

Sound Advice

This is an edited transcript of a telephone interview recorded in April 2009.

Ken Reibel is the father of a son who has autism and the creator of the blog, Autism NewsBeat. Welcome, Ken.

Reibel: Thank you.

Q: How old was your son when he was diagnosed with autism?

Reibel: He had just turned three.

Q: What were some of the early signs you noticed?

Reibel: Well, I didn't notice anything. We were just kind of oblivious to his development, as a lot of parents are. He was in daycare that summer. He turned 3 in August, and it was actually a daycare worker who said that Chris seemed a little obsessed images, letters, signs. He was pointing, for instance, to a map of the world and pointing out countries and I thought, "Well, he's obviously a genius," but the daycare person said, "Well, this really isn't normal and he seems a little bit obsessed with, oh, just with words and signs and colors and logos and things." So, we got him checked out and sure enough, we had a diagnosis of PDD-NOS.

Q: Was that a difficult diagnosis to hear as a parent?

Reibel: Oh, yeah. I mean nothing prepares you for it. I had never heard of it. It had never occurred to me there's anything wrong. He just seemed like a little "Ken" to me and it was hard and it was very frustrating at first trying to find services and trying to find answers. That was a lot of running around, going to different schools and really never getting a satisfactory answer from anybody.

Q: What do you think caused Chris' autism?

Reibel: I'm sure it's genetic. I mean I look at him and he's me to the 10th power really. I mean I was always a little bit off as a kid and a little bit withdrawn and I was always fascinated with books and signs and shapes and things, but not nearly to the extent Chris is. So, I'm certain there's a genetic component there.

Q: Why do you think some parents blame vaccines?

Reibel: Well, people don't like randomness. They want an explanation for everything. I mean even when you look up at the sky and see a cloud, you'll see a bunny rabbit or a racecar or a toaster oven or something. I mean we don't like things that are random. We want to make sense of everything and that's just way we're wired as humans and when people see a child with

autism, their child, they may think that, you know, there might be some guilt there. You know, “Oh, you know, he’s me. You know, I brought my problems on to him.” And a lot of it too is just is just the stress of dealing with the situation. There’s a lot of guilt and I suppose there’s a grieving process there too.. you know, the denial and anger and bargaining and so on.

Q: Did you ever think vaccines might be a cause of your own son’s autism?

Reibel: Yes, I did. I went through that period. It didn’t last more than a week or two, but I went to the Internet to look up autism because I wasn’t getting satisfactory answers from anybody. And I read about the measles hypothesis. This was back in ’98. So, I think it was right after Wakefield’s paper and I, you know, printed out a lot of papers and stormed into my pediatrician’s office and said, “Okay. What’s this?” and he looked at it for about three seconds and said, “Okay. This is garbage” and he sat down and explained why. And I respect him enough to believe him and of course, I’ve learned a lot more since then, but yeah, I went through that, sure. I think just about every parent does.

Q: What treatments have been most effective for your son?

Reibel: Well, the only thing we’ve really done is ABA and, of course, I’m lucky enough to live in Wisconsin where the state Medicaid waiver picks up the cost of applied behavior analysis. So, Chris was an ABA kid for four years, maybe longer. That helped an awful lot. And then, of course, just OT and physical therapy and so on. He’s in a terrific school right now too where he’s with teachers who understand the disorder. He had one teacher for two or three years who used to be an ABA therapist and that was wonderful. It’s really good to get your kid into a learning culture where autism is understood and accommodated, and I’ve been lucky enough to do that with Chris.

Q: Can you describe ABA, or applied behavioral analysis?

Reibel: Well, it’s called discrete trial therapy, I think I got that right, and it’s basically teaching very basic skills to the kid in very discrete steps. So, your neurotypical kid, for instance, will know that when someone smiles at them and says, “Hi, how are you?” then the child will say, “I’m fine. How are you doing?” and they’ll pick up on social cues and so on and know how to start a conversation. But, a child with autism basically just has to start at square one and doesn’t really intuit anything and you just have to teach them, “Okay, when Mary says hi, you say hi back.” You have to teach them one small step at a time, using rewards each time so that they learn the proper social skills.

Q: Have you tried any alternative treatments for Chris?

