

# SIBLING FORUM

WINTER 2007

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A Newsletter for Students with Siblings with Disabilities

## FROM THE EDITOR:

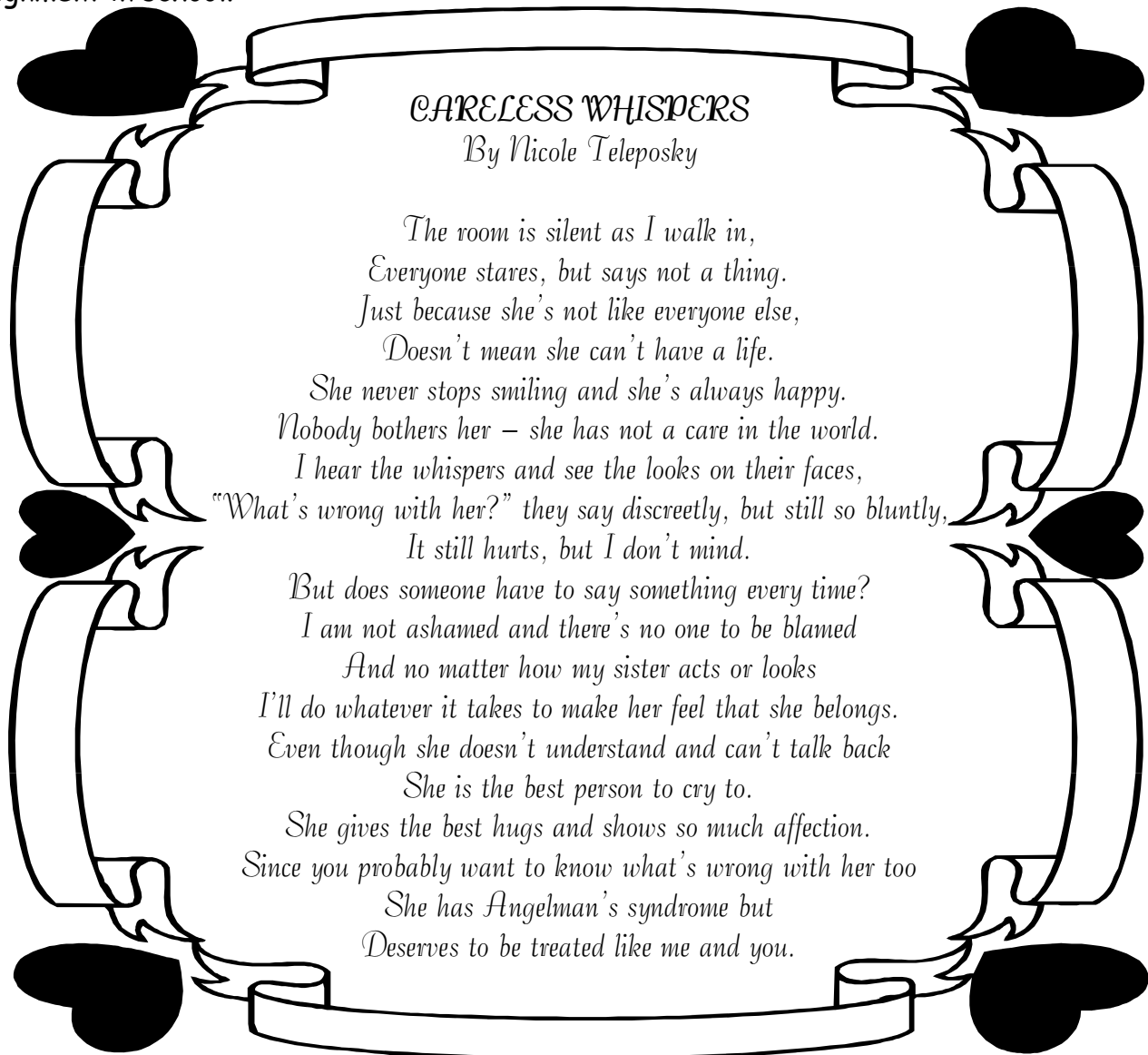
Life can get very complicated, can't it! There are always so many things to deal with in the life of a busy student - schoolwork, sports, friends, parents and getting along with your brothers and sisters. When you have a sibling with a disability, sometimes even the best of relationships can take a little more effort or lead to other complications. In this issue of *Sibling Forum*, you'll read about a couple of things that got more complicated for two siblings who wrote to the newsletter a few years ago. One of the students attempted to educate her peers through a school essay. But both students were trying to find the best way possible to live reasonably happily within a different kind of family. Some possible solutions are included that were helpful to them, and may be helpful to you if you've found yourself in a similar tough spot.

