

Content warning – This episode discusses child abuse.

“It’s scamming parents—and through that the children are suffering”: Interview with Emma Dalmayne

June 29, 2019

Transcribed by Julie Ann Lee

(Theme song – soft piano music)

Anne: Today’s guest is an amazing autistic self-advocate from the UK. A mom of six, a home educator and co-founder of Autistic Inclusive Meets. She organizes meetups for autistics of all ages as well as activist actions on issues that impact our community and advocacy at the governmental level.

Emma leads a campaign against autism pseudoscience and is the one who first raised the alarm about MMS, an underground movement of parents who claim to “cure” their autistic children with bleach enemas, uncovering dozens of MMS [networks] in the UK. Indeed her work on autism pseudoscience established the groundwork for the UK Parliament to begin researching and working towards regulation and enforcement against phony autism cures, with policymakers now acknowledging we need to put a stop to this.

Thank you for being here, Emma.

Emma: Thank you for having me!

Anne: Can you tell me a bit about the group you co-founded – Autistic Inclusive Meets?

Emma: Yes! We’re mainly autistic lead. So, there’s me and then another four directors. Three of them are autistic as well. We fight against autistic mistreatment. We hold three weekly groups. One on a Monday, one on a Thursday, and then we work with Charlton Athletic Softball, which is like a football association here, and hold a group there as well – a football session.

It’s been nice. It’s a lovely organization. It’s been great for getting the kids out into the community, you know, in an accepting environment with their peers. We don’t have an age limit. So, we have children as young as 18 months mixing with autistic adults. It’s really nice for the parents as well who have just had their child diagnosed, or are thinking that their child might be on the spectrum to meet older children and adults as well.

Anne: That’s wonderful.

Emma: Yeah... it's also fear of the unknown and they don't know how their child will, you know. We always get "oh, do you think they'll not get married, do you think they'll do this, do you think they'll do that,?" and we say we don't know but we will be there to support you every step of the way.

Anne: That's great.

Emma: Thank you.

Anne: About four or five years ago, is that when you began working specifically around the issue of phony autism cures?

Emma: Yes. My son was diagnosed – my youngest son, my ten year old -- and that's when I started to look at myself and my other children and realized that we're all on the spectrum. I opened a couple of Facebook groups to support parents and just so they wouldn't feel as lost as I did and that's when we became aware of people posting about "have you heard of this? Does it work?" I thought, *this is terrible*. So I started investigating it. Not only [MMS] bleach users using so many other things on their children...they're using turpentine, a banned blood product called GcMAF, the Nemechek protocol which involves inulin which is a dietary supplement with fish oils. You know there's so many different things that they are just sort of experimenting on.

Anne: How did it feel for you, for such a long time campaigning before there was any action by the government? Did it feel like a long time to get the ball rolling where regulators really woke up and saw that this was a problem?

Emma: Yes, it was. It was terrible! No one wanted to do anything. No one wanted to listen. I'd phone those papers up and say "I've just reported a parent for using bleach on their child" and they'd laugh. They'd be like *what?* It took a long time to make people *actually take it seriously*, especially when I'd say "in an enema." They'd think that was hilarious. Because they wouldn't believe it. It was *too unbelievable*. I got hung up on, people weren't willing to listen...until Barry did something. Barry Sheerman, the MP from the Labour Party. But then still, we still don't have legislation in place.

Anne: That's right.

Emma: Nothing's finalized yet.

Anne: We have here Health Canada and like you said when it was first being brought up, by activists and people that were seeing it happen, there wasn't a real response. Then finally Health Canada got on the dark web and they started seeing people selling these things and how prolific that it was. And Health Canada has begun to crack down on it, but in terms of actual government regulation, I think we're behind [the UK]. You met with the MP Sheerman and they authored a report about the problem of all these pseudoscientific cures in the UK, is that right?

[4:50]

Emma: Yeah. They launched a survey first, which I helped work on. Us being many of the autistic people and their carers ...and parents, asking if they've been offered any quack cures, have they been offered MMS, what have they been offered, how they were offered it. Where was it available, you know that sort of thing.

And they found out that there was a problem that did need to be looked at. So, then they launched a report which had, I think six pieces of my work in it... And yeah, so they are hoping that the next step will be legislation.

