

My Brother Can be a Pain, But I Love Him Anyway

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“Hi there. My name is Judy, and I am 11 years old. I have been asked by a friend of mine, Dr. Martin, to tell you about my brother, Sam. He’s nine and in the third grade. I could say a lot of things about Sam. Sometimes he can be a world class pain. That’s because he has an attention disorder and can’t sit still, gets in my stuff a lot, and has trouble at school. Other times I love him to death cause he really doesn’t want to do bad things and sometimes he can be really nice. That’s what makes it so hard. I never know whether Sam’s going to have a good day or a bad day. Mom and Dad have a tough time too. They call Sam a “high maintenance kid.” I guess that means it takes a lot of energy to figure out the best way to handle Sam. However, things are better than they used to be. Before our family started getting some help, I was ready to move out. Even if that meant living in Tasmania.

It’s taken a lot of work to get things settled down at our house. First there were lots of doctors appointments and meetings with people from the school. Our family has read lots of books about learning problems. We’ve watched videos about ADHD and stuff. I’ve even gone to a fun class where we learned about living with a brother or sister who has special kinds of problems. I’ll tell you more about that later.

I better start from the beginning so you get the whole picture. Dr. Martin says you counselors like to have everything spelled out real clear and orderly. I was worried that I wasn’t smart enough to write something for grownups, let alone for a bunch of people with lots and lots of college. Dr. Martin said all I needed to do was tell my story and he would fill in some of the grownup stuff that you folks like to read. He said that kind of information could go in something called a side bar, whatever that is. So here goes.

How it all Began

Mom says she knew something was different about Sam from the time he was born. He had trouble sleeping, was a fussy eater, and didn't like to cuddle and snuggle up to mom like I did. I thought its cause he's a boy and lots of boys just don't like that kind of lovely dovey stuff. One of the books I read, however, said that these early signs can be found in both boys and girls with learning problems. So maybe it's not just a boy thing.

Anyway, when Sam got into kindergarten the teacher told my folks that Sam had trouble sitting still in circle time and didn't seem to pay attention like the other kids. At home Sam was always getting into trouble for not obeying and he never could seem to follow directions. Mom would ask Sam to go pick up his toys before we went someplace and he'd end up building a castle with his Legos in the corner. Mom would go see what happened to Sam and find him playing with his toys. Then she'd get really mad and yell at him, make us all hurry to the car cause we were going to be late, and everybody ended up being grumpy. I just hated it when that happened. I never could understand why Sam just didn't do what he was told. We all began to think he was trying to make life miserable for all of us. Maybe he was just some kind of mean, bad kid. Sometimes I felt sorry for Sam, but mostly I felt mad because he caused so many problems for our family.

One day in church I was so embarrassed I thought I would die. The preacher was praying for the offering and all of a sudden Sam started playing "Twinkle Twinkle Little Star" on his kazoo. After that mom always checked Sam's pockets before church. Later my friends asked me why Sam was always doing weird things. I couldn't give them an answer.

For a long time I thought I was the only kid with a brother or sister who had problems. Later I learned there are lots of special needs kids. Besides all those with medical problems like asthma, heart conditions, and cancer, there are probably 1 or 2 boys or girls in every classroom with attention disorder, and maybe another 2 or 3 with some type of learning disability. Then there are lots of kids who's parents have divorced and they have just one mom or dad at home and others who have had bad things happen to them like being abused and stuff like that. So, all in all, maybe I don't have it so bad and it's nice to know I'm not the only one struggling with some kind of problem at home.

Definition and Incidence of

Learning Disabilities and Attention-Deficit/Hyperactivity Disorder

Learning Disabilities

Learning disability is a problem of likely neurological origin that affects specific areas of learning and behavior in an otherwise competent person.

The areas usually affected are oral comprehension, listening comprehension, written expression, basic reading skill, reading comprehension, mathematics calculation, and mathematics reasoning.

Variations in definitions make exact estimates of incidence difficult. However, most experts suggest that from 5 to 10 percent of the school population has some type of learning disorder.

