

All About Jennifer
by her mother, Jill

Jennifer is the oldest of two children. She is six and 1/2 years of age and has a sister named Julie that is 4 and 1/2. Because she was our first child, we weren't proficient at being parents and consequently we weren't sure what we were doing. At first, there were subtle things that seemed a little odd, but like I said, we didn't have a lot of experience being parents.

One of the first things we noticed was when Jen was about six months old she didn't like to be held. She wouldn't conform to your body. She was like holding a sack of potatoes. I guess I really didn't notice it much a first until one day my mother-in-law was holding her, and out of the clear blue sky she said, "She doesn't like to be held very much does she?" She would arch her back as if to say, "Let me down." It would be just one of the many silent warnings that would go off in my head over the next two years.

From the time she was four months old until she was eighteen months old she had one ear infection after the other. Of course during all of the ear infections and antibiotics she wasn't hearing the early beginning sounds that are so vital for the development of a child's speech. Because of all the ear infections, she didn't sleep much at night. I would be up with her four and five times a night and the only way I could console her was to rock her to sleep in the rocking chair. The first time she slept all night long she was two years old. I thought this was normal and all my friends kept saying she will grow out of this phase. She was also a very late walker. Art and I would work with her every night and she just couldn't get her balance. Once again she reminded me of a limp sack of potatoes. She didn't seem to have good muscle tone.

She finally walked at fourteen months which from our pediatricians stand point was normal. But there were other things too. When she finally did learn to walk it was on her tip toes which seemed a little odd but nothing to get very excited about, after all she was finally walking. Probably one of the most dramatic things for us was how tough she seemed to be. Later we learned from her occupational therapist that this was very normal for a child who had Sensory Integration Dysfunction. After Jennifer was born I joined a couple of play groups with mothers of small children about Jen's age. She was very active and always getting into everything. She was very accident prone and she would collide by accident with another child. They would hit heads and fall on the floor. Jennifer would rub her head and then get up and run off while the other child lay in a heap on the floor crying hysterically. I would just smile and think to myself, "Wow, isn't she tough? She's not a cry baby." All of the parents would marvel at how tough she was compared to their little boys. Art was particularly proud of his tough tomboy. She didn't seem to feel pain like the other children.

Always in the back of my mind was the uneasy feeling that something bad was going to happen to her if I took my eyes off of her for more than a second. Was she going to run out in the street in front of a car? Was she going to fall down the stairs? The scariest activity was when we went to the playground and she would try to play. She didn't have the foggiest idea how to play. This sounds so ridiculous, but she would look at the equipment and not know where to begin. I would sit and marvel at the other

mothers that could actually sit on the park bench and read a book while their children played effortlessly on the playground. I was never able to leave Jen's side. Once again I felt bad about my parenting abilities. Did these other parents not care as much as I did or was I being too over protective? The latter was what many of my friends thought.

Instinctively I knew if I walked away Jennifer would somehow get hurt. She was always falling off the slide or walking in front of someone swinging. She did this a couple of times and really got hurt. She had no concept of what was going on around her and worst of all no sense of fear. She didn't know her spatial surroundings we later learned from her occupational therapist, Susan. These were some of the most stressful times in my life and I was supposed to be having so much fun with my precious toddler.

I had the time to hover over her because she was my only child and I didn't have anything else to do but watch her. It was so exhausting. There were days on end I would search for the perfect toy that would capture her attention. So many times I would try to sit and play with her and get her interested in a toy.

From the time she was nine months old it really became noticeable that she would stay for a few seconds with the new toy I had just bought her and then be easily distracted by something else she saw. One of the hardest things then, and still we struggle with today, is her inability to respond when her name is called. I remember when she was two years old being at the Arboretum and calling and calling her. I couldn't get her attention to come and by this time I had an infant that required almost all of my time. I was so frustrated that I left Julie in her stroller and ran up to Jennifer and just started screaming, "Didn't you hear me when I called you? Why are you ignoring me?"

She was so shocked and surprised by my outburst and had no idea that I had been calling her for two minutes. The only thing she was interested in was the flowers she had been picking and throwing into the water. She immediately began to cry and I truly think she had no idea why I was so upset. If there had been a bridge right in front of me I think I would have jumped. I was at my wits end. How could she have so willfully ignored me? She was only two years old. Was she just being bad?