Anne: That's great. So, is it kind of "in committee" right now?

Emma: It's just hanging there at the moment. Nothing is happening, and it's very frustrating, you know it really is. It's heartbreaking because I just want – I want my life back to be honest. You know, I'm constantly going in and out of Facebook groups under fake profiles seeing more and more parents doing this to their children and the thing is they get away with it. I report them to the police and the Social Services and they either go, take the stuff, give them a caution and leave. Or they go and they get the sob story of "I'm so desperate my child's autistic, it's so dreadful" and they're let off, and they're back in the groups complaining that their [MMS] was taken.

Anne: Wow. And then they can just get more. It's not too hard to get those kind of products, right?

Emma: Oh no, it's not hard to get at all. If you put it on the internet it's there straight away. I mean, in this country, too, children have been removed after I've reported them which was obviously, I wouldn't say *good* cause I hate having to – it's not nice having to report children and have them taken away from their parents...but obviously if a child's life is at risk then you don't have a choice.

Anne: Right. When you look at things like physical abuse, or what you might call medical abuse, but it's not really medical, then many times in the eyes of the law, **intent doesn't really matter, harm is harm**; abuse is abuse and we need to react to the harm and in the welfare interest of the child. What I find interesting is there's sometimes a double standard where if a neurotypical child was being given this kind of abusive treatment by a parent, I think authorities would act relatively quickly and in some cases when it's an autistic child, there isn't as quick of action. There does seem to be a double standard about what you can do to your child.

Emma: What, you can do anything to an autistic child. You can throw them off a bridge and get off. You know you can gas them, suffocate them, cut them even and get told, "Oh she was so desperate. G-d, what must have driven her to that, it's so hard looking after that child." You know and they're let off. They're actually let off.

Anne: Right, and there's hard data. We know this is true about filicide –murder of disabled children by parents ,for example, we know that when juries over-sympathize with the parents

and think “oh the parents are desperate” that’s when the copycat [crimes] occur too. So, it perpetuates more of the problem.

I think in the law it’s very inconsistent in terms of how they apply these child welfare laws across the board. Sometimes it’s fair, sometimes it’s very, very unfair. Sometimes it is unfair to the extent that it’s perpetuating a problem of violence against children, especially disabled children.

Emma: Well, the message is that it’s acceptable.

Anne: Mm-hmm. People feel the need to say to me, like if people ask me about my campaign, even media people will say to me, “well, it’s not the parent’s fault, they’re just desperate.” And then they look to me to kind of nod along with them and I just wonder why they feel the need to say this to me and or sort of suggest that I shouldn’t be “mad” at the parent. But it’s not really about being mad, it’s literally about protecting the children’s welfare.

Emma: Yeah. Exactly. Exactly, which you say, I don’t know in the case of caregivers to old people, you know who would batter an old person, or suffocate them. Would you say, “oh well they must have been really desperate, the person must have been really difficult that day” – No! It wouldn’t be said, would it? People would be horrified if someone said that, but in the case of an autistic child or teen or adult, it’s fine.

Anne: What needs to change, and who needs to make change in terms of how autistic children are perceived? How can people that are in leadership positions improve the situation?

[9:49]

Emma: Well, first of all, there needs to be a legislation in each country stating that if you are promoting, selling or recommending a cure for autism, you’re immediately arrested. Because there is no cure for autism. To suggest there is, is false. You know, it’s a scam. It’s false advertising. It’s everything you can think of that’s not right, you know.

It’s **scamming parents and through that the children are suffering** because they’re being given things that will do them no good. Autism cannot leave. It’s there permanently, it’s in our brains. It’s a different neurological wiring and these supplements, any chemicals that are given to an adult or a child are not going to rid them of their autism. It’s just going to cause discomfort, pain, sickness and in some cases death.

Anne: Right. And emotional harm, I think to the relationships in the family, especially a child.

Emma: Oh my G-d, imagine knowing that your parent wants to cure you of being you, knowing that you, in your parent’s head, are not good enough, that you’re at fault, that you need to be fixed when you have nothing wrong with you apart from being neurologically different.

Anne: Mm-hmm. Why do parents want to do this? Where are they getting the message that this is okay? I see people tend to put all the blame on the people selling the products and accountability is lost in all other areas.

