

SIBLING FORUM

Fall 2008

FROM THE EDITOR:

With the cooler weather greeting you as you head out the door to school in the morning, you are probably thinking more about football and Halloween these days, and less about summer sun and the beach! I hope you are doing well with the start of school, and that your brother or sister who has a disability is happily in school as well!

Six years ago, Christina Masco, then aged 13 from Middletown, NJ helped write the featured story for *Sibling Forum*. In it, Christina shared her personal experiences with her older sister, Lisa, who has multiple medical and developmental disabilities. Christina also helped examine the very special qualities that brothers and sisters (like you) come to develop because they have a sibling with a disability. After you read Christina's story, take a minute to think about the qualities you are developing because of your experiences with your brother or sister.

Have you ever wondered what will happen when your brother or sister gets older? Check out the information inside on different living arrangements for adults with disabilities or learning differences. When you're done reading *Sibling Forum*, send me an e-mail and have your family story be part of the next issue! Our other readers would love to hear from you. See inside for details.

Sue Levine
Editor





EXAMINING THE QUALITIES THAT MAKE US SPECIAL

By Christina Masco and Susan Levine

My name is Christina Masco and I was happy to help Sue Levine write this month's article for the newsletter! I am 13 and in 8th grade. I have a brother James who is 9 years old and in 4th grade. Our sister Lisa is 17 years old. She has a chromosome abnormality called 8p+. As a result of that, she has cerebral palsy, hydrocephalus and a shunt, and has brain damage. Lisa uses a wheelchair to get around. She can't talk, but she can be very noisy! Lisa has feeding problems and all of her food must be blended. She needs help with feeding, dressing and most other things. Lisa attends a special education class at the regular high school in our town. She likes attention from all of us around the house, and she loves it when you sing to her. Since I take voice lessons, Lisa gets to hear me sing a lot!



The good part of having a sister with special needs is that I feel special too – in a positive way. People ask me questions about Lisa and disabilities and I like educating people by giving the answers. I also like being “the oldest” at home because I like being in charge! I've always liked the book “I'm the Big Sister Now” by Michelle Emmert. The story is about a girl with an older sister with severe disabilities like Lisa who becomes like the big sister because she is more capable than her sister is. I feel like that's the story of my life!



The difficult parts of having a sister like Lisa is that she can be very noisy at home and it can be difficult to concentrate! People also tend to stare at Lisa when we are out. Often I'll stare back and then they quickly turn around and pretend they weren't doing anything! It's funny though, everywhere we go, it seems that at least 3 people come up to us because they know Lisa from school. Sometimes I think she knows more people than I do!

Lisa's needs also place limitations on what we can do as a family. We often have to get someone to watch her so we can go places that would be difficult to bring her. And finding someone isn't always easy. We also have to leave early from the beach in the summer so we can be home when Lisa gets home from her camp.

When Sue asked us at the last sibling group meeting to come up with a list of qualities that would be good for kids to have when they have a sibling with special needs, the group came up with a few important things. And here they are:

Patience: When Lisa has temper tantrums, I need patience to keep me calm! You can't explain to Lisa why she doesn't need to have a tantrum – you just have to learn to live through it. Also, because it takes time to get Lisa in and out of the van in her wheelchair, going places takes longer. It seems I am always 5 minutes late for everything! Having patience helps me get through those moments. Other students felt that being patient was also important because it takes a child with special needs longer to learn things and you get used to waiting for new things to happen.



Understanding: Having information about my sister's disability has helped me to have a good relationship with her and to communicate with her. Understanding special needs by having the proper information about the disability is important for every brother or sister in my situation to have.

Helpfulness: Being helpful with things related to your sibling's special needs is important too. I babysit for brief periods when my mom has to go out and I sometimes step in and help at mealtimes too. My sister also gags easily and you have to be quick and prepared to prevent disaster!

Being Able to Control Your Anger: Everyone I've met through sibling group meetings gets angry from time to time at their brother or sister with a disability. It's normal to feel that way but it's important to deal with your anger appropriately. You can't really get mad at what your brother or sister can't help, but you can get frustrated as a result of it. I've had to learn to control my anger, holding it in at times and letting it out in productive ways at other times. My favorite way to get rid of my anger is to go to my room and bang on my keyboard. I also listen to classical music or a rainstorm tape I have that is supposed to help calm you down, and it really works! Other kids in the sibling group go outside and run or do something physical, listen to other kinds of music or write about their feelings. Sometimes I might even pick on my little brother when I get really mad!

