy Debate. 2020.

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Staff. Daily Echo (Southampton, UK). 2016.

<u>Bolivia's new government is encouraging people to take toxic bleach as a cure for COVID-19, a victory for a months-long disinformation campaign</u>. Tom Porter. Business Insider. 2020.

Ecuadoran Bishops call for use of Bleaching Agent to Treat Covid-19. Inés San Martín. Crux Magazine. 2020.

# Secretin (off-label drug use)

What it is: Secretin is a peptide hormone that stimulates the secretion of digestive fluids from the pancreas, the production of pepsin from the stomach, and the production of bile from the liver. It is prescribed for certain pancreatic issues—NOT as an autism treatment.

Regulatory status: Secretin is not approved as an autism treatment in Canada, the UK or US.

Marketers claim: Secretin can cure/treat autism.

What the science says: Secretin does not cure/treat autism. Autism is not caused by pancreatic issues. There is no evidence of benefit and clear evidence of risk in the use of secretin as an autism treatment. There is no plausible mechanism to justify researching secretin as an autism treatment.

Due to one anecdotal report, there was a flurry of research into secretin in the early 2000s. All of the subsequent studies showed that there is no evidence of benefit in the use of secretin as an autism treatment (see Barrett, in citations).

#### Discussion

Following one anecdotal report, there was a flurry of research into secretin in the early 2000s, all showing no evidence of benefit in the use of secretin as an autism treatment.

It was another case of hype-itis. The New England Journal of Medicine outlined the problem in an editorial: "The extensive media attention when substantive supporting data were absent was clearly premature and unfortunate. Parents scrambled to obtain this "cure" for their children in the absence of data on safety and efficacy—aided, in some cases, by well-meaning, if not well-informed, health care professionals [sic].

"Unfortunately, claims may be made on the basis of uncontrolled, single-case reports with all the attendant problems (e.g., ambiguities regarding diagnosis and the nature of the treatment and the fact that some children improve without intervention). Pursuing unproven treatments risks depleting the financial and psychosocial resources of families."

Physicians are not immune to hype. With autism, that temptation may be especially strong, with some researchers so focused on finding the secret key to "solving" autism (and the payout they imagine it would bring) that they lose perspective on science altogether. In the worst case, researchers know that they are bending rules or exaggerating claims but have a financial stake in them—and in some cases, their papers end up being retracted. But these retractions may take years, as was the case with Andrew Wakefield's flawed "autism-vaccines" research.

By then, the research, no matter how flawed, has entered the public consciousness and its hold is strong. Among parents of autistic children, some may only wish to see "hope" and ignore the science de-bunking a particular claim. These parents are vulnerable to scammers who take the research (regardless of whether it was retracted, debunked or ignored by the science community) and leverage it to sell their services or products. Some of these scammers are MDs, prescribing chelating drugs, antifungals, secretin, stem cells and other regulated drugs off label, as they present parents with a single case study or even a retracted paper as 'the truth." For one example of this, see Suramin, below.

#### Sources

<u>Do Not Use Secretin to Manage Autism in Any Circumstance</u>. NICE (Govt of the UK) Guidelines. Published 2013. Updated 2021.

Secretin Found Ineffective for Treating Autism. Stephen Barrett, MD. Quackwatch. 2015.

Special diets: Defeat Autism Now Diet/MAPS Diet, Camel's Milk, Nemenchek Protocol

#### What they are

**Camel's Milk** is typically sold through Multi-Level Marketing scams or by providers who take a share of product sales.

**The DAN/MAPS** diet's main premise is that it will detox children from their vaccines. It is sold as a program "prescribed" by "MAPS-certified" MDs or Naturopaths.

**The Nemenchek protocol** is a special diet that focuses on olive oil and inulin supplements. It is marketed by MDs, NDs and in sponsored social media groups.

**Regulatory Status:** None of these diets or products are banned by regulators.

**Marketers' claims**: Camel's milk treats autism. Autistic children need special "MAPS" diets to detoxify their bodies from their vaccines. Autistic people are lacking autonomic nervous system function that can be fixed with the Nemenchek protocol.

## What the science says

Autism is not caused by vaccines, nor by autonomic nervous system function nor by a dearth of camel's milk in one's diet.

All 3 interventions have no evidence of benefit and clear evidence of harm. There is no plausible mechanism to justify researching any of these interventions.

#### Risks and adverse events

In one reported <u>case</u>, a child was admitted to hospital due to the effects of being prescribed 12 different supplemental treatments, including silver, camel's milk and a range of nutriceuticals to "treat autism".

Restrictive diets such as the MAPS or DAN diet specify minimal starches/carbohydrates, depriving children of essential calories. They can stunt growth and also cause social isolation from sharing meals with other children.

Restrictive diets can also cause or accelerate ARFID (fear of eating certain foods leading to a highly-restricted diet) or orthorexia, the fear of being made impure by foods.

