

SIBLING FORUM

A Newsletter for Brothers and Sisters
Who Have a Sibling with a Disability

Summer, 2009

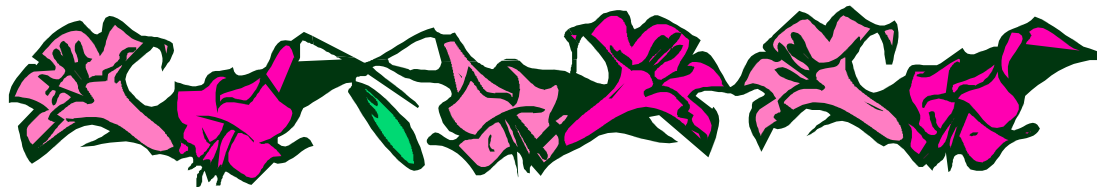
FROM THE EDITOR:

It's summer! I hope you are enjoying the sun and warm weather, and your time off from school and homework! While you are off from school, your brother or sister who has a disability might still be going to classes. Summer school or "extended school year" is very common for kids who have learning challenges. Keeping up with classes and therapy helps your brother or sister to keep on learning so that some day, he or she can be as independent and capable as possible as an adult. Have you ever thought about the future for your brother or sister? While it can be hard to imagine just what your sibling will be able to do when he or she are older, you've probably thought about it somewhat. Keep reading for an interesting discussion by one of our readers on the future she imagines for her sister who has Down syndrome.

And read on to find out more about autism and seizure conditions as well. After all, even if it is summer, you can keep learning new things too! And if you have a minute, why not write to share your story of life with your brother and sister with learning challenges or a disability? Our readers would love to hear from you!

Susan Levine

Editor



FOCUS ON FEELINGS:

The two stories featured this month were written several years ago by two girls, one with a brother and the other with a sister with a disability. The girls were both *Sibling Forum* readers for many years, and one of the girls regularly attended a sibling group just for brothers and sisters. Their thoughtful essays might sound like something you've been thinking about or something you've experienced with your sibling.....

AMY'S STORY

Life with a child with special needs has its ups and downs. I am a fourteen year old girl named Amy, and I have a six year old brother named Adam. Adam has a seizure condition. Adam had his first seizure just before his second birthday. It scared me to death. I had never seen anyone have a seizure before and didn't really know what it was. We lived in a small town so it wasn't long before everyone knew about it and we all got used to the idea. At first, I didn't like it because Adam was in the hospital a lot and he was getting all of the attention. After a while, I realized that he was really sick and this wasn't something they could just cure with a shot or medicine. I began learning about all the different types of seizures and medicines to treat them, and I developed an interest in medicine. One good thing about living with Adam is that he has taught me a lot about patience. I've also met many wonderful people because of Adam's disability.

When you think about it though, we are all special kids in one way or another. We may not all have epilepsy or cancer or Down syndrome, but all of us have limitations. Some of us don't have enough patience or we are shy, etc., but we all have some kind of disability, even though it may not be visibly noticeable. So when you look at it that way, living with a "special kid" is not any different than living with someone who is so called "normal."





Amy's experience with her brother led to her interest in medicine, and maybe even to a decision about what to study once she gets to college. She also discovered what all of you know about disabilities such as seizures, Down syndrome, autism, and cerebral palsy. No medicine or shot can cure it. These are life-long conditions, meaning that they affect how the person will learn and live throughout their lives. While brothers and sisters with disabilities might get more attention at home, if they had the choice, they probably would prefer to be just like you.

Amy also points out that we all have differences. We each have strengths and weaknesses. Our weaknesses are less problematic than a lifelong disability, however. While we make adjustments due to our areas of need (for example, sitting in the front of the classroom if we have trouble seeing, or getting some tutoring if we need help in a class in school) we can live independently as adults and take care of our own needs. People with more significant disabilities make adjustments too. For example, they learn to take the bus if they won't be able to learn to drive, or they might use a wheelchair if they are unable to walk. But most of your brothers and sisters will probably need more assistance from other adults to help meet their needs once they are out of school.

Most likely, your parents have also thought about this and begun to make some plans for the future. You may find it interesting to sit down with your parents and ask them about the future they imagine for your sibling with learning challenges. Parents take on the job of planning and worrying about the future, so you don't have to. However, because you probably will play a part in those plans, checking in with your parents might help you plan ahead too.

LAURA'S STORY

"My sister has Down syndrome and she is pretty capable. When she is an adult, though, she will probably need someone to look after her, at least some of the time. She might be able to live in a group home nearby to my parents, or in an





apartment with a roommate. She would like to see herself happily married with children of her own. She would also like to be able to drive. I'm pretty sure she won't be able to drive or have children.

The responsibility would be too much for her. I'd love it though, if she could marry another man with Down syndrome. Because she loves kids, I think the best job for her would be a nursery school helper because she would be able to spend time with children. And the children would learn at an early age that people with differences can do many things. "

Laura's story points out her vision for her sister's future. Because her sister has Down syndrome, the expectation is that she will need some help as an adult. Laura worries that her sister will be disappointed that she won't be able to do everything she dreams about. But Laura hopes that her sister will have a happy life, enjoying a job and friends, and as independent a life as possible. Laura feels that she will be involved in her sister's future and at least call her and visit her regularly.