Tolerance: Being tolerant of my sister's behavior issues is another good quality to have. When Lisa starts screaming in the middle of Six Flags Amusement Park, I have to be able to stay calm and say, "Lisa, Shhhh!" It's not helpful if you get easily embarrassed! That takes practice though. It's good to try not to let things bother you as much. It's better to stay calmer.

I feel I am more mature for my age because of all the practice I have gotten at taking care of someone who needs me. I'm more sensitive and more tolerant of other differences in life too. Having a sister like Lisa is hard sometimes, but after the tough times, I'm glad I have a special sibling.



FOCUS ON..... Qualities that Make Us Special

Christina gave a wonderful description of qualities that make kids growing up with a sibling with disabilities, special people too! Through her own experience and the experiences of other students in the sibling group to which she belongs, she can describe what they all have learned. I'm sure you've learned some of these lessons and developed some of these qualities in your own life too! Tolerance, understanding, patience, ability to control anger and helpfulness help make life run a bit more smoothly in a family with differences.

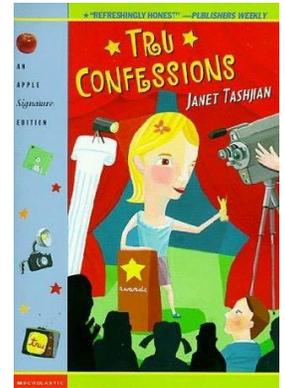


LIBRARY CORNER:

Looking for a good book with a focus on siblings and disabilities? Here are a couple of good ones to look for the next time you visit the library.....

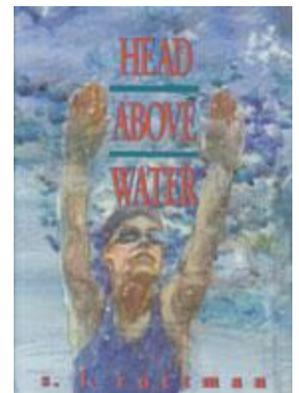
Tru Confessions by Janet Tashjian

Tru is a 12 year old girl who has a twin brother, Eddie who has a disability. Tru has two great wishes...to find a cure for Eddie's disabilities, and to create her own television show. When Tru finds out about a contest being held by a local TV station, she decides to work hard to win the contest by making a video about Eddie. As Tru goes on to make the video, she learns more about her brother's learning issues. Eddie can be very frustrating to deal with at times, but Tru knows he is also one of the most important people in her life. This story is told as if Tru were keeping a diary on the computer. The story is funny and contains lots of very real feelings...feelings that brothers and sisters often have with a sibling who has a disability.



Head Above Water by S.L. Rottman

Skye is a 16 year old high school junior who has a lot of responsibility at home. Her mom is a single parent who works two jobs. As a result, Skye is expected to do a lot to help with her 19 year old brother, Sunny, who has Down syndrome. Skye is also trying to keep up her grades, and practice her swimming skills to qualify for the state swim championships. Skye is hoping to get a scholarship to college through her swimming. Along with all of that, she has a new boyfriend who she wants to spend more time with, and her brother wants her to teach him how to swim. Sunny qualifies for the Special Olympics in swimming, but Skye's own swim meet is going to take place on the same day. Skye finds Sunny to be both challenging and frustrating at times, but as she struggles with the many complicated things in her life, she grows up a little and finds out what's really most important. This is another story full of sibling feelings!



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SPECIAL DEFINITIONS:

The definitions this month focus on the future and possible living arrangements for individuals with disabilities who are not fully independent as adults. Your parents may have an idea about what they think will be possible for your sibling when he or she is an adult. Be sure to check in with them if you want to know more about their plans....



SUPERVISED INDEPENDENT LIVING:

Individuals with more minimal disabilities may be able to live independently in the community provided they are given some supervision. These people may live in a boarding house, a co-op, their own apartment alone or with a roommate, etc. Supervision may be given through a social worker or other individual (paid by the state or a private agency) who makes occasional visits. Areas in which help is often required include money management, cooking and nutrition, bill paying and apartment maintenance. Individuals in these settings live almost independently and they are responsible for their own cleaning, shopping and transportation to and from work. Supervisors provide training to help the individual learn about the necessary transportation and other information about apartment living.



