



# Complex Child E-Magazine

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## Adult Diagnosis of Asperger's Syndrome

by Molly Lou Conrad

My adult son, Michael, has Asperger's Syndrome, which is a high functioning form of Autism according to some doctors. Michael also has many interests including Origami, designing and constructing Lego Models, computers and the Internet, reading, keeping up to date on movie and Broadway show information, knowledge of the history of toys, playing different musical instruments and performing Magic Tricks.

### Early Signs

Our family's story really begins when Michael was born with a Cleft Lip and Palate that required several surgeries to correct and may be associated with his numerous other medical and neurological problems. In addition, when Michael was two weeks old, he was diagnosed with a Staph infection in his bones and joints, which damaged several growth plates in his knee and shoulder. He was hospitalized for a month and this hospitalization may have contributed to developmental delays in his motor skills, growth, and maturity. He also has other psychiatric disorders, including mood and anxiety disorders, that have affected Michael's ability to function independently and to be able to be self-supporting.

We also had problems with Michael fitting in with others his age in Hebrew School classes. One synagogue would not allow him to participate in the grade level he attended in public school. Michael was very upset about this and as a result we changed to another synagogue where he was accepted. Michael had his Bar Mitzvah a year later than most Jewish boys to give him more time to prepare. Luckily, we had a Cantor who was very patient with Michael's learning style and his voice idiosyncrasies. He had an arrangement with Michael that he would pat Michael on the back if Michael began to sing higher than his natural voice. The amusing thing is that my father in law didn't know about this arrangement and thought the Cantor was hitting Michael. Michael had a wonderful Bar Mitzvah ceremony in which he participated as much as he was able. He also went with his confirmation class to Israel after many discussions with people chaperoning the trip. He was very homesick the whole time he was there but often mentions something he saw or did in Israel.

Although he required special education intervention from preschool, he graduated with a regular degree from our local high school. From the time he was a few years old, he

would put on plays and magic shows at family get-togethers and was in shows at our synagogue and at the schools he attended.

## **Diagnosis**

Michael's Asperger's was identified when he was attending a Community College in Florida. This was just a few years after the diagnosis of Asperger's Syndrome became known to most doctors. We were lucky and found people who were very informed in the characteristics of the disorder. We also tried to identify any relatives who might be undiagnosed to see if there may be a genetic link. We think a few relatives may have Asperger's characteristics but it has never been confirmed.

The sad part of this diagnosis is that there are few doctors who treat adults with Asperger's. The late diagnosis gave us some answers about Michael's behaviors but then we find out that there were many services we should have had for Michael in his early years. As long as I can remember, Michael would not go to fireworks but would stay home and watch them on television. We thought this was just a quirky behavior of his but now realize this is one of his Sensory Integration behaviors. Other Sensory Integration issues we have now identified are his very limited appetite for different types of food and his clothing restrictions. For example, he won't wear button down shirts except for dressy occasions.

Of course, one of the biggest questions answered was his lack of social skills that might be better today if he had Social Skills training when he was younger. This has affected his having friends, obtaining a job, and influenced other areas of his life.

As a child, he had stomach problems that were treated by a pediatric gastroenterologist, and after several years we thought his problems had been corrected by medication. For several years now he has been complaining often of stomach pains and now we are trying to find a GI doctor who knows about the possible connection between Autism and GI problems.

Michael gets very frustrated because he thinks he should be able to do everything that people without developmental disabilities can do and he feels he doesn't need the housing for adults who are developmentally disabled that he lives in now. We keep reminding him that he can't live on his own without the extra help he is receiving.

## **Difficulties**

I feel like a parent who has neglected her son's problems because I don't know what to do about some of them. It is very overwhelming now.

My husband and I are trying to get ready to retire and to prepare for Michael's future. We are in a financial crisis and we may still be in debt for our son's care when we die.

We have NJ Plus College Loans for Michael that total over \$70,000. Because of our son's disabilities, he is currently earning very little income but occasionally gets jobs doing technical work in Theater, which is his love and obsession.

When he graduated High School we thought he would attend College and then be able to work at a well-paying job. But aside from income from Social Security, he does not have any income to offset the costs of the program he is in, his living expenses or his student loans. It would not be healthy for him to live at home due to conflicts that would arise and because it is the opposite of what numerous professionals have recommended. He is and should be an independent adult.

We had a horrible situation a few years ago when Michael's money, which was supposed to be for his college loans, ran out. He was using the money to live in an apartment that was connected with services for adults with developmental disabilities. We went to the NJ Division of Developmental Disabilities (DDD) requesting they pay for the apartment he was in as an emergency placement. This dragged out from October until May, when he was finally given a placement we weren't happy with but he had to take if he wanted NJ DDD housing. He obtained the service of NJ Protection and Advocacy to help him with this placement.

In the meantime, the absentee landlord of the apartment where Michael was living found out that Michael hadn't paid rent for all those months and started to harass me over the phone on a regular basis and ultimately sued us. We went through several months of Hell. The judge did the right thing and ruled in our favor because we luckily hadn't signed the lease. Unfortunately, this serves as a reminder to parents of adults with Asperger's not to cosign for anything with their child.

Things get worse when a person with Asperger's ages out of the public school system because there aren't laws to help to protect an adult with Asperger's. Today's parents of children with special needs often receive educational, informational, financial and emotional supports, but parents of young adults over 21 have had to struggle with minimal or no support, and are now in crisis.

It is hard dealing with all the government services, especially since there isn't enough money allotted for this population. I have nightmares about the lack of help for adults with developmental disabilities. I hope to start presenting a speech on this topic to parents and professionals that work with this population. My goal is to help the parents avoid my family's financial situation and to make professionals aware of what adults with Asperger's go through on a daily basis.

**Very little is being done for those born before the "age of enlightenment" who should now be living independently and not with their parents. This issue must be addressed.**

*Molly Lou Conrad's son, Michael, 30, was diagnosed with Asperger's Disorder in his early 20s. This article is based on her experiences of obtaining adult services for her son. Most of what she has done has been done by trial and error, although she has reached out for the help of many professionals. She has gotten a large amount of her information from websites and by emailing professionals and parents who have gone through the same situations. Maybe because he is an only child, Molly Lou is able to do everything she can to help her son live on his own. Her email address is [miconrad@verizon.net](mailto:miconrad@verizon.net).*