

Connect-Ability

A newsletter on disabilities awareness prepared by and for students



A message from Maria Neira, NYSUT vice president



Maria Neira



Lee Cutler, NYSUT secretary-treasurer, meets with editorial board members at the March Writing Workshop.

NYSUT is proud to sponsor *Connect-Ability*, an annual statewide disabilities awareness publication designed to bring together students with and without disabilities. This summer I once again experienced the power of students' voices. A dozen high school students, who themselves deal with disabilities conducted research, asked questions and read articles on several disabilities. Using fictional characters they wrote imaginative and informative articles that will help individuals with and without disabilities respond to challenging situations. As you read this issue I will let you experience for yourselves the students' enthusiasm, humor, talent and commitment to educating others about people with disabilities.

I must share with you my own experience with the editorial board members. At the conclusion of their last writing workshop in August, they invited me to participate in a short exercise designed to test my knowledge of disabilities. I was challenged by their questions, intrigued by their presentations and genuinely pleased by what I had learned from them. Fortunately, they proved to be good teachers and I passed their "test." No one was more pleased with my performance than the students who had worked so hard to make this issue of *Connect-Ability* such a success. I am certain you will also learn from their sharing and incredible insights.



Editorials

Mitchell Goliber, Co-Editor

When I first started working with the newsletter, I believed that my mother was making me do it so that I would be more social. It wasn't long before I started to enjoy myself. I have written a whole bunch of articles, including the one with the most ingenious title, "Do you want fries with that Asperger?", which started off my journey with the newsletter back in 2005. This newsletter is designed to educate people, especially those who do not have disabilities, about disabilities. It was formed by high school and college students with and without disabilities, who are kind to one another. We have joined together so that people with disabilities aren't considered outcasts in society. The more we know, and the less we fear, the faster we can grow into a better community.



As a member of the newsletter's editorial board, I participated in writing workshops and did research. We worked as a team to write quality articles. In the meantime, I was learning about many disabilities, other than my own. The newsletter get-togethers always included some time to have a little bit of fun. I got to speak at a conference sponsored by Mount Sinai Hospital in NYC, see a

stage play at Proctors (Grease), stay at the Hilton Garden Inn and have dinner at the Gideon Putnam Hotel. I went on a tour of the NYSUT headquarters in Latham.

The original sponsor for the newsletter was the NYS Commission on Quality of Care but when they withdrew funding, NYSUT (New York State Union of Teachers) stepped in to save the day. At NYSUT we came up with a new name for the newsletter - Connect-ability. It was created by the students who felt connected by the newsletter experience. The NYSUT facility is very high-tech, lots of computers, a large printing area, great lunches, and beautiful conference rooms where all of our writing workshops take place. We feel that our newsletter now has a great home base and we're happy to be there during our writing workshops.

As I prepare to leave for college next fall, I realize that there will be no one to take my place as a Schenectady representative on the editorial board of the newsletter. It is my hope that other high school students with or without disabilities will join the newsletter.

Challenge yourself; know that there are people in this world who need just a little push to taste success. Like my mother always told me; "Those who are successful, know **what** they need, and **how** to ask for it." I need, NO, we need students to join with us, and we are asking you. We are asking for your "abilities." Let's "connect" with you!

We want you!!!

Alexis Kim, Co-Editor

The beginning of the school year is a great time to set goals. We not only set goals for learning, but personal goals as well. When we accomplish our goals we can begin to shape our dreams, which help us to visualize our future. One of the most important goals I have had over the past few years is to become a better listener. I know that it can make a difference. Listening with an active heart is something I have developed over the last three years by working and socializing with my many friends who are editorial board members of Connect-Ability.



At age thirteen, I joined the editorial board because I wanted an opportunity to write for a newsletter. Three years later, I now realize that not only did I gain valuable writing experiences, I formed friendships, and developed a passion for advocating for people with disabilities.

Connect-Ability brings together students with and without disabilities from across New York State, who all share the common goal of informing other students about disabilities. We have had the good fortune of having the New York State United Teachers (NYSUT) support our efforts. It is amazing how much advocacy and education takes place (not to mention how much fun we have) when we get together to work on this publication.

When I initially began working on this newsletter, the

differences between myself and some of the other members on the editorial board were obvious to me. After the first meeting, I found myself comfortably relating to other students my age who had disabilities, quickly finding more similarities between us than differences. This realization lowered my inhibitions, and inspired me to form many new friendships back in my own school with classmates who have disabilities. My amazing experience working with Connect-Ability has allowed me to be more open minded and has given me a chance to learn important lessons from people I never would have expected would be my "teachers."

My advocacy for disability awareness originated at a young age when I witnessed the process of a learning disability in my own family. I saw the long hours my brother spent trying to achieve work that came very easily to me. I have felt the pain and sorrow of my parents, never for shame, but for the sheer unfairness of how he was treated. He ultimately succeeded because of their bolstering love and support.

We must remember that most people share the same feelings and fears, and are much more alike than they are different. All students want to feel socially accepted and do not want to feel different or be labeled as such. We can all be advocates for each other. No matter where you fall on the educational spectrum, you will most likely be in class with a student with a disability. By learning to accept and respect people with disabilities, we can all help each other find our inner champions. Learning to support others is something that I have found deep within myself through working on the Connect- Ability Newsletter.