ADHD

Attention-Deficit/Hyperactivity Disorder is a problem affecting attention, impulse control and overarousal. Attention disorders are found in two independent dimensions. One consists of motor hyperactivity and impulsive behavior, the other of inattention, disorganization, and difficulty completing tasks.

Three to 5 percent of the childhood population (as many as two million students), is said to have some type of attention disorder. The impulsive, hyperactive characteristics occur in 30 percent or less of all children with ADHD.¹

How Sam got some Help

Well, by the middle of Sam's first grade his teacher was really concerned. Sam seemed to be smart enough but he was having a hard time learning. Besides all those problems with sitting still and paying attention, Sam was struggling with learning to read. He had always seemed to like to be read to at home, but when he was asked to read even simple books, he'd get upset and try to get out of it. I love to read and I learned to read pretty well in the first grade, so my folks had a hard time understanding why Sam was being so ornery about reading.

That's when Sam's teacher suggested my folks have him tested for ADHD and learning disabilities. So mom and dad filled out some papers at school and started something called a Focus of Concern for Sam. That means several people from school like Sam's teacher and the nurse, along with others with special skills in testing and reading, would meet with Sam and find out why he was having all these problems. I know this was hard for my folks cause they are kinda private people and don't like everybody knowing our family is having problems. I think that's about the time they also went to see Dr. Martin. He doesn't work at the school like the rest of the people who worked with Sam. He's in private practice, so it cost extra money to go see him. However, he's a

Christian as well as being a specialist in learning problems. My folks wanted someone who believed in God and could use Christian ideas to help our family. I thought that was a good too.

Side Bar 2

Qualifications For Selecting or Referring to a Learning Specialist

<p>Has appropriate professional degree and licensing—PhD, PsyD, EdD, MD, MS, MSW, etc.</p> <p>Has experience working with learning problems in children.</p> <p>Has specific training on assessment and treatment of learning disabilities, ADHD, depression and other emotional problems</p> <p>Is able to manage a multidisciplinary approach to assessment and treatment.</p> <p>Is able and willing to work closely with a student’s school and teacher.</p> <p>Seems to appreciate complex nature of learning problems and is able to draw on many community resources to help the child.</p> <p>Has balance perspective on learning problems. Recognizes the long term nature of the problem, but is encouraging about degree of help available.</p> <p>Makes no promises of instant cures or proposes unorthodox procedures.</p> <p>Was recommended by satisfied client or some other professional familiar with their work.</p> <p>Has a sensitivity and ability to deal with spiritual issues. Is a Christian who can relate faith and practice to the student’s needs.</p>
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It took about a month to get everything done for the Focus of Concern. Then mom and dad went to a meeting where everybody reported on what they had found about Sam. I guess it was kind of a good news, bad news meeting. The good news was that they found out why Sam was having so many problems. By knowing what was wrong everybody could start working on how to help Sam. The bad news was that he has both ADHD and a specific learning disability. Kind of an unfair double whammy if you ask me.

How the Family Reacted

We all felt bad when we got the news. Mom cried for two days, and dad was real grouchy. At first I didn't know what had happened at the meeting. Eventually I got up my courage and asked what was wrong with Sam, and mom told me what the doctors had found.

Then I felt kinda weird. On the one hand it was nice to know there was a reason Sam was having all those problems with learning and paying attention. On the other hand, I felt guilty for thinking he was doing all this stuff on purpose.

Hearing all these results was hard for our whole family. For example, my grandma and grandpa thought the whole thing was some kind of new fangled excuse for not disciplining Sam hard enough. It took several talks by my folks, reading some books and going to some meetings before grandma and grandpa began to understand. When they did, mom and dad felt a lot better.

Side Bar 3

Family Reactions to a Diagnosis

The diagnosis of a learning disability or attention disorder often activates the phases of grief. Many of the same feelings and reactions brought about by a significant loss such as death, become a part of the family's emotional processing.