And speaking of essays, check out the *Library Corner* for an essay from the sister of a teen with Down syndrome that got some NATIONAL attention! People all over the country live with differences in their families. It's nice to know you're not the only one! Consider writing your story for *Sibling Forum*. That would provide you with national attention too!

Susan Levine  
Editor

**FOCUS ON FEELINGS:**

A few years ago, *Sibling Forum* received the poem below from Nicole Teleposky, who was then a 16 year old tenth grader from Parlin, NJ. Nicole's sister is a child with Angelman's syndrome, a rare disability also known as the Happy Puppet Syndrome. Andrea is a very happy child who does not speak and is developmentally delayed. Nicole has often seen people stare at her sister and question her appearance and behavior. In response to this sometimes painful experience, Nicole wrote the following poem as a creative writing assignment in school.



Just like Nicole, you may have found yourself in a similar situation out in public. Although Nicole is not really embarrassed by her sister, she wishes Andrea did not stand out in a

crowd. She wishes that people could just accept her sister and treat her like everyone else. After living with her sister for her whole life, Nicole is able to focus on the truly beautiful qualities Andrea shows - her gifts of hugs, affection and listening. Nicole knows that these qualities are of greater importance than physical appearance. She only wishes that others could see through the differences to see Andrea's wonderful qualities.

Here are some ways to cope with staring:

- Ignore it
- Answer questions simply and point out the good qualities.
- Avoid public situations if and when you can.
- Write about it in a school essay (like Nicole did), or write a letter to the school paper. Use this kind of opportunity to educate others with the input from a teacher to help answer questions in class. You might be happily surprised by the response you get!
- Write in your journal about how you feel
- Talk to your parents about it.
- Remember that people in public notice all kinds of differences and respond by staring whether it is a disability, a strange outfit, a 3 year old's tantrum, etc. It's not just your brother or sister that everyone stares at!



It's not unusual to have strong feelings about your brother or sister with a disability. Unlike Nicole in the essay above, the strong feelings might include extreme embarrassment and even anger—at your sibling! Adam, age 13, also wrote to *Sibling Forum* a few years ago about his 9 year old brother with major learning disabilities:



"My brother does not take care of himself even though he is 9 years old. He does not want to go anywhere without my mom. My brother sometimes cannot answer simple questions like, 'When did mom leave?' He plays with 4 year olds and does not play anything with me. My parents do not punish my brother the way they punish me. When we go places I get embarrassed. I am angry that my brother is like this and other kids have normal brothers. Why did God do this to me?"

Adam describes so many different feelings and concerns in his short paragraph! His brother's disability has made so many things so much more complicated for him. Adam is very angry that things are different in his family. He wishes he could have a normal family

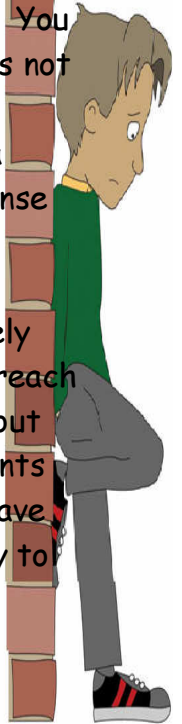
like everyone else he knows! Adam even wants to know why God allowed this to happen to him.