Editorial Board Members Walk in Four Pairs of Moccasins

We know that understanding the perspectives of others is key to getting along in this very diverse world. From an early age we are advised (especially when we misbehave) to put ourselves in someone else's place. Whenever we've done something we shouldn't have, we're asked "how would you feel?" Our reaction is to try to imagine being someone else and it usually puts us back on a path to self-correction. It allows us to look at our own behavior and to change it for the better. But seeing something from someone else's perspective isn't easy. It takes practice.

*Do not judge your neighbor
until you walk two moons in
his moccasins. – Cheyenne*

Like Sal in Sharon Creech's award winning book, *Walk Two Moons*, we ought to practice walking in someone else's moccasins more often. In the book, Sal and her grandfather make a game of it but it's a serious game. Together they turn a lot of the difficult experiences they observe other people having into things they can relate to and understand. They start out by playing a sentence

completion game. It goes like this.

If I were in Jamie's moccasins when he found out his mother was having a baby with a disability, I would _____ or if I were in Tiffany's moccasins when she found out about the accident, I would _____. Then Sal and her grandfather move beyond the initial sentence and start talking in paragraphs as if they were Jamie or Tiffany. As they practice walking in someone else's moccasins together they begin to start looking at a lot of things through someone else's perspective. They become less judgmental and more tolerant. They get along better with others and life becomes easier for them.

The editorial board members of Connect-Ability agreed to walk in one of four pairs of moccasins this past August when they met at NYSUT Headquarters to participate in two days of writing workshops. They listened and learned and talked to one another from the different perspectives of four individuals with disabilities. Working in small writing groups, they responded to eight questions about their disabilities. The four sets of moccasins belonged to these four people.

Bill - a 72 year old man with Tourette syndrome who lives in an assisted living apartment. Bill is retired and loves to play chess.

Tim - a 47 year old man who has a traumatic brain injury

TIM



William Williams 08

as a result of a motor cycle accident. He lives with his sister and her husband and works in a local supermarket.

Jason - a 12 year old student with a learning disability. He excels at running.

Sara - a 25 year old woman with an eating disorder. She and her best friend, Jen, have known each other since childhood and have been inseparable since they graduated from college together.

What's it like having a disability? How do you define disability?

Jason: It's easier for people to point out my faults because the world sees me for my disability. Learning and reading takes a lot of time for me and I have developed patience. I take my time and really appreciate learning. I am more disciplined because unlike a lot of people, I have to study. It's not an option for me. I feel angry, frustrated, and jealous sometimes when I think of how easy it is for everyone else. They can just pick up a book and read through the whole thing in two or three sittings. I take hours to get through a chapter. I always feel as if I have to catch up with everyone. My mom says that everyone wants to feel competent and accomplished and that I can only do my best. I feel that I need to show people more of myself than my disability. I need to show people that I am good at other things. That's why I love running and math because I can show my talents and the person behind my disability.

Bill: When I was younger, my disability left me feeling frustrated. Other people thought that I was a big nuisance. I thought the same about my disability. I just wanted to cover it up. If I had things my way, I would never let anyone know that I had Tourette's. I believe that my definition of a disability would've been a big pain in the neck, and leaving me feeling different from everyone else. Nowadays, I'm living in an assisted living facility, surrounded by people with many different life stories and conditions, and I feel more comfortable.

Sara: People ask me all the time what it's like having an eating disorder. I tell them it's terrifying until you are able to accept it and do something about it. For me, that began when a nurse wearing a blue gown peeked her head through the doorway of my hospital room, came in and unbuckled the restraints tied around my arms. She began asking me if I knew today's date and once I realized that about 3 months had passed since 'yesterday,' I knew there was a serious problem. The nurse told me I had almost died of starvation; she was surprised that I didn't even remember being brought in. I guess that nurse defined my disability for me. It was pretty scary.

Tim: My life is completely different from the life I had

before my motorcycle accident. Now I use a wheelchair and I'm dependant on my younger sister to help me do simple daily activities such as getting out of bed. For me, having a disability makes me work harder than others.

How does your disability frustrate or challenge you?

Jason: When talking about movies, my friends always say "the book is better!" I have never had that feeling. Reading is a chore for me and I never enjoy it. A friend recommended Harry Potter. I was nervous about admitting I had problems reading so I said I wasn't interested and that I didn't like Harry Potter. Some people think I am stupid, but they just don't understand that I only have trouble with reading and that everyone learns differently.

Bill: I always find it hard to communicate with other people because of my disability. As a child, I never did have many friends; I always assumed that other people would make fun of me because I behaved differently from everyone else. I never had a social life. I wished that I had pushed myself to be more social, to do more things with other people. I'll always regret the things I should've done but didn't do because of my disability; I could've done a lot more. On a day-to-day basis, some of the people I lived with understood me, while others didn't. When I was still in school, I didn't have any accommodations, this limited

my opportunities in the working world which led to my self-esteem issues. Now there are laws protecting kids with disabilities and supporting them to be more involved in regular activities with their peers in school and out in the real world. It's different now.

Sara: In the beginning my disability made me feel as though