Reibel: Not that I can think of, no. I just never have. I think I just caught on early enough that there’s an awful lot of fraud out there and a lot of people who are basically preying on parents’ grief, desperation, guilt. You know, parents of these kids are awfully easy marks and there’s an awful lot of people out there who want to take advantage cause some of these providers, too, may even be well-meaning. You know, they may honestly think that such and such a treatment is going to help, but there’s an awful lot that know better too. So, I’ve always been very wary of that.

Q: Why do you think some parents do try these alternative treatments then?

Reibel: Well, there's a feeling that you're battling time and I went through that for a long time where you think, "Well, you know, the earlier we start on therapy, the better. I want to do everything perfect because I don't get any do-overs and if I slack off for one day, then that means that he's going to be at a disadvantage sometime and I don't want to do that to the kid." And some kids' parents will take that a step further and say, "Well, I'm going to try everything possible because what's the harm of trying." So, you put them through these diets and pretty soon, you're putting [them] in hyperbaric oxygen tents and then chelation and the antivirals and, you know, antifungals and everything else. I don't think that's really good for a kid. It sends a very strong message to a kid that "You're broken. I can't accept you the way you are. You need to be fixed." And of course, these treatments don't work, or at least there's no evidence that they work. So, you really risk teaching this kid someday that you're not cured because you didn't try hard enough. It didn't work on you. That's not a really good start for any kid to have in life.

Q: Ken, what advice do you have for parents who are getting this diagnosis for the first time?

Reibel: Well, first of all, seek out other parents. That really helps a lot because there's a sense of isolation that parents will have when they first get the diagnosis. It's easy to think that this has happened to no other parents. You're the first time. You know, the first time it's ever happened is for you. Of course, that's nonsense. There's lots of other parents, lots of other support networks out there and that helps an awful lot.

The Internet is a great source too, but then again you have to be really careful who you're listening to there. Another really important thing is to just be very skeptical, to use critical thinking skills, ask lots of questions. You know, if someone offers some kind of a treatment, you think, "Well, okay." You have to ask yourself, "What is the proof that it works? You know, what is the evidence?" and don't fall into these logical fallacies of thinking that just because, you know, A follows B, therefore B must cause A and all these other little fallacies that you know, bedevil our puny human minds because we're really not very good at picking very clearly on ourself and intuiting cause and effect by ourselves. So, it's really important to ask for evidence and to be very, very careful, you know, what particular treatments you're going to believe in.

Q: What inspired you to start your blog, Autism NewsBeat?

Reibel: I used to be a general assignment reporter, and I'm aware of the difficulties of that job sometimes, the deadlines and so on. But also, general assignment reporters tend to write about subjects they're not terribly familiar with. One way you compensate for that is by going to sources. But I found that when it came to covering autism, particularly autism and vaccines, sources were not always being that honest with reporters, and reporters were missing a huge part of the puzzle, namely the science and the fact that science had closed the door a long time ago on the autism and vaccine connection. And so I started the blog to help reporters better understand the ramifications of the story, just how important it was to get it right, and also to point out stories that did get it right, and say this guy did a good job here's why, and here's some people

who didn't do that great of a great job and they fell down. I try to be constructive and say this story suffered because, and go into the details. I'm getting a lot of good feedback on it.

Q: How is Chris doing now? Are you hopeful for the future?

Reibel: He's doing fine. He's getting good grades. He's getting good support in the school. I've seen an awful lot of growth in him and, you know, it's just a wait and see. I mean there really is no way to predict these outcomes. All you can really do is just give them the acceptance and accommodation that they need and not treat them any differently. I don't want him growing up thinking that he's damaged goods and I think that's probably the worst thing you can do for these kids - to send them the message that you're a mistake, you're damaged, you're vaccine injured, you're mercury poisoned or whatever. It's just not the case and you just, you want to make this kid feel as accepted as any other kid and that's what I'm trying to do. He's a real bright kid and very energetic, very cheerful, incredibly polite and I think those will get him through most trades. I think that just like any kid, you want to build on strengths. Any neurotypical child has his problems, and his strengths and his weaknesses, and rather than look at Christopher as a kid with autism, I look at him as a kid with his own strengths and weaknesses and I think that's the best way to get through. A lot of parents tend to forget that. They only see the autism, but they don't really see the whole kid, and I think that's the faith that I have in this -- in Christopher, that he's got an awful lot of good qualities and I'm sure he'll do fine.