Parents who believe vaccines cause autism do not vaccine their subsequent children nor keep their families up-to-date on Covid, flu or other routine vaccinations. This impacts their families and the community.

#### Sources

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Siobhan Fenton. The Independent. 2016.

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What is Orthorexia? Dr. Stephen Bratman. Homepage. 2013 (updated 2020).

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# Stem Cells (off-label use)

What it is: Stem cells are used in medical research and to treat specific blood-based conditions like leukemia—NOT as an autism treatment. They are often sourced from blood in severed umbilical cords after babies are born.

**Regulatory status:** Canadian, UK and US regulators do not approve stem cells as an autism treatment, although there is currently a series of flawed trials at Duke University.

**Marketers' claims:** Stem cells can cure autism, can make non-speaking children talk, can make children more compliant and more loving.

What the science says: Stem cells do not "cure" autism. Stem cells do not make non-speaking children talk. Stem cells do not make children more compliant and more loving. There is clear evidence of harm in using stem cells as an autism treatment. There is no plausible mechanism for studying stem cells as an autism treatment.

Alycia Halladay, chief science officer at the Autism Science Foundation, <u>in a Scientific American</u> <u>article last year</u> called stem-cell based autism treatments "unproven," and criticized media outlets which hyped the treatment.

Of Duke's 3 trials so far, all failed to show evidence of benefit. The studies also show clear evidence of harm. Duke's most recent <u>findings from a Phase II randomized controlled trial</u> show no convincing evidence of benefit, concluding: "Overall, a single infusion of [cord blood] was not associated with improved socialization skills or reduced autism symptoms." Other studies, <u>such as one conducted in 2018 by scientists at the University of Sacramento</u>, also found no benefits for autistic children given stem cells.

**Product risks:** The use of unlicensed stem cell hospitalized 17 people in the US from 2018 to 2019, The Washington Post reported.

The FDA has documented <u>risks</u> associated with stem cell treatments that include allergic reactions; the ability of cells to move from placement sites and change into inappropriate cell types or multiply; failure of cells to work as expected; and the growth of tumors. In Phase II of Duke's trials, with participants aged 2-11 years, two children experienced <u>severe allergic reactions</u>, with one suffering <u>anaphylaxis</u>.

Most autistic children have had to be <u>sedated</u> while receiving stem cell infusions, because the process caused them trauma and meltdowns. Duke researchers <u>described</u> emotional reactions by the children as "aggression, agitation, anxiety, defiant behavior, depression, emotional lability, insomnia, intentional self-injury, and stereotypies." Researchers <u>noted</u> in the Phase II study that "The most frequently occurring event, agitation during the infusion procedure, was associated with the requirements of placing and maintaining an IV and being confined to a hospital room for the infusion."

In July, autistic adults launched a <u>petition</u> that has gained more than 15,000 signatures, demanding that Duke's autism-related stem cell trials be shut down and calling for "full accountability by Duke University".

**Regulatory action:** The FDA has issued warning letters to many clinics in the US offering stem cells as a phony treatment for autism, cancer and a host of other conditions.

#### Discussion

There are hundreds of clinics around the world offering stem cells for unproven uses, at exorbitant fees. Autism is one of their revenue streams.

As Tom Porter of Business Insider has reported: "Some exploit lax local regulations over the use of stem cells, allowing them to be used for conditions where evidence of the effectiveness is weak, according to a study published in respected periodical <a href="The Bone and Joint">The Bone and Joint</a> <a href="Journal">Journal</a>. Hundreds of loosely monitored clinics have also emerged in the US in recent years."

As discussed in the Medical Tourism section above, parents travel with their children for stem cell treatments. Throughout 2020 and 2021, families have been flying across the US to take part in a Duke Expanded Access Program where the families pay to have their children take part in the research. According to Snyder and Turner, who have been <u>researching</u> stem cell-based medical tourism, Duke charges \$15,000 to \$20,000, with a median price of \$15,000.

Hype about Duke's stem cell autism research has also led parents to seek stem cells for their autistic children through medical tourism outside of the US, often to the Stem Cell Institute in Panama (SCI). According to Snyder and Turner: "Stated costs for stem cell interventions (excluding reported travel and accommodation costs) at SCI ranged from \$13,500 to \$20,000,

with a median cost of \$17,000." Some parents are also confused about whether Duke's lead researcher (Kurtzberg) endorses the work of The Stem Cell Institute of Panama, an idea that STI's CEO, Neil Riordan, has reinforced by posting a photo of himself with Dr. Kurtzberg and making <u>assertions</u> that he was <u>asked by the Marcus Foundation</u> to review the Duke proposal. "A lot of families tie the Duke program and the Panama clinic together and kind of think of them as not as the same thing but as a continuum," Paul Knoepfler, a stem cell biologist, <u>told</u> Business Insider.