Just about anyone who has found themselves in a difficult situation asks at some point, "What did I do to deserve this?" "Why do bad things happen to good people?" "Why does God allow bad things to happen at all?" Have you ever asked yourself these questions? You can be sure your parents have asked these questions too! The answer, unfortunately, is not an easy one to accept. Bad things happen to good people because they just happen. Differences are a part of life just as illnesses are a part of life. Finding ourselves in a difficult situation causes us, like Adam, to feel really ANGRY. Anger is a normal response to an abnormal situation.

You can't change your life situation, but you can express your feelings and constructively figure out what to do about it. Anger can, in fact, be very helpful. It can cause us to reach out for help and information just as Adam did. When you reach out for help, you find out you're not alone! You're not the only one coping with a difficult situation. Other students are living a life like yours and just like you, they are learning to cope with it. Others have been in your situation and have figured out a comfortable way to deal with it. They try to educate others, and in doing so, find people who can be supportive.

Ways to work out a problem situation include:

- Going to your parents for help and advice
- Going to a school counselor for help with a problem in school, with friends, or at home. Counselors, social workers and psychologists are trained to help people work out problems. If you don't like the counselor at school, ask your parents to help you find someone in the community to talk to.
- Go to sibling groups - in your area or on line - for advice.
- Read and write to *Sibling Forum*.
- Find one or two understanding friends who are good listeners and who can make you laugh.
- Spend time at a friend's house to "get away" from the problem at home for a while.
- Write about your feelings in a school assignment or newspaper.
- Get involved in helping your sibling learn better social skills. Sometimes it can feel good to know you can be a part of helping to manage a difficult problem in your own family.
- Realize that coping with problems is helping you grow into a mature, caring adult with wonderful skills for coping with differences in life! (This is hard to appreciate now but someday you will!)



## SPECIAL DEFINITIONS:

**MICROCEPHALUS:** When a baby is born, doctors always weigh the infant and measure both his length and the size of his head. For the next year or so, pediatricians continue to measure all three of these things to make sure growth is occurring as expected. Some babies are born with a below normal head size. For other babies, head size may be normal at birth but the growth might slow so that the baby's head is abnormally small for his body. A child who is born with a small head size or who develops a small head size may be diagnosed with microcephalus (micro = small and cephalus = head).



Microcephalus may result from a variety of conditions during pregnancy including viral infections, drugs, alcohol, poor nutrition to the developing baby or poor nutrition for the mother. Problems during the birth process (such as lack of oxygen for a while) can cause damage to the brain and lead to microcephalus. With some children, doctors may never be able to pinpoint the actual cause.

Microcephalus is a concern because it usually means that the brain is not growing quite right. If the brain is not developing properly, then the child is very likely to have some learning problems. Children with microcephalus may have varying degrees of problems. Some children with this diagnosis have very severe learning and physical problems. They may have seizures and other medical conditions too. Other children may just have very mild learning problems and fit into regular classes with just a little bit of extra help. The extent of the problem depends on the amount of underlying brain damage or abnormality.

## LIBRARY CORNER:

**MY TURN ONLINE: MY BROTHER IS NOT HIS DISABILITY** by Colgan Leaming, Special to Newsweek, [www.msnbc.msn.com](http://www.msnbc.msn.com) (June 1, 2006)

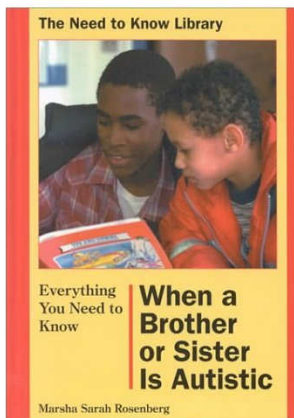
The Newsweek logo, featuring the word "Newsweek" in a bold, white, sans-serif font on a red rectangular background.

