

Sibling Forum

A Newsletter for

PreTeens & Teens who have a Brother or Sister with a Disability

Spring, 2009

FROM THE EDITOR:

With Spring blooming all around us, the end of the school year can't be very far away! Some of our readers may be coming up to their 8th grade graduation, while others may be graduating from high school in June. Our lead story this month was written by Andrew Cecchetti for his college applications. At 18, Andrew is younger brother to Sean, who is 19 and has Down syndrome. Andrew writes about Sean's high school graduation and all of his accomplishments during his time in school. As Andrew, himself, leaves for college in the Fall, he will take with him many lessons learned from his older brother.

Andrew's brother may one day be able to live on his own in an apartment. While not everyone with a disability is able to be so independent, there are other living arrangements that are possible for people who need additional help. Inside this newsletter, you can find out more about opportunities for adults with disabilities.

If you have a minute, send an e-mail to Sibling Forum, and include a photo of you with your brother or sister. The readers of Sibling Forum would love to hear from you!

Susan Levine

Editor



College Essay

By Andrew Cecchetti



As I looked out over my high school football field on June 20, 2008, I could feel the significance of the day for my family and me. I stood behind the soccer goal that I had defended for the past three years and listened to the principal's voice call out the name of many friends. Every time a name was called, I remembered all of the memories we had shared. Then one name was called that was all too familiar and I turned to center stage and saw a very anxious young man grasp his diploma and shake the principal's hand. The silent audience then began to roar with congratulatory cheers as he raised his arms like a heavyweight boxer after a championship fight. The student had completed the hardest fight any champ ever had to endure. And now, witnessing the momentary pause and raucous cheer for one of the most important people in my life, a small tear which I was not able to hold back fell down my cheek.

Rewind to a week before Christmas break when senior superlatives were being announced over the loud speaker and I was curious to see which of my friends had won. One of my friends won "Best to Bring Home to Parents" and then another won "Best All-Around." The "Most School Spirit" was being read and I heard that familiar name again. I ran out of the class in an attempt to hide my tears of pride.

Now let's go forward to the senior prom a few weeks before graduation. Everybody in school was always gossiping about which girl is going with whom and the drama that entails. Brittany, the prettiest and the most popular girl in the school, asked the same young man I have been talking about, that senior. When prom night arrived, I was at my friend's house and, all of a sudden, my phone started to vibrate, not once, not twice but 18 times! I will never forget seeing the number of text messages. "He is on the Prom Court," they would read, so I ran out of the house and called my mom. Fifteen minutes later, as I was getting home my phone started again with 24 messages reading, "He is Prom King!" There was not a dry eye in my home.

Who is this young man who can make people smile and cry and feel really special? He is my brother Sean. He has accomplished all of these things and so many more in his 19 years. He has scored 20 points in a basketball game. He has had solos in the school chorus concerts. He has brought home straight A's. Many other people have accomplished these and other things than Sean has, but this is where he blows them all out of the water. How many of them have Down syndrome?

FOCUS ON FEELINGS:

You can tell from Andrew's essay just how **proud** he is of all the things his brother has accomplished. He is especially proud because his brother has done all of these things even though he has Down syndrome! Sean has accomplished some pretty great things, but Andrew and his family are proud of the little things too. When you have a brother or sister with a disability, you see how hard it can be to learn small things too, like how to brush your teeth yourself, spell your name, or say "hello." Small accomplishments can feel just as great as the big ones. As a brother or sister, you see all the work that it takes for your sibling to learn things that we do easily every day. What small accomplishments have you celebrated with your brother or sister?



This year, it will be Andrew's turn to graduate from high school. Then in the Fall, he is going on to college at Holy Cross in Massachusetts. Like his brother, Andrew has accomplished many things himself in high school. He has been on the school soccer, volleyball and basketball teams. He is a member of the National Honor Society, and he has spent much of his free time working with students, like his brother, who have disabilities. Andrew and his friends have run recreation programs and organized dances for Sean's group. Andrew has also worked hard to make sure his friends in school and the neighborhood have included his big brother. Because of Sean, Andrew has learned a lot about disabilities. And he has helped so many of his own friends to be more sensitive and educated about differences, just like you probably have because of your brother or sister.



Andrew has also looked after his brother when their parents were out. He has helped Sean remember how to behave appropriately when they are out socially. And he has been careful to

make Sean feel like the older brother, even though Andrew is in many ways like the big brother now. Andrew looks out for Sean, but Sean looks out for Andrew too!