Duke's autism trials are solely funded by a grant from The Marcus Foundation, a philanthropy established by Home Depot co-founder Bernard Marcus. Marcus is a proponent of stem cells for many conditions. Mr. Marcus and his wife have also <u>been patients</u> at The Stem Cell Institute. Stem cells for the Duke trials are provided in part from the Carolinas Cord Blood Bank and Duke project partner Cryo-Cell. Last year Cryo-Cell entered into a <u>patent option agreement</u> with Duke University, with an option to get licensing to manufacture and sell products based on Duke's patents. The Duke team's research lead, Dr. Joanne Kurtzberg, is <u>Medical Director for Cryo-Cell International and Director of the Carolinas Cord Blood Bank</u>.

As with some of the other treatments in this paper, stem cell autism treatment is a concept that, although shown in research to have no benefit, has taken hold in parents' imaginations as beneficial simply because it was studied and reported as "promising" in news media. Subsequent negative study results were not deemed newsworthy by news media. Without follow-up on the so-called *promising* cures, the public only knows about the original hype—and this is easily exploited by scammers. Not only are parents victims of stem cell scams both financially and emotionally, the children pay a terrible price in terms of trauma.

#### **Sources**

<u>Boosted by celebrity endorsements and a controversial research program, clinics are peddling stem cell</u> autism treatments questioned by experts. Tom Porter. Business Insider. 2021.

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<u>Historic Spring Storm of FDA Letters to Stem Cell Clinic Industry</u>. Paul Knoepfler. The Niche. 2020. <u>Crowdfunding, stem cell interventions and autism spectrum disorder: comparing campaigns related to an international "stem cell clinic" and US academic medical center</u>. Jeremy Snyder and Leigh Turner. Cytotherapy. 2020.

# Suramin (off-label use)

What it is: Suramin is a drug used to treat trypanosomiasis, commonly known as African sleeping sickness and onchocerciasis, commonly known as river blindness. It was first developed in 1916.

The major proponent of Suramin for autism is Judy Mikovitz, a disgraced scientist and one of

the forces behind the *Plandemic* movie (which promotes health misinformation about Covid-19). Mikovitz's papers have been retracted for fraud and she has been prosecuted for theft of lab notebooks and proprietary items from the University of Nevada campus in Reno, where she had been employed. She claimed the materials had been "planted" in her house. She is also involved with Autism One, a network and conference promoting abusive autism treatments.

Mikovitz has recruited several MDs into her scheme, including Dr Robert Naviaux of UC Davis, who ran a small, biased and poorly-designed study on Suramin as an autism treatment.

**Regulatory status:** Suramin is not approved for use as an autism treatment in Canada, the UK or the US.

Marketers' claims: Marketers falsely state that the retroviruses in today's biological therapeutics, including vaccines, are contributing to diseases like cancer and conditions like autism. Marketers state that Suramin can reverse the effects of these retroviruses, treating AIDS, cancer and autism. They also state that the "truth about Suramin" is being covered up by Big Pharma.

What the science says: Autism is not caused by vaccines. Suramin for autism has no evidence of benefit and clear evidence of harm. It does not warrant any study as an autism treatment.

Studies on Suramin by the UCSD are a prime example of research that undermines the integrity of an academic institution and, by association, degrades the credibility of academic research in general.

**Product risks and adverse events:** Severe side effects may include cardiac events and death, low blood pressure, kidney problems, low blood cell counts and decreased levels of consciousness. Common side effects include nausea, vomiting, diarrhea, headache, skin tingling, weakness, sore palms of the hands and soles of the feet, trouble seeing, fever and abdominal pain.

Studies on HIV-AIDS-ARC patients were banned in the US due to the number of fatal adverse events.

#### Sources

<u>Seen 'Plandemic'? We Take A Close Look At The Viral Conspiracy Video's Claims</u>. Scott Neuman. National Public Radio. 2020.

<u>Lack of Response to Suramin in Patients with AIDS and AIDS-related Complex</u>. Lawrence D. Kaplan et al. American Journal of Medicine. 1987.

Supplements: probiotics, vitamins, minerals, herbal supplements

For B12 injections, please see Vitamin B12 Injections, below.

Marketers' claims: Dietary supplements can cure autism or "treat core symptoms of autism".

What the science says: Dietary supplements do not cure or treat "core symptoms" of autism. It is not safe to use supplements in an attempt to treat/cure autism.

**Risks and adverse events:** Vitamins and mineral supplements consumed over the recommended daily allowance are known to cause toxicity. Probiotics carry their own serious health risks for children. (See Regulatory Action, below.)

All supplements, as unregulated products in Canada, have been found to be routinely mislabeled containing unlabeled, allergenic and dangerous substances. A 2014 study of DNA barcoding of supplements by Steven G. Newmaster et al. at the Centre for Biodiversity Genomics at the University of Guelph found that supplements are routinely mislabeled containing unlabeled, allergenic and dangerous substances: "One-third of these also contained contaminants and or fillers not listed on the label. Product substitution occurred in 30/44 of the products tested and only 2/12 companies had products without any substitution, contamination or fillers. Some of the contaminants we found pose serious health risks to consumers."

