

Cultural Daily

Independent Voices, New Perspectives

Afsanhe Chamlou: “What Now?”

Afsanhe Chamlou · Thursday, August 18th, 2022

My son’s name is Pendar. The word Pendar stems from the [Zoroastrian religion](#) — good sayings, good actions, good ponderings. I remember when he was not even a year old, he was diagnosed as being on the autism spectrum. And as he grew older he became severely autistic. My life was filled with reading books on “fixing” autism, going to school IEP (Individual Education Plan) meetings, gatherings with other parents who had autistic kids to see what worked or didn’t work. I wanted to get him the education he needed to become as independent as possible. I was told that the earlier we started his special education, the more functional he would be as adults. Early Intervention is what this program is called in my county. And he started it as soon as he turned 2 years old.

At the beginning, type-A that I am, I was sure I could figure this thing out, never mind that the only previous exposure I had to autism was the movie *Rain Man*. I mean look at *Lorenzo’s Oil*! His parents figured out how to fix this rare ailment in their son. All I had to do was read all that was out there. Check out the research. Talk to specialists. I was sure there was a cure. All I had to do was find it. It turned out to be the needle in a huge haystack. I am still waiting to prick my finger on this illusive pin.

One of the main goals was to get him to communicate. Sign language did not work for Pendar. Neither did PECS, the Picture Exchange Communication System, where you point at pictures to say what you want. Then came a method called [Rapid Prompting Methodology](#). RPM teaches non-verbal kids to communicate by writing. Non-verbal means that they cannot speak to express themselves. A person’s communication skills are based on their expressive or receptive abilities. Expressive indicates how well they can express what they want to say. Receptive indicates how much they understand what you say to them. The cost of RPM therapy, by the way, was not covered by insurance. And, even after a year of taking him to the training center, it did not help Pendar express himself.

Then there were the books that claimed that the root of many disorders is gastronomical. Fix the gut, fix the kid by putting them on the right diets and supplements. The Leaky Gut Syndrome theory is that after multiple antibiotic treatments, the lining of the stomach is severely compromised, allowing food that isn’t fully broken down to enter the small intestines. These particles damage the villi or microvilli of the intestine, allowing small food particles to enter the blood stream. Some of these foods like gluten or casein can act like opioids that can make the person giddy and addicted to that type of food. My son loved bread! He would devour an entire loaf in 10 minutes. The other side effect is loose stools. We had to take him to a doctor who practiced alternative medicine to see if Pendar had LGS. He had to be taken off gluten, casein and

soy for 15 months until his gut healed. After a week of doing this, he could sleep through the night and his stool was solid. But he was still severely autistic.

Some claimed it was the mercury that was used as a preservative in the vaccines that caused autism. Many parents saw regression in their kids after the Measles Mumps and Rubella vaccine that kids get at 18 months. So, I got them vaccines that did not have the mercury preservative in them. Even a medical treatment called chelation, which strips the kids of all heavy metals, specifically mercury, and reintroduces the ones they need back into their system, like iron, zinc, or copper. We read reports of miraculous improvements. We ignored the reports of one or two kids dying from this procedure. But I had to give it a try in case that was the one thing that would cure him. It didn't.

As you can see, I was desperate, sure that the cure was just around the corner. Maybe it was as simple as giving him special vitamins. Maybe more behavior plans, like Applied Behavior Analysis (ABA) that trained the kids to behave appropriately by rewarding good behavior with things they liked. Behavior plans created by behavior specialist that the insurance companies did not pay for.

I was so desperate for a cure that I felt like I was always waiting for the next snake oil remedy. It felt like I had come to the state fair either a day too early or a day too late. Looking around in disbelief that there was nothing to do. What had I missed?

Other problems arose as he got into his teenage years. Violence and destructive behavior started to rear their heads. At school they put him in his own room with only a beanbag to sit in. He was throwing chairs at teachers. I finally had to hire an advocate to convince the county that he had to go to a private school that specialized in students with special needs. Fairfax County agreed and sent him to this great school. He has since graduated from this school. You could say we both graduated. He is still severely autistic, and I have yet to find a cure. Now what?