While Andrew is certainly a very caring brother, he and Sean don't always get along! Sometimes they annoy each other, and sometimes Andrew doesn't want to have to include Sean in an activity with his friends. There certainly have been times when Andrew has felt embarrassed! And he doesn't always want to change his plans to stay home with his brother so his parents can go out on a Saturday night! Andrew and his parents have had discussions about this. Usually, Andrew's parents let him know well in advance if they need him to be around to spend time with Sean.

Andrew likes knowing that Sean has many friends of his own, including students with Down syndrome and other disabilities. One day, he hopes that his brother will have a job he enjoys too. While Andrew will be far away from home when he goes away to college in the Fall, he will check in with Sean often, through e-mail and the phone.

Thanks, Andrew, for sharing your essay, and a little bit of your life with Sean. Good luck at Holy Cross!



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....

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 Association for Retarded Citizens, the Association for Children with Learning Disabilities 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:

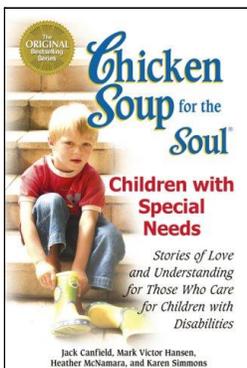
Some individuals who have disabilities may live in a residential facility. These are usually large facilities servicing many children and adults with a variety of disabilities. Some are run by the State and others are privately owned and operated. These placements include living quarters as well as school and vocational training. Individuals share 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 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.

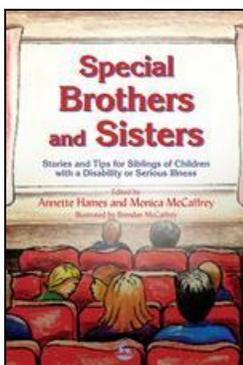
LIBRARY CORNER:

CHICKEN SOUP FOR THE SOUL: CHILDREN WITH SPECIAL NEEDS: STORIES OF LOVE AND UNDERSTANDING FOR THOSE WHO CARE FOR CHILDREN WITH DISABILITIES by Canfield, Hansen, McNamara, and Simmons



If you like the "Chicken Soup for the Soul books, you might be interested in this one which focuses on children with special needs. The stories are written by parents, caregivers, teachers and siblings. You'll read about many different disabilities and challenging situations. This book will make you feel good!

SPECIAL BROTHERS AND SISTERS: STORIES AND TIPS FOR SIBLINGS OF CHILDREN WITH SPECIAL NEEDS, by Harnes and McCaffrey, Jessica Kingsley Publishers.



This book includes a selection of real life stories from siblings aged 3-18 who have a brother or sister with a disability. The writers are from 40 different families. They explain in their own words what it is like to have a brother or sister with learning challenges. There are also tips to help siblings cope. A glossary of terms explains everything from ADHD, to cystic fibrosis, Down syndrome and cerebral palsy.

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THE FORUM:

Sibling Forum is always looking for students who would like to contribute their thoughts to the pages of this newsletter. Including the thoughts, ideas, concerns and advice of our readers is what makes this newsletter so helpful to others. We'd like to hear from you, too! You can e-mail your own, personal story to **Sibling Forum** to slevine@frainc.org or you can answer the questions below and send them in (Sibling Forum, 35 Haddon Ave, Shrewbury, NJ 07702). Either way, we're counting on you to be a part of the action next month!

1.) In Andrew's story this month, he shares many of the things that make him proud of his brother, even though he has a disability. What are you most proud of with your brother or sister?

2.) When you have a brother or sister with a disability, there are always challenges with learning, whether it's learning how to behave in a social setting, learning something in school, or learning how to do something physical (such as walking, playing basketball, or dancing). What do you wish your brother or sister would learn to do better?

3.) Do you have a question about your sibling's disability, or do you need some advice about how to handle a difficult situation with your sibling? Include it here and we'll answer it in our next issue!



4.) Your name _____ Age _____

Your sibling's name _____ Age _____

Your sibling's Disability _____

Address _____

Your e-mail address _____

Thanks for sharing your thoughts with the readers of *Sibling Forum*. Look for the next issue either on line at www.frainc.org (*click on newsletters*) or in your mailbox in the summer!

If you live locally, why not call FRA to join our **Sibling Group** for siblings aged 10-15 who have a brother or sister with a disability or developmental delay. We meet quarterly: 3 meetings a year take place at a Bowling Alley in Shrewsbury, NJ and one meeting is held on the Point Pleasant, NJ Boardwalk.

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