A systematic research <u>literature review</u> by the U.S. Agency for Healthcare Research and Quality (AHRQ), concluded that safety assessments of probiotic supplements are incomplete. Due to the unregulated nature of these products, there is no guarantee that over-the-counter probiotics or other supplements are safe from contamination, nor that they contain the ingredients specified on their labels.

Supplement regimes also send a message to the child that being autistic (e.g., being who they are) is wrong. As Bethany Sheldahl wrote in her essay How Diets to Cure Autism Gave Me an Eating Disorder and Internalized Ableism: "It took me years to stop pathologizing myself."

## **Regulatory action**

In 2014, the FDA issued public warnings and warning letters to sellers following the highly-publicised death of a pre-term Connecticut infant from an invasive fungal disease of the gastrointestinal tract after a so-called probiotic supplement was used in a hospital neonatal intensive care unit. The <a href="CDC case summary">CDC case summary</a> recommends that Solgar ABC Dophilus "should not be used".

Health Canada and the US FDA regularly issues recalls, market withdrawals, safety alerts and warning letters regarding contamination, false claims and other issues that are endemic to the supplement industry.

#### Discussion

Supplements are a multi-billion dollar industry, promising to cure every ailment, condition or

complaint that a consumer may have. Because the industry is so big (and because of the strength of its lobbies), it is largely unregulated for quality, truth in claims and product integrity. Health Canada and other regulators do not have the reach or capacity to keep up with regulating supplements.

"One of the biggest issues I see with the FDA is the dietary supplement industry has grown tremendously," <u>says Eaton</u>. "The FDA used to only monitor a thousand or so natural health products. Now they have countless products to monitor that are necessarily on your store shelves. They are online. They're promoted in places that the FDA does not inspect."

In assessing whether parents' use of dietary supplements on their children is reasonable, physicians and authorities can use the "1,2,3" test. If parents are using one supplement, such as a multivitamin for a child who is a picky eater, this could be considered low risk. If parents are using another supplement (such as low doses of Vitamin D in the wintertime), this could also be considered low risk. However, if the parent is using 3,4,5,6 supplements—or introducing supplements to the child through injections/infusions, this is cause for intervention. Often, parents who give their children many supplements are also experiencing "cure creep" and may be using other phony products in addition to the supplements.

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<u>Autistic boy hospitalised after receiving a mix of 12 alternative medicines, including camel milk and silver</u>. Siobhan Fenton. The Independent. 2016.

<u>Herbal Supplements are Not Often What They Seem.</u> Anahad O'Connor. New York Times. 2013. <u>DNA barcoding detects contamination and substitution in North American herbal products.</u> Stephen G. Newmaster, et al. BMC Medicine, 2013.

Infant Death Triggers FDA Health Provider Warning On Probiotic Risks. David Kroll. Forbes. 2018.

The Problem with Probiotics. Aaron E. Carroll New York Times. 2018.

Recalls, Market Withdrawals and Safety Alerts. US Food and Drug Administration. Website.

Search Recalls and Safety Alerts. Health Canada. Website.

## THC, CBD, Medical Marijuana

**What it is:** Marijuana is a mixture of the dried flowers of *Cannabis sativa*. It is available in smokable and edible forms. You've probably seen it.

Elements of marijuana, such as THC and CBD are also marketed separately in the form of oils or edible candies. CBD and THC oil are increasingly being marketed through Multi-Level Marketing schemes on social media.

With increased legalization, the above-ground market for marijuana products is ever-expanding. Some estimate that the market for CBD <u>will be worth</u> approximately \$22 billion by 2022. Some biotech companies are eager to capitalize on the hype, embarking on their own

research. One company in California is even running a bogus "ASD pilot study" on "identifying Cannabis-Responsive™ biomarkers in saliva of children with autism".

**Regulatory status:** In most states, marijuana is prohibited for use on autistic children. Unfortunately, this use has recently been legalized in several US states (including Colorado and Michigan). It is a sad testament to the tenacity of the marijuana lobby and the gullibility of the lawmakers who approved it.

**Marketers' claim:** Marijuana or its ingredients cure/treat autism. The group Mothers Advocating Medical Marijuana <u>states</u>: "Medical marijuana offers doctors as safe alternative to pharmaceuticals."

What the science says: Marijuana does not treat autism. Marijuana or its ingredients, including CBD, carry risk and should not be prescribed as an autism treatment. There is no mechanism to suggest that marijuana should be studied as an autism treatment.

While there are studies underway to study if there is potential of CBD or THC in the treatment of seizure disorders, the majority of autistic children do not have seizure disorders. In the case of seizure research, marijuana products should only be used as part of a controlled, clinical trial.

A 2015 <u>review</u> of studies on medical marijuana for use in pediatric autism and ADHD concluded that "cannabis cannot be safely recommended," citing links between ADHD and autism and problematic substance use, as well as "the myriad long-term consequences of regular cannabis use on neurocognition and brain structure." The review also noted acute side effects of THC.