Emma: It starts at diagnosis. It starts with the attitude [of practitioners saying] “I’m so sorry to tell you, your child has autism.” You immediately think (not me) but these parents do, you know they immediately think, “oh G-d, I wanna help my child.” So, they go on the internet, they look up treatments for autism, therapies for autism, and one of the first things you will find is [claims about] heavy metal poisoning. Now these mindset of parents want someone or something to blame.... so they blame vaccines and they blame the government and they blame that their child has been made autistic and they believe the government has done this on purpose because autistic therapies are so lucrative. So, they think “the government’s done this, you know this conspiracy against me. I need to cleanse my child of heavy metals,” so they start with chelation, they start with the GAPS diet because they’re told that gluten and casein cause autism, and they’ll move on to MMS.

Anne: Hmm.

Emma: Also Autism Speaks, organizations like that put across the rhetoric of you know “it’s an epidemic. Autism is sweeping the planet, ‘it’s going to take over.” They’ll terrify parents thinking “my G-d, all these children are gonna be dependent on us, how are we gonna cope with that.”

Anne: Right. I think people see it as a disease or as a pandemic, and science is clear that it’s not.

Emma: Yes.

Anne: Right.

Emma: They do see it as that, and heartbreaking.

Anne: I think it’s really hard, and like you said it’s on a continuum, because with the special diets...I get push back on the special diets because people will say to me, “oh well, it’s just food.” But food is such a central part of how we socialize, how we communicate, how we bond.

Emma: Yes.

Anne: And a restrictive diet...

Emma: It causes difficulties...and they’re on a very restrictive diet as it is. If you’re on MMS, you’re not allowed to have certain fruits, you’re not allowed to have lemons, oranges, you’re not allowed to have potatoes or carrots. You know there’s loads of things that are cut out of the diet. So, if you’re going to restrict it by cutting out gluten....Most of these kids are given bone broth with the Nemechek protocol and the paleo diet, because that’s what the parents are told they have to give them.

So, you've got a child that's weak from not eating properly, and given things like GcMAF which are in conjunction with it, because you know that's meant to "shut down the immune system and then reboot it," so they're not autistic anymore. When they "reboot", you can end up with a very sick child.

Anne: Have you spoken to children or adults who underwent these kind of treatments or special protocols?

Emma: Yes, I have. And , the most memorable one who's in Germany and obviously I can't say his name, he asked to be kept anonymous, but he felt that he had to cure himself because he was told that there was something wrong with him, that he had parasites. He was terrified, he was in one of these groups and I spoke to him. I managed to get him out of there, and get him to go to a hospital because he'd been giving himself bleach enemas and had been drinking it. It's the idea that you know that you're not good enough and you need to cure yourself. And it's disgusting.

[14:55]

Anne: I've spoken to people too who've said that they have to put on an act to please their parents, because their parents wanted this kind of result and, and trying so hard to please the parents because if they failed and if they were just a regular kid being a kid, normal developmental moods and being angry and being crabby or crying, that they had to repress all of that as a way to please their parents, and show their parents that it was working, because if they didn't their parents would do more of these terrible things to them.

Emma: I mean you show any kid an enema and say "look, you're going to have one of these cause you've got monsters living in your stomach and we're going to get rid of them, and your monsters cause you to stim, to do this, to do that," the child will stop all that behaviour because they don't want this to happen to them.

Anne: I think the work that you've done, that your organization has done and all autistic self-advocates in the UK is really a model, and I certainly use it as a model in my own work for how to do activism, build community, build capacity, and also build coalitions and connections so that there is a way to break down that barrier that's happened in policy.

Emma: We did have something good happen, we have a guy called David Noakes who was selling GcMAF, he was touting it as a cancer treatment and he heftily touted it for autism treatment. I actually interviewed him a couple of years ago, saying that he uses ultrasonic probes on autistic children's temples to "break down the blood barrier". He'd give it to them in nebulizers, intravenous injections, and he was actually jailed for 15 months for selling [GcMAF]. So, that it something, at least.

Hopefully reporting people for selling these things will now lead to something a little bit more serious than just a slap on the wrist. Now, I've reported 2 people over here for selling MMS and nothing was done.