All of these thoughts were whirling around in my mind and I still didn't have any answers to these questions that haunted my every waking hour. It was so frustrating not to be able to communicate with her about how I felt and especially how she was feeling. Because of her exceptionally fast pace she required a nap every day and when I would finally get her to go to sleep she would sleep two to three hours. She had to have some down time or our afternoons would be one melt down after another. I remember lying in her bed looking at my beautiful daughter and wondering where I went wrong? How could I have failed her so miserably?

Some people would say to me, "If only you would spank her more she would be better behaved." Every time I tried to spank her it only seemed to make matters much

worse, not to mention how horrible it made me feel. She would not know what she had done to make me mad even though all of my body cues should have warned her to stop, look, and listen. All of the things we take for granted were not there for her to see.

Jennifer attended a mother's day out program at our church from the time she was six months old, and they had always seemed to cope with her very well. I never heard any complaints about her behavior or the problems that I thought she was having. She was almost three when I really started to notice not so subtle differences between her and the other children in her class. One day toward the end of the school year I went to pick her up. She had just awakened from her nap and as I sat there putting on her shoes I began to listen to all of the other children talking to their moms. It hit me like a freight train. All of these other children were talking in complete sentences with these incredible thought processes. I think I cried the whole way home because deep down I knew there was something really wrong. I just had no idea what it was.

At this point Jen was three and only speaking two word sentences. The last day of school that year my worst fears were confirmed. Her teacher asked to have a conference with me. She tried to make it sound casual but I knew someone was finally going to tell me what I had feared for so long, that Jen had some pretty involved problems. It was no longer a question of me being paranoid. Art and I met with Cindy, Jen's teacher the following morning. I think this was probably one of the hardest things she ever had to do as a teacher.

The preschool had just started using a test to track a child's developmental progress. Jennifer scored good in some areas and much lower than her peers in other areas. She explained to us how Jen could not sit in group for even two minutes with the other children. She would get up and run around the room unable to stop or calm herself. Her attention span was extremely short and she also whirled around on the playground until she became so dizzy she would fall over. Her social skills were not good and she was becoming much more aggressive with the other children. Of course we were devastated but we knew everything she was saying was true because we had experienced some of these behaviors at home.

Art and I had taken a positive parenting class, so we decided that talking to the instructor was as good a place to start as any. This situation was so frustrating for us because we didn't have a handbook to tell us what to do if our child was broken, a "how to fix it" book. The instructor was so helpful when we met with her. She went and observed Jennifer at the preschool and confirmed what Jennifer's teacher had told us. She felt she probably had some sort of Processing Disorder and possibly some other things going on and most importantly where we could go to get a professional diagnosis.

One of the turning points in this story for the whole family was when we met with the parenting instructor for the second time to discuss Jennifer further. She handed us the XXX School newsletter and explained although she wasn't sure this was where Jen needed to be, it was an excellent school for children with Speech, language, and

learning differences. At first I was horrified and still in denial that my child might be different from other children. I took the news letter home that night and read it from cover to cover. The inside story was an article about Sensory Integration Dysfunction. There were fourteen characteristics for the dysfunction and Jennifer had all fourteen problems. I will never forget the moment I read this. I should have been extremely upset. Instead I felt this tremendous sense of relief, like a weight had been lifted off of my shoulders. Finally it seemed we knew what was wrong and we had a direction we could go to get some help for our child and our family.

These feelings and thoughts were not just in our heads; there truly was something wrong and it wasn't only our parenting skills or lack thereof. Claire suggested we have one of the occupational therapists evaluate her. We went to see Susan, an occupational therapist. Susan was the second professional for us to come in contact with and from the moment I met her I knew Jennifer was in good hands. She was like an angel to me, someone who gave me hope from the beginning. It only took her about thirty minutes of watching Jen play to confirm the Sensory Integration Dysfunction diagnosis.

When we began therapy all Jennifer could do was try to run away from Susan. She was totally out of control and it was so hard to sit and watch my child struggle with the simplest tasks but through it all Susan was always there telling me, "Don't worry. Soon she will be able to do these activities without running away. I know it will be all right." I will always be so grateful to Susan for the hope, patience, and love she had and still has for Jennifer. She also saw me through some of the darkest days of my life and I will be forever grateful for her friendship and support.