#### **Product risks**

THC: The negative impacts of THC on development and cognition are well-documented.

CBD: As the potential developmental risks associated with CBD have not yet been studied, it is not safe to assume that any amount of CBD is safe for children.

**Regulatory action:** The US FDA has issued many warning letters to companies claiming to treat autism or ADHD with CBD oil and/or THC products.

#### Discussion

As the market for marijuana products has grown, so has the media hype. As <u>Timothy Caulfield</u>, Canada Research Chair in Health Law and Policy at the University of Alberta notes: "A study by the group <u>Health Feedback</u> — a collection of biomedical academics that assess the credibility of news stories — found that the top social media story of 2018 was one that claimed marijuana was one hundred times less toxic than alcohol. A claim that is, at best, a hefty exaggeration."

When visited by authorities, parents may say that it is safe to use THC on their autistic children, citing industry hype or showing bogus "research papers" on THC as an autism treatment. Keep in mind that THC has no evidence of benefit and clear evidence of harm for children. Online

marketers of THC as an autism treatment have coached parents on how to defend their use of THC on children. Sometimes, medical marijuana may be <u>prescribed by an unscrupulous MD</u> that prescribes other bogus autism treatments. Other times, parents may buy the products online, through MLM or other sources, without indicating it is for use on their child.

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FDA Warning Letter to Company Marketing Unapproved Cannabidiol Products With Unsubstantiated Claims to Treat Autism. US Food and Drug Administration. 2019.

<u>CBD Oil Products Promise Miracle Cures, but Does Science Support the Hype?</u> Timothy Caulfield. NBC News (Think). 2019.

Mothers Advocating Medical Marijuana for Autism. Website. Accessed 2021.

<u>LARA Director Approves Eleven New "Debilitating Medical Conditions" for Michigan Medical Marihuana</u> Patients. Michigan Department of Licensing and Regulations. 2018.

Medical Marijuana: Review of the Science and Implications for Developmental Behavioral Pediatric Practice, Scott E. Hadland, et al. Journal of Developmental Behavioural Pediatrics. 2015.

## Vitamin B12 Shots

What it is: Vitamin B12 in an injectable form.

**Regulatory status:** B12 injections, which are typically given by parents, are not currently regulated. Regulation is needed due to risk.

Marketers' claim: B12 injections treat autism by addressing "oxidative stress".

What the science says: Autism is not caused by oxidative stress. There is no evidence of benefit and risk of harm. There is no plausible mechanism to justify the study of B12 injections as an autism treatment.

**Product risks:** Vomiting, diarrhea, injection site infections and emotional trauma associated with injections. Anecdotal reports from survivors indicate that the shots, typically given in conjunction with a vast array of other supplements, made them feel as though their families believed they were very ill and/or a burden simply because of being autistic.

#### Sources

How Diets to Cure Autism Gave Me an Eating Disorder and Internalized Ableism. Bethany Shendahl. 2017.

This section has only outlined some autism scams. Other scams are out there, as part of the broader market forces of health misinformation. Wherever you see a fake autism cure, you can be fairly certain that just a few clicks away the same scammer will be selling a false "immune

boosting" Covid cure, a cure for cancer or treatment for a host of other conditions.

While there are many victims of health misinformation, children and dependent disabled adults are among the most vulnerable, because they can't escape —and the "treatments" are often perpetrated by a person in a position of trust. All too often, there is no enforcement to protect them.

Together, we can change this. We can create better safeguards to protect the health and well-being of autistic and other disabled people. For further discussion of strategies for change, please see Part 4.

## **Appendix**

# 2020 has not been a good year for ABA: A research review

This paper looks at recent research reviews of ABA, outlining 4 themes.

- 1. Research and retrospective reviews of ABA research show no evidence of benefit for ABA.
- 2. Conflicts of interest are pervasive in ABA research, with more than 70 percent of research being done by persons with a financial stake in positive outcomes.
- 3. ABA research design is flawed, with small sample sizes, absence of RCTs, detection bias and typically no assessment of risks or adverse events.
- 4. There are many negative impacts to ABA, which are only recently being researched.

# Intro: What is ABA and why is it controversial?

Applied Behaviour Analysis (ABA) is an offshoot of radical behaviourism, the theory that human and animal behavior can or should be explained in terms of conditioning, without appeal to thoughts or feelings. ABA imposes "operant conditioning" (compliance training) on autistic children and adults through intensive repetitions, rewards and punishments.

ABA was founded by O. Ivor Lovaas, a behaviourist who also co-founded a form of gay conversion therapy. Much like gay conversion therapy, ABA is based on a reward/punishment system to "train" children to act in compliance with ABA providers (known as BCBAs). Rewards may range from a piece of candy to access to a beloved special object. Punishments may range from denying play time to electroshocks. In IBI, the most intensive form of ABA, toddlers and preschoolers are segregated full time in an institutional setting (IBI centre), where they undergo "discrete trials" all day long in place of spending time with their peers. A year of IBI can cost upwards of \$30,000-\$90,000 per child.