Anne: Nothing was done.

Emma: Nothing! Nothing at all.

Anne: They were reported to the Health Ministry, or who do you report to there?

Emma: I reported them to the MHRA and I reported them to the police. So, yeah, nothing was done. The thing with MMS is, you cannot get rid of Chlorine Dioxide. It's always going to be on sale because it is a water purification. You know they use it in swimming pools, they use it to bleached wood pulp. It's something that's always going to be there. It's the way it's marketed that they need to look at. You know if you've got it, as a cure, as MMS, Miracle Mineral Solution then those people need to be *arrested*, not just told "Oh actually you can't call it that."

Anne: Right, because they can just sell it in another way, under another name on the web.

Emma: Well, yeah.

Anne: Right. And the regulation to me is a really key part. It's essential because it sends a message that it's not okay to do this to children. But then the step beyond it is to raise awareness and consciousness among parents and among providers like you suggested earlier with clinicians, and doctors and assessors who...

Emma: Well yeah, it starts from there.

Anne: Right.

Emma: The problem over here is you can report it to the MHRA but because it's not a medicine, they won't touch it. They'll send you to Trading Standards, who will say, "Oh but it's being touted as a medication, this needs to go to MHRA." So, it's such a grey area, it's so hard to get someone to take responsibility and the whole time I'm just thinking that these kids are being anally raped on their bathroom floors while everyone is dicking about deciding whose responsibility it is.

Anne: In the UK now, what is it that needs to happen to make things happen and keep autistic kids safer?

Emma: Legislation and funding by the government and for children's education because it is being cut all over the place. SEN education is being cut everywhere. Parents all over the UK are pulling children out of school to home educate them, not because they even want to but because their children are not receiving the care that they should be in schools. They're getting bullied, they're not watched. It's not good enough.

Anne: Right, and your organization gets a lot of calls from parents, from families whose children didn't have fair access to inclusive public education, is that right?

[19:42]

Emma: Yeah, we have it all the time and we support home educators. We support people who pull their children out completely. You know one of our groups on the Thursdays runs during the day during school hours so that those children can come along and socialize, you know, access the computer, access fitness equipment. And it's not ours, by the way. We're not funded and we don't have our own building sadly, but we've been very lucky with community organizations around that have allowed us to use their space.

And that's what's needed. If these children are going to be coming out of school, they need somewhere to go, and the parents need somewhere to go for support and you know talk to other parents about which educational tools they are using, if any. Some de-school or unschool completely because their children have troubles with structure and need that freedom to learn as they do. It was done out of necessity, you know, our kids needed something. I was taking my children to home-education meetups and the kids weren't autistic and they'd still get treated the same as they were treated in school. They'd still be shunned, they'd still be run away from, [wondering] why they didn't want to play with them. And I just thought *no, they need their own little community*, so that's what we've given them.

Anne: What is a meetup like? Can you describe a typical meet up for youth that you would hold?

Emma: We usually have a big tray of sensory play so that they can regulate. And, you get a lot of alongside play because you know a lot of autistic kids, they won't interact with each other too much. They'll play alongside each other but we do have a lot of friendships being formed which is lovely to see. But, yeah, they'll ...do skits, and their parents will sit with their tea or coffee and the children will go off and, you know... talk or not talk. Some of them are non-speaking and what is lovely to see, is that the non-speaking attendees get treated no differently by the other children, at all. You know they're still invited to play. They're still tugged by the hand to go about and run around in the outside area that we have at the Monday building. So, it's beautiful. It's lovely to see.

Anne: Well, thank you again for coming to be on the show, Emma Dalmayne, I really appreciate you being on the show, and the wonderful work that you do.

Emma: You're very welcome. Thank you for having me, and keep up the good work over there.

(Theme song – soft piano music)

Anne: We were just talking with autistic advocate Emma Dalmayne. Thanks for listening. You've been listening to Noncompliant. I'm your host Anne Borden King. Noncompliant was recorded

at D.B. Audio and M.C.S. Recording Studios. Various episodes were engineered by Dave Boir, Nathan Grevatte, and T.J. Liebgott. Thanks to our engineers and thanks for listening.

Definition: SEN – Special Education Needs