He currently lives in an adult supervised house with two other individuals with intellectual disabilities. We go for walks or drives whenever I find time. The house is understaffed and those that work there are underpaid. They don't have the people it takes to fully engage him or the other two housemates. He sits on a couch and watches *Barney* or *Sesame Street* reruns on his iPad most of the time.

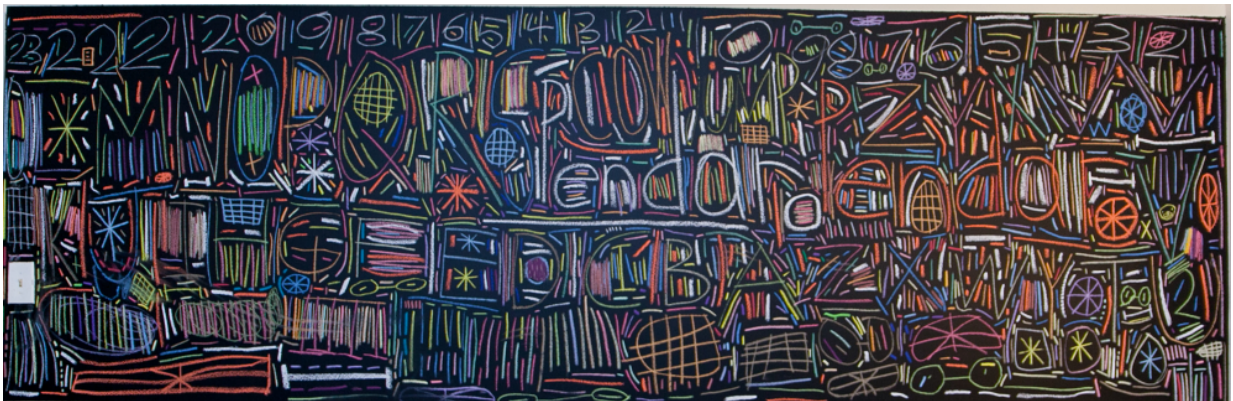
I guess the next step is to find a job for him. Something to help get him out of the house for a couple of hours a day, maybe 2-3 days a week. What can he do as a non-verbal, sometimes violent adult? He can't bag groceries at a store. He would eat half the stuff he has to bag. I am hoping to get him a job folding towels at a hotel or sports spa. DARS, Department for Aging and Rehabilitative Services, is the county office that should help find him a job. But like every other public organization, after COVID they are understaffed. It took me 2 months to get a phone appointment with them.

In the meantime, I heard of these other companies that find jobs and shadow people with special needs once DARS claims that they can't help. This whole thing is new to me, much like special education was some twenty years ago. I feel like I just finished a marathon. Drinking water, catching my breath, stretching my tight muscles from this long educational ordeal. Ready to relax and revel in the glory of having passed the finish line. Suddenly, I become aware that it is actually a triathlon. Now I need to get ready to swim 26.2 miles to get him through this part of their lives.

This is followed by a 26.2 mile bike ride to help him through retirement. Having kids looked so much easier when I was childless and young and so busy giving parents advice on how to raise their kids.

I ended up applying for a job in one of these employment companies that help find jobs for people like my son, earning a bit more than minimum wage. My main goal is to become aware of resources that are available for my son in this phase of his life. I am now a vocational counselor and I shadow 2-3 individuals on their jobs to make sure they behave appropriately. One individual cleans tables at a McDonalds. A quarter of a century ago, I would not have believed it that one day I wished my son could clean tables at McDonalds.

My focus is still to help Pendar learn to communicate, so that he can express what he wants or doesn't want. Below is a drawing he did on a blackboard. What a twist of fate that my beautiful Pendar who has an amazing mind has no way of telling us what he is pondering.



What now? I guess it is to find out what the right thing might be to do in this phase of his life.

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