SPECIAL DEFINITIONS:

Autism:

Children with autism experience problems in almost all areas of development. Socially, they are often withdrawn and don't seem to enjoy spending as much time with people as other children. Eye contact is limited and they often prefer to be alone. Some of these children like "sameness" and seem very upset when familiar things in the home are out of place. Some of their behavior is "perseverative" (repeated behavior with no purpose – like rocking, hand flapping, sucking their fingers, or repeating what other people say) which interferes greatly with learning. Although they can hear, they may have trouble making sense out of language. Some children can't seem to look at something and at the same time listen to what is being said. As a result, they seem to block out what is said to them. Many of the children learn to talk, usually starting with words that have to do with what they want or need. Sign language and a communication system called PECS (a picture exchange system) have helped some children with autism learn to communicate. In the PECS system for example, the child may have small photos or pictures of things they may want like a cup of juice, cookie, TV, a toy, etc. When the child wants something, he hands the picture of the item to the adult when asked. It can take a long time to teach sign language skills or PECS but it





can help children and families a lot. Usually, these methods of communication are used only until the child learns to speak.

Children with autism don't always play with toys well. They might use the toy differently than another child would – for example, they might spin the wheels on a car rather than push it, or turn the pages in a book over and over without looking at the pictures. They might repeat activities over and over, or spend a lot of time watching videos on TV. When children with PDD are around other children, they may not look at or talk to them, at least in the beginning until they are more comfortable. They might enjoy being with other children but they just don't know how to act with them.

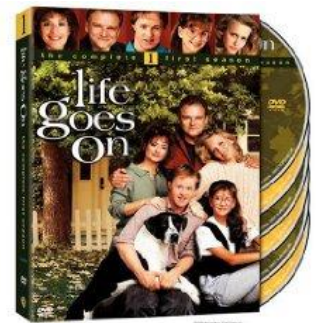
The child with autism can walk, but while some of the kids may even be good at climbing and jumping, other children may have problems with coordination, balance and ease of movement. They also may have sensory issues, meaning that their sense of touch, taste, smell or hearing may also be different. Gentle touch may feel rough and uncomfortable to them, and loud noises might seem to hurt their ears. Because of all of these problems, learning is very difficult for children with autism and they may have behavior problems as well. Most children with autism continue to have unusual behavior even as adults, although some seem to “outgrow” their disability or become very functional. The cause of autism is unknown, but it is felt that brain abnormalities are involved.

Pervasive developmental disorder or PDD is a term used to describe children with a milder form of autism. Most children with PDD eventually learn how to talk quite well and to play better with toys. They, too, may continue to have learning and social issues when they are adults.

LIBRARY CORNER:

LIFE GOES ON: A DVD OF THE COMPLETE FIRST SEASON:

“Life Goes On” was a TV show that aired between 1989 and 1993 that focused on the everyday life of a family with 3 children, a college aged daughter and two other children who were in high school. The boy in the family also happened to have Down syndrome. This was the first major TV show to feature an individual with a disability as one of the main characters. The first season focused



on how the family coped with a child with Down syndrome, and how they worked to include him in their community. The show also looked at how Corky's two sisters felt about their brother, and how they included him with their friends.

Because you have a brother or sister with a disability, you would probably be interested in this show. You might find that what this family experiences is a lot like what your family experiences! You might be able to find this DVD in your local library, or on www.amazon.com.

EXCEPTIONAL PEOPLE WITH DISABILITIES by Deborah Kent and Katheryn Quinlan.

This book contains 3-4 page essays on 48 people with disabilities. The people in the book include Helen Keller, Stephen Hawking (a scientist), and Harriet Tubman, as well as a former Miss America and a famous singer. You'll find out interesting things about how these people accomplished amazing things even though they had some physical or learning differences. The book also discusses equal rights for people with disabilities, and how technology helps people with limitations. For example Stephen Hawking can no longer speak because of his disability, but he is able to work a special computer which speaks for him. The reader will also enjoy the black and white photos of the exceptional people featured in the book.



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Editor: Sue Levine
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THE FORUM:

Here's your chance to contribute to *Sibling Forum*. Just answer the questions below and send them back via mail (Sibling Forum, 35 Haddon Ave, Shrewsbury, NJ

07702) or e-mail (slevine@frainc.org). We'll feature your answers in an upcoming edition of this newsletter! Our readers love to hear what other brothers and sisters are thinking. It's always an amazing experience to find out that someone else has the same worries, thoughts and difficult moments that you do. You're not the only one living a different kind of a life, and that is very good to know!

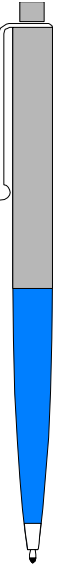
1.) What do you think your sister or brother might be able to do when he or she grows up? Will she or he be able to have a job? If so, what kind of job?

2.) How independent do you think your sibling might be as an adult? What kind of help will he or she need? Will he or she be able to live alone?

3.) What is your dream for your brother or sister?

4.) What role do you think you will play in your sibling's life when you are both adults?

5.) Do you have a story to share, or a question to ask our readers? Add it here!



6.) Your name _____ Your age _____

Your sibling's name _____ Age _____

Your sibling's disability _____

Your address _____

Thank you for reading *Sibling Forum*.
Look for the next issue in the Fall of 2009.



Sibling Forum
Family Resource Assoc., Inc.
35 Haddon Ave.
Shrewsbury, NJ 07702
www.frainc.org