This essay is written by college student, Colgan Leaming about her 15 year old brother, Kevin, who has Down syndrome. Colgan responds to a friend who said that it must be hard to have a brother who is mentally retarded. She finds that some

people respond to her brother as if he were a disability, and as a result, they miss

out on his many abilities and talents. Colgan feels she has not been burdened by her brother. In fact, she feels that her life is happier because of him. Check out this great article the next time you are on-line!

**WHEN A BROTHER OR SISTER IS AUTISTIC** by Marsha Sarah Rosenberg. Rosen Publishing Group, New York, 2000.

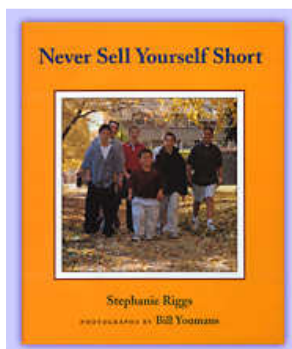


This book explains many facts about autism, including its causes and characteristics of children with that diagnosis. Certain children with autism may not be as severe as some of the children discussed in the book, however. The last chapters focus on the feelings of siblings when they have a brother or sister with autism. The book also talks about the ways siblings of these children can help out at home. Having a brother or sister with a disability can help you grow as a person and learn more about yourself. These opportunities for personal growth are discussed in the later

chapters as well.

*The next book focuses on a totally different disability. We learn more about dwarfism through the main character in this story....*

**NEVER SELL YOURSELF SHORT** by Stephanie Riggs. Albert Whitman and Company, Morton Grove, IL, 2001.



Josh is in many ways, a typical teenage boy. He likes sports and spending time with his friends. He can't wait to drive and hopes to be a commercial pilot someday. But Josh is different from other teens because he has a type of dwarfism called achondroplasia. Daily life brings many challenges including finding clothes to fit, and dealing with other people's attitudes. But Josh is determined to accomplish anything - he places no limits on himself. Josh has

many friends and he helps others be more comfortable with his differences through his outgoing and confident personality. This book is an inspiring photo essay for readers of all ages.

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**THE FORUM:**

The real life stories, problems, and solutions printed in *Sibling Forum* help both the writer and the other students who read what they have to say! It can be great to write about how you handled something with your sibling, and it can be helpful to write, looking for a solution to a tough problem. The readers of *Sibling Forum* live with differences too and they can give great advice! There are two ways to write. You can write back the old-fashioned way through the mail(!) or you can send e-mail to the editor at [slevine@frainc.org](mailto:slevine@frainc.org). We'd like to hear your successes, or print your problems for other readers to help you with. There's nothing like real life experience to help you solve a tough problem!

- 1.) If you have an issue or concern you'd like help with, write it here!

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- 2.) If you'd like to help, read the problem below and send your solution or your ideas about how to help a sticky situation. Your solution will be shared in the next newsletter. "My sister with a disability and I are very close in age. When I was in primary school and middle school, everyone knew my sister and most people were comfortable with her. We all grew up together. When I went to high school, I went to a specialized school where I knew no one. I never told anyone about my sister, and because she went to a different school, it didn't seem like I had to. It's been two years and I've never said a thing about my sister! I can't imagine telling anyone now, but it's getting harder and harder to keep people from meeting her. I'm afraid I'll lose my friends if I try to tell anyone about her now. The situation is very stressful! HELP!"

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- 3.) Do you have a poem, essay, college application essay, or story about disabilities that you've completed for school and would like to share? Please mail or e-mail it!

4.) Your name (if you want to tell us) \_\_\_\_\_ Age \_\_\_\_\_  
Your sibling's name \_\_\_\_\_ Age \_\_\_\_\_ Disability \_\_\_\_\_  
Address \_\_\_\_\_

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Thanks for sharing with the readers of *Sibling Forum*. Look for the next issue of the newsletter in the spring!

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Editor: Sue Levine  
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Family Resource Associates, Inc.  
35 Haddon Avenue  
Shrewsbury, NJ