ABA is used mostly in the United States and Canada, where it has strong lobbies. Although there is a movement to promote ABA in the United Kingdom (where ABA is not generally used nor publicly funded), ABA has not gained traction there because the Health Service doesn't support services that are not evidence-based. Some ABA marketers have also sought to bring ABA to new markets in Africa, Latin America and Indigenous North American communities. These efforts have not had much success due to their racist/colonialist overtones.

When surveyed, autistic people consistently oppose ABA. In a recent <u>survey</u> of 3,431 autistics, just 5.19% supported ABA. ABA is also rejected by many parents—and, of course, entire disciplines like psychotherapy. While this dissent should be persuasive enough to pivot policy away from funding ABA, policymakers are slow to act for a number of reasons. Meanwhile, ABA

research is increasingly being examined as an unsustainable practice, especially as newer approaches begin to dominate the research world.

This paper primarily examines research on ABA/early childhood autism interventions from the year 2020 (with two papers from 2019). For more information about why most autistic people oppose ABA, please see our <u>report</u> on the ethical issues with ABA.

# Key research on ABA, 2020

## Lack of evidence

US Government (DOD): TRICARE Comprehensive Autism Care Demonstration report
The US Department of Defense, as an insurer of more than 1.4 million Americans, reported to
Congress that after 1 year of ABA treatment, 76 per cent of autistic patients had no change in
symptoms and 9 per cent WORSENED by more than 1 standard deviation. The report, based on

16,111 beneficiaries, reaffirms statements from previous years that the effectiveness of ABA on autistic children is "unproven".

Cochrane Review, Reichow B, et al: Early intensive behavioral intervention (EIBI) for increasing functional behaviors and skills in young children with autism spectrum disorders. This meta-analysis from Cochrane Review looks at five EIBI studies (one RCT and four CCTs) with a total of 219 children, concluding: "There is weak evidence that EIBI may be an effective behavioral treatment for some children with ASD; the strength of the evidence is limited because it mostly comes from small studies that are not of the optimum design. Due to the inclusion of non-randomized studies, there is a high risk of bias and we rated the overall quality of evidence as 'low' or 'very low'." (This paper is from 2018).

BMC Psychiatry, Strydom, et al: <u>Clinical and cost effectiveness of staff training in the delivery of Positive Behaviour Support (PBS)</u> for adults with intellectual disabilities, autism spectrum disorder and challenging behaviour - randomised trial

In a multicentre, cluster randomised trial conducted in 23 community psychological/psychiatric services in England, participants were randomly allocated to either the delivery of PBS or to treatment as usual (control group, 113 participants). Researchers found "neither primary nor secondary outcomes were significant between autistic participants and the control group...Results suggest lack of clinical effectiveness for PBS."

## Conflicts of interest in ABA research

Journal of Child Psychology and Psychiatry, Bottema-Beutel, et al: Research Review: <u>Conflicts of Interest (COIs) in autism early intervention research – a meta-analysis of COI influences on intervention effects</u>

Researchers sought to assess evidence for psychoeducational interventions for autistic children, but were unable to, due to the overall weak evidentiary basis of ABA and other early

intervention research. "Across intervention types, there were <u>too few high-quality studies</u> for us to compute reliable statistics."

In this secondary analysis of a comprehensive meta-analysis of all group-design, nonpharmacological early intervention autism research conducted between 1970 and 2018, comprising 150 studies, the team found that a full 70% of the studies had conflicts of interest and less than 6 per cent of them declared the conflicts. Bottena-Beuten et al. concluded that "Conflicts of interest are prevalent but under-reported in autism early intervention research. Improved reporting practices are necessary for researcher transparency and would enable more robust examination of the effects of COIs on research outcomes."

## Failure to report adverse events in ABA studies

Journal of Child Psychology and Psychiatry, Bottena-Beuten et al: <u>Adverse event reporting in intervention research for young autistic children</u>.

Bottena-Beuten et al. also looked at "how often studies reported on whether adverse events (physical or psychological distress to the participants) or adverse effects (adverse events that are thought to be caused by the intervention) had occurred". Of the 150 reports they reviewed, only 11 mentioned adverse events. However, 54 studies described reasons for withdrawal and 18 of those had reasons that could be categorized as an adverse events or adverse effect "and an additional 12 studies had reasons that were too vaguely described to determine whether they were adverse events or not."

"We recommend that autism intervention researchers develop more systematic methods of looking for and reporting adverse events and effects, so that professionals and families can be better informed when choosing to enroll their autistic children in interventions."

