

When Down Syndrome and Autism Intersect

“The Teacher” by Lisa V. Kouchakdjian

In 2005, two years after getting married, my husband I gave birth to our first child. He was a boy and we named him Aram. After taking Aram for his APGAR scores, the nurse told us they thought there was a problem. They suspected Aram had Down Syndrome. Eventually, when Aram’s diagnosis was confirmed, the first thought that went through my mind was “what will happen to him when I die?” Thus began our journey with our son.

Luckily, Aram appeared to be physically healthy overall. He had a small ASD (hole) in his heart that we were told would resolve over time. He also had very low tone. We enjoyed our son and his infancy. When he was six months old, however, Aram suffered from something called infantile spasms, a seizure disorder which affects approximately seven percent of children with Down Syndrome. After receiving appropriate treatment and therapy, Aram was seizure-free within a week of entering the hospital, and has been since.



After receiving Early Intervention services through his toddler years, Aram entered school at the age of three. He had some behaviors that were a little unusual.... some we thought were kind of cute in nature though. He liked to spin Tupperware and watch fans spin, and we did not attribute these mannerisms to anything initially. However, as time went on Aram’s speech did not develop and his behaviors became more pronounced. He started rocking and tapping everything. He also began to have self-abusive behaviors.

We started suspecting that Aram had autism, but our belief was not supported by others around him. Eventually, we had him evaluated, and at age 5, he was diagnosed with autism. This news was devastating to us,

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but a close advisor told us this would be the best thing that ever happened to Aram. It was.

It was extremely upsetting to us that we did not diagnose our son for several years, never sufficiently differentiating between developmental delay from Down Syndrome and behaviors associated with autism. Aram’s conduct was atypical behavior, but we did not know that at the time. Statistics show that early recognition and treatment of autism can help to improve lifestyle and prognosis significantly. Treatment through the appropriate use of Applied Behavioral Analysis (“ABA”) and discrete trials, by people who are properly trained to implement this programming, can help to lower stereotypic behaviors, and sometimes eliminate them. We missed that opportunity with our son.

The behaviors that Aram exhibited were mistakenly attributed to his Down Syndrome, but ASD diagnosis can be difficult because both Down syndrome and autism are on a broad spectrum, and it can be challenging to differentiate which is which. After everything we have been through, we would suggest to any family with a child with Down Syndrome to have your son or daughter evaluated to make sure this diagnosis is not missed.

Since Aram’s evaluation and diagnosis, he has made remarkable progress. His behaviors, although mostly still present, are down in number. For a child that is completely non-verbal, life has not been easy for him. Imagine a world where you have no way to communicate with anyone....no way to be able to tell someone what you want, or that you need help. That was our son’s world before he entered his present program. Aram is now part of a program our town has with The New England Center for Children of Southborough, Massachusetts (“NECC”). NECC is a school that specializes in treating children with autism. Within one month of being in this program, Aram learned to sign “more”. His eye contact increased exponentially. His self-abusive behaviors were minimized and are virtually non-existent now. He learned to self-feed with his hands, something that he was previously unable to do, and told that he may never do. Finally, our son is with

the MDSC is there

“The Teacher” continued

people who understand what his problems are, and know how to help him.

As a parent, sometimes it is difficult to recognize and accept that you have a problem with your child. Of course, it was extremely difficult for my husband and me to accept Aram's diagnosis. But, we have been thrilled with the progress, however slow, he has made. We even think Aram is a happier child now that he has an ability to communicate some of his wants and needs.



There is a critical benefit to the dual diagnosis of Down Syndrome and autism. ABA has a very well defined educational methodology, which provides clarity to parents regarding their child's progress. Down Syndrome children in an inclusion setting or other special needs program may not get this same level of structure.

Unfortunately, society is still coming to grips with autism. Autistic children learn in a very particular way, through a very particular methodology. As a society, we need to recognize and accept how these children learn, and support that teaching method. Luckily Massachusetts is one of the most progressive and proactive states (if not, the most progressive) in supporting people with autism. Giving these children what they need at the youngest age possible will only help them in the future.

Having the dual diagnosis of Down Syndrome and autism, we realize our son has many battles ahead of him. We recognize and accept that he will never be a doctor or a CEO of a major corporation, and that he might never even be able to be employed somewhere. Still, he has a career already. At 8 years old, our son is a teacher. His job is to teach people, and our society, how to be loving, compassionate, and respectful of people with special needs and disabilities.

We have often said that even if Aram helped to make just one person a better, more tolerant individual to people with special needs, his life would be more than productive and successful. But

The MDSC Serves the DS-Autism Community

The MDSC is committed to serving all families affected by Down syndrome, including those whose loved ones have a dual diagnosis. Our affiliate, the Down Syndrome Autism Connection, holds monthly chats to support parents whose children have Down syndrome and Autism. Another new resource is now available for these families, *When Down Syndrome and Autism Intersect*, the first-ever book on the subject as far as we know. It is written by Margaret Froehlke & Robin Zaborek and is available through the publishers at WoodbineHouse.com.

Also, we have secured a renowned expert on dual diagnosis, Karen Levine, Ph.D., an Instructor in Psychology at the Department of Psychiatry at Harvard Medical School and a practicing Psychologist in Lexington, MA to present at our 9th Annual Educators Forum on Nov. 18. Dr. Levine is the co-founder and co-director of the Autism program at Boston Children's Hospital in the 1990s. Her workshop will provide an overview of 'whole package' treatment approaches for children with Down syndrome and Autism, including ABA/Discrete Trials, Early Start Denver Model and Floortime in addition to strategies for treating anxiety and behavioral issues.

At the MDSC, we want to be sure that all families are welcomed and have access to the resources and supports they need.

For more information, contact DSAC@mdsc.org

he has done so much more. He has already changed the perceptions of many people who are uncomfortable around individuals with special needs. His charm, enthusiasm, and loving nature are intoxicating to all those he encounters.

As his parents, we couldn't possibly be prouder.

The Kouchakdjians live in Sudbury. Lisa by education is a litigation attorney presently staying home and caring for their four children. She is the Vice Chair of the Special Education Parents' Advisory Council in Sudbury and an active member of the special education community. She may be contacted at lisa.kouchakdjian@gmail.com