GROUP HOME:

Many individuals with disabilities are not able to live fully independent lives as adults. Group homes offer one alternative to independent living. In a group home, 5 to 8 people with disabilities live in a house with "house parents" or supervisors. Each resident has their own bedroom or a room they share with a roommate. They are usually responsible for the care of the room as well as chores around the house if they are able (cooking, cleaning, setting the table, doing yard work, etc.). "House parents" supervise the activities in the home, coordinate group outings, and assist residents with their work schedules, transportation, etc.

People who live in the group home may have a job out in the community (like McDonalds, or a store) or they may work in a sheltered workshop. If the group home is located in a town, residents may use public transportation so they are able to get to and from work. The group home is usually relatively close to where the individual's family lives, so he/she can invite guests to visit.

Some group homes are designed specifically for individuals with mild disabilities while others cater to those with autism, physical challenges or severe disabilities. The group home provides the opportunity for an independent life away from the family, as well as pride in this accomplishment.

In New Jersey, group homes are operated by the ARC, and other private organizations. You might be able to make arrangements to visit a group home by contacting an agency like this in your area.



RESIDENTIAL PLACEMENT:

Some individuals who have disabilities may live in a place called a residential facility. These are usually large facilities servicing many children and adults with a variety of disabilities. Some are run by the State in which you live and others are privately owned and operated. These placements include living quarters as well as school and vocational training. Individuals share a room with one or more individuals. Teachers, nurses and therapists are employed to teach and supervise the residents and coordinate recreational activities.

Usually the people who live in a residential setting have more serious problems than people who live in group homes and other community settings. Many are unable to care for themselves and require special care both day and night. Residential placements are not always near the individual's family. Weekends at home are arranged on a regular basis and families can visit the residential facility regularly.



LIVING AT HOME:

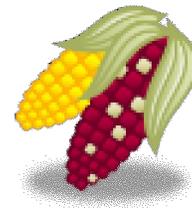
Sometimes, adults with disabilities continue to live with their parents at home. In many cases, the person is given more responsibilities, like some cooking and cleaning, laundry and shopping. Some families create an apartment at home for the adult, in the basement or in an apartment attached to the house. When the adult is taught to have more responsibility, he or she becomes more independent and eventually can look toward living on their own, out of the house. When parents get older and can no longer take care of their adult child at home, moving in with another family member, or out into the community is the next option.





DID YOU KNOW?

If you have younger brothers and sisters, in addition to your sibling who has learning challenges, there is another newsletter, like this one, for younger readers. Brothers and sisters aged 4 to 9 can get ***For Siblings Only!*** ***For Siblings Only*** contains stories, as well as games to play that help teach your sibling who needs extra help to learn. The newsletter also includes ideas for books to read about feelings and differences and other fun things for younger readers. So, share the news! ***For Siblings Only*** can be downloaded from the agency website www.frainc.org (then click on newsletters), or you can sign up to have one mailed by calling 732-747-5310 or e-mailing me at slevine@frainc.org.



THE FORUM:

This section of ***Sibling Forum*** gives you the opportunity to be part of the next issue! You can share your thoughts by answering the questions that follow, or you can write up your own story to share. Please consider sending an entry to ***Sibling Forum*** because YOU are what this newsletter is all about! The more we hear from our readers, the more valuable and helpful the newsletter becomes!

1.) Christina Masco highlighted some of the important qualities that brothers and sisters often learn because of a sibling with a disability. They are tolerance, patience, learning to control your anger, being understanding and helpfulness. Of those five qualities, which do you think is the most important to have as a brother or sister of someone with a learning difference? Why_____

2.) Did Christina and her sibling group miss one? Can you think of another important quality? If so, please share it here and tell us why you think it's important.

3.) Of the five qualities mentioned, and including the other one you thought of (if you did), which quality is the hardest to learn...and why?

4.) Would you like to share your family story, including any difficult moments or lessons you have learned? If so, we can do a phone interview, or you can e-mail your thoughts to me at slevine@frainc.org. You can also include your telephone number here along with a good time to call you... _____

5.) Your name _____ - Age _____
Your sibling's name _____ Age _____ Disability _____
Your address _____

Thanks for reading *Sibling Forum* look for the next newsletter in the New Year!

<p style="text-align: center;">"Sibling Forum" A Newsletter for Preteens & Teens with Siblings with Disabilities Editor: Sue Levine Published by Family Resource Assoc., Inc., 35 Haddon Avenue, Shrewsbury, NJ 07702 Phone: 732-747-5310 Fax: 732-747-1896 www.frainc.org www.techconnection.org (No part of this newsletter may be reprinted without permission of Family Resource Assoc., Inc.)</p>



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