Throughout all of the therapists, pediatrician, and child psychiatrist evaluations it always just blew my mind how quickly they came to these conclusions about my child. All along I kept fantasizing about some doctor saying to me, "Oh there has obviously been some horrible mistake. There is nothing wrong with your child; she is just fine." Of course deep down I knew that would never happen. I went through a long grieving process. It finally got so bad I went and talked to the pastor at our church. He helped me to understand what I was going through and he called it grieving. It was almost like a death of some sort he explained. All of the dreams I had for my child the day she was born would maybe not be the same hopes and dreams I had for her now. I was feeling very angry and guilty all at the same time. Wondering if it was somehow my fault and yet knowing I really had no control over what nature had dealt Jennifer. With his help and some real soul searching I was finally able to get passed the guilt and anger I felt and move ahead to do what was best for Jennifer.

About the same time we discovered XXX School, another wonderfully helpful and supportive person came into our lives. Susan, the OT, felt after working with Jennifer for a couple of months it was time to get a child psychiatrist involved. She sent us to Dr. XYZ. She met with us for the first time in the winter of 1993. She spent about an hour and a half with us and told us Jennifer had Attention Deficit Hyperactive Disorder with expressive and receptive language disorder. She didn't know how severe it was, but

there was no question about the diagnosis. She felt Jen was going to need a great deal of special attention but she was also very positive about such an early diagnosis. So many times with these children the attitude is to wait and let them fail and then intervene with the heavy artillery. Her belief was to keep the child's self esteem intact and intervene with special schools, therapy, and medication so the child could have as normal of a childhood as possible.

It was pretty overwhelming to think about all of these new possibilities for Jen but we felt we had no choice. To do anything else would have been so detrimental to her and her ability to function later in society. So, for the third time I called Amy back at XXX School. We had talked several times over the summer and we were now ready to look at the program seriously and see what they had to offer for Jen. Its so funny how at times the things we are most afraid of turn out to be the blessings that turn our lives around.

We had many ups and downs that first year at XXX School, but instinctively, I knew this was the right place for Jen. The staff was probably some of the most gifted, supportive, and loving people I had ever known when it came to Jen and her problems. They truly had Jennifer's best interest at heart and felt she would be able to succeed with the right combinations of school, speech and occupational therapy, medication, and the right atmosphere in her home life.

Jennifer loves Kindergarten this year and especially her teachers Ms. Louise and Ms. Elizabeth. This year, we added a comprehensive speech program with Stephanie, Jen's speech therapist. Stephanie has been more than Jen's speech therapist, she has been our friend. Jennifer has worked very hard with Stephanie on answering where, what, why, when and how questions. She still has trouble with sequencing processes, but she is now talking in longer sentences, and we have those wonderful talks that I feared we would never have. She is able to tell me how she feels, her likes and dislikes, and that she loves me. There was a time not to long ago when I thought these interactions would never happen between us. Everyday I am so thankful for all of the help and intervention Jen has received from these wonderful professionals that have become some of my closest friends.

In closing I wanted to pass on one more bit of information. If you take nothing else with from this article please take this. I attended a seminar in Dallas about a year ago and the speaker stressed over and over again how important a child's self esteem is and how we should preserve it at all costs. These children need to be in a positive, loving, and nurturing environment. He wasn't really worried so much about their academic level because he felt they could always catch up at some point. But if their self esteem becomes permanently damaged it will be extremely difficult for them to turn their negative experiences back into positive ones. If your child feels like he or she is bad, then they will be bad. If your child feels like he or she is good, then chances are they will strive to be that way.

XXX School does everything possible to help our children feel good about themselves. They encourage each child to find something they are good at, and they always look for the best in the child even if that particular day there doesn't seem to be anything good going on. Their philosophy is, there are no bad children in this world. Only those who need to be understood and heard on their terms. Every child does not fit the perfect mold. They are unique individuals with their own special talents. Amy feels that the school's job is to find the key to unlock the doors that hide a lot of these children's special traits.

The school has been our lifeline. I truly believe we would not be where we are today if it weren't for Amy and the staff at XXX School.

We have to be our children's biggest advocates. I read a book about adults with ADHD. At the back of the book the author asked these adults about the biggest factor in their life that helped them rise above their problems and become successful individuals. Each adult said, "I had someone who believed in me. No matter what, they were always there for me in good times and bad. They knew that because of who I was I would succeed in life someday." I will always be there for Jennifer, and I thank God everyday for the gift of her life.