The well known phases of denial, guilt, anger, depression, and acceptance begin their cycles. Anguish, fear, helplessness, hopelessness, anger, guilt, and shame are some the related feelings that are likely to emerge at this time.

It is important to keep the entire family system in mind when dealing with any kind of learning problem.²

Later we saw a video about attention deficit disorder and learned that kids with ADHD probably have something different in their brain that makes it hard to sit still, pay attention and not act out. It really does help to know Sam does want to do the right thing. He just needs lots of structure and support to learn how to stop and think before he does things.

When I was little I even wondered if whatever was wrong with Sam was catching. For a while I wouldn't drink from the same glass or anything as Sam for fear I would get the same thing he had. Now I know these are pretty much things you have when you are born. Your family and school and how everybody handles things can make it better or worse.

Sam's learning disorder complicates things. I also learned that about 40 percent of kids with ADHD also can have a learning disability. In Sam's case he has trouble with understanding everything he hears. Our pediatrician thinks it may be because Sam had so many ear infections when he was little. This may have kept him from developing his ability to hear different sounds. Especially when Sam was about 4 and 5 years old. Not hearing sounds the right way can make it real hard to learn to read.

What was Done to Help Sam and the Rest of Us

Anyway, the past two years have been a lot better. Several things have helped and yet there are still days when I would like to move to Tasmania. One of the things is that Sam started taking some medicine and he can pay attention and concentrate much better. Sometimes at night he gets a little rowdy, but most of the time the medicine helps a lot.

Sam's teacher has also made some changes in his classroom that have helped a lot and Sam has also been getting some additional help from a special reading teacher. They have worked real hard on phonics and Sam can sound out words much better than before. All in all, Sam is doing much better in school and now says he really likes to go to school.

Side Bar 4

Accommodation and Remediation for Learning Problems

Accommodation

Accommodation is the modification and adaptation of materials such as textbooks and worksheets, as well as assignments, and classroom routine. The intent is to help the student work around (accommodate) his or her specific disability so that the student is more successful.

Examples of accommodations include:

Taped textbooks so student can listen to content rather than read

Allowing oral presentations instead of written for student who has trouble expressing his thoughts in writing

Ability to take tests orally instead of written.

Computer assisted instruction, multimedia presentation, and technology enhancements for various special needs

Remediation

Remediation is the process of using individualized instruction to improve specific skills.

Remediation consists of:

Identifying the precise needs and deficits of the student.

Some type of task analysis where concepts and skills are analyzed and broken down and taught in small, incremental steps.

A slower pace of instruction and frequent repetition of concepts. The deficit skills are presented and practiced multiple times in a variety of ways and modalities to help the student overlearn the material.

Matching the instructional style of the teacher to each student's learning style

Utilizing a variety of instructional materials and methods that best helps the student.

Immediate reinforcement for correct responses. Often rewards, progress charts, contracts, and various incentive systems are used to keep a student on task and motivated about the process.

A high degree of structure and organization. Expectations for students will be clearly outlined.

Close monitoring of student progress. This detailed monitoring procedure allows more clarity about the affects of various interventions or curriculum changes as they happen.¹

One other thing that really helped me was going to a fun thing called a Sibshop. This is an activity that took place about once a month where I met other kids who had siblings with special needs like autism, Down syndrome, leukemia and severe learning problems. We did lots of fun things like go bowling, cook, and learn how to paint with a toothbrush in our mouth. Most of all, it was neat to hear how other kids got along with their sibling who had serious medical or learning problems. We supported each other and eventually learned to see the good parts of having a brother or sister with special needs. I understand the Sibshop is going in at least 38 states. It sure helped me.³

How it All Worked Out

Well, that's about it. When this all began I was ashamed and embarrassed by my brother. I wanted to run and hide every time he came into the room. I was also a little bit mad at God for giving me such a creepy little brother. Things aren't perfect now, but I feel lots better. I love Sam because he's my brother. He might be different from some kids, but we are all different in some way. I know God loves each one of us just the same. That's how I can love Sam. Bye.

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