#### **Detection Bias in ABA research**

Journal of American Medical Association-Pediatrics, Sandbank, et al: <a href="IBI Intervention">IBI Intervention</a>
Recommendations for Children With Autism in Light of a Changing Evidence Base
Sandbank and his team completed a systematic review and meta-analysis of quasi-experimental and randomized studies evaluating results from early intervention autism research (150 reports representing 6,240 participants.) They noted "detection bias" rated as high as 77.05 percent of outcomes in behavioral studies. (Detection bias refers to the risk of bias that arises when assessors are aware of the group assignment of individual participants.) Caregiver/teacher reports were common, posing the greatest risk of bias, though researchers also noted that professional assessors with detection bias is also problematic.

"It is common for researchers to rely on parents or teachers to assess outcomes via standardized interviews and/or report forms... [They are] likely to be personally invested in the outcome of intervention. This combination ...can yield a 'placebo by proxy' effect, which can positively bias results..." Researchers noted the need for independent evaluations to replace

this. "Outcomes from caregiver report are highly subject to systematic measurement error and may positively bias summary estimates of intervention effects."

# Absence of Random Control Trials in early intervention/ABA research

In the <u>same study</u>, Sandbank et al. noted that assessing the evidence of behaviorist early autism interventions was stymied by a lack of random control trials (where ABA participants' outcomes are compared with non-ABA participants). They noted "not enough RCTs of behavioral interventions to permit summary effect estimation for any outcome type."

"Much research on ABA was established using single-case experimental designs whereby a treatment is administered by the investigator in different phases to the same subject, who acts as their own control; measured outcomes are then related to treatment phases to draw inferences on their causal relationship," they wrote. "Although these n-of-1 studies generated useful findings, group comparison of treatment effects following randomisation remains the standard to evaluate treatment efficacy.

## Bioethical concerns in the use of ABA

Kennedy Institute of Ethics Journal, Wilkenfeld, et al: <a href="Ethical Concerns with Applied Behavior">Ethical Concerns with Applied Behavior</a> <a href="Analysis for Autism Spectrum Disorder">Analysis for Autism Spectrum Disorder</a>

Wilkenfeld et al. argue that from a bioethical perspective, critics of ABA "are fully justified in their concerns—the rights of autistic children and their parents are being regularly infringed upon. ... Employing ABA violates the principles of justice and nonmaleficence and, most critically, infringes on the autonomy of children and (when pushed aggressively) of parents as well."

In their analysis, they identify a key ethical weakness in ABA, built around its core views about people and how their behaviour can be (or should be) manipulated. "The radical behaviorist worldview has no room for the principle of respect for autonomy. Thus radical behaviorism is a worldview that deeply conflicts with contemporary bioethics, and specifically with the recognition of respect for autonomy."

## Adverse effects of ABA

Advances in Autism, McGill & Robinson: "Recalling hidden harms": autistic experiences of childhood applied behavioural analysis (ABA)

McGill and Robinson interviewed 10 autistic adults who had been through ABA as children, the majority of whom spoke of being harmed by ABA's methods, noting: "Participants indicated a sense of 'training' or negativity from the repetitive nature of the therapy." Four participants reported that the experience gave them PTSD, with another participant relating ABA to their depression and another relating it to an anxiety disorder. "The majority of participants'

reflections (n=7) referred to being left with feelings of self-rejection and a sense of self-loathing as a consequence of their experience of ABA."

In this small study, the majority of participants viewed their ABA experience as creating an undue dependency on authority figures, based upon accompanying fear of punishment. One participant illustrated this by stating: "The focus on compliance made it harder for me to say no to people who hurt me later." The study confirms a view held by many who experienced ABA, that it left them more vulnerable to abuse because of the ways that ABA's compliance training had conditioned them to relate to people in authority positions.

# **Cogent Psychology, Herlinda Sandoval-Norton:** <u>How much compliance is too much compliance:</u> Is long-term ABA therapy abuse?

This paper (published in 2019) reviewed research literature to identify "unintended but damaging consequences [of ABA], such as prompt dependency, psychological abuse and compliance that tend to pose high costs on former ABA students as they move into adulthood." It identifies the adverse effects of "intensive and chronic conditioning" as leading to problematic levels of compliance, low intrinsic motivation, and lack of independent functioning.

"It is heartbreaking but not surprising to learn that the odds of being a victim of a violent crime is doubled among individuals with disabilities, and individuals with cognitive disabilities have the highest risk of violent victimization (Harrell & Rand,  $\underline{2010}$ ). Additionally, individuals with disabilities are sexually assaulted at nearly three times the rate of those without disabilities (Disabled World,  $\underline{2012}$ ). So how much compliance is too much compliance?"

The paper identifies that many professionals, such as physicians, educators/consultants, counselors and policymakers often recommend or support ABA while knowing little to nothing about its methods and effects, imploring professionals "to ask themselves whether or not this archaic approach to treating ASD is in line with their oath to do no harm."

Cogent Psychology, Shkedy, et al: Treating self-injurious behaviors in autism spectrum disorder Shkedy et al. discuss the preventing and treatment of self-injurious behaviour (SIB), questioning the use of ABA, which they identify as an "unscientific approach" to the problem. They critique a common practice in ABA and some educational settings of creating "functional behavioral assessments (or FBAs), that identifies a specific behaviour, track it and target it for behaviouristic intervention. They note that this unscientific approach is also being used by persons who have no training in the management of SIBs and often can create trauma and worsen conditions. "ABA therapists and other paraprofessionals with evidently no training in human psychology or child development are engaging the kind of maltreatment [which] is incompatible with any formal education or knowledge regarding current research and appropriate ways to address SIB. A therapist is duty bound to Do No Harm, and yet by these very actions we are causing more harm."

They note that behaviourist responses to SIBs are typically punishment-based, citing the example of misting the child in the face with water or taking away desired objects. "Other responses include withholding attention from the child, ignoring the child, or removing the child from the situation (Carr, 1977; Minshawi et al., 2014; Weiss, 2003)."

They observe: "It is unclear why one would think these responses are appropriate for someone who is engaging in SIB since these responses do not follow any evidenced-based treatment or theoretical orientation. A psychologist or therapist would not respond to any client this way

# **National Education Policy Centre, Alfie Kohn.** <u>Autism and Behaviorism: New Research Adds to</u> an Already Compelling Case Against ABA

after discovering their client has been or is engaging in SIB."

"When a common practice isn't necessary or useful even under presumably optimal conditions, it's time to question whether that practice makes sense at all." Kohn is talking, of course, about ABA. Kohn, an expert whose research and writing on motivation has appeared in the Harvard Business Review, Education Week, The Chronicle of Higher Education, The New York Times and countless other publications, argues that ABA "isn't just problematic theoretically (reflecting a truncated understanding of human psychology) and ethically; it also fails from a practical perspective, as has been demonstrated repeatedly."

Kohn identifies fatal flaws with the ABA approach for autistic children: "it is dehumanizing and infantilizing; it ignores internal realities; it creates dependence; it communicates conditional acceptance; it undermines intrinsic motivation; and it's all about compliance". Kohn counters ABA's behaviourist position by affirming that an autistic person "is not a passive object to be manipulated but a subject, a center of experience, a person with agency, with needs and rights. We have an obligation to look beneath the behavior...attempting to understand the whys rather than just tabulating the frequency of the whats."

Kohn notes that the autistic community's opposition to ABA must be considered by schools, policymakers and other decision-makers when choosing whether to support it. "It is nothing short of stunning to learn just how widely and intensely ABA is loathed by autistic adults who are able to describe their experience with it. Frankly, I'm embarrassed that, until about a year ago, I was completely unaware of all the websites, articles, scholarly essays, blog posts, Facebook pages, and Twitter groups featuring the voices of autistic men and women, all overwhelmingly critical of ABA and eloquent in describing the trauma that is its primary legacy. How is it possible that their voices have not transformed the entire discussion? ...And yet the consistent, emphatic objections of autistic people don't seem to trouble ABA practitioners at all."

## The future of ABA

With endemic conflicts of interest, an absence of random-controlled trials in addition to other problematic methodologies, the ABA industry's claim to be "evidence-based" is not credible. The ABA approach is also not commensurate with the values of a democratic society that values autonomy and human rights--because at its core, ABA values compliance over quality of life.

(Indeed, this is one reason ABA is also used in prisons as a means of total control). So while some ABA may meet the goal of temporary compliance (at all costs) from autistic children, it does not improve their quality of life and there is no compelling evidence to continue funding it in any context.

As Kohn observes, there is a broad-based movement by autistic people and the neurodiversity movement to de-fund ABA. Policymakers and educators now need to ask themselves: when the people being targeted by a therapy organize against it in such numbers and with such passion, is that therapy truly sustainable? The answer is no. This, combined with parent demand for alternatives, new research and the high cost of ABA compared to other services, has weakened its support among policymakers.

Each year, fewer developmental pediatricians are recommending ABA and more are recommending better approaches. Governments are less willing to fund ABA as autism therapy for ethical and fiscal reasons. Families/consumers of autism services are demanding better approaches. What this means is that ABA is gradually being de-funded, with public funding for autism-related ABA in Canada likely to be obsolete by 2030.

There are better ways than ABA. Aside from psychotherapeutic approaches, there are many evidence-based, practical Speech Language Pathology services, Occupational Therapies and Communication platforms (AAC, for non-speaking or partially-speaking autistics). Access to AAC is a human right and should be centred in autism policy. Policymakers should also be researching and funding programs that work around concepts of inclusion, communication and sensory needs, like Foundations for Divergent Minds and the SCERTS program, which offer inclusion and accessibility training to schools and families. It is crucial that our governments fully fund these types of services, which have immediate and long-term impact on autistic people's quality of life.

As this and other research shows, it is time for policymakers to rethink their assumptions about ABA, to consult with autistic-led organizations, as well as families and non-ABA providers and develop a robust funding approach that truly meets the needs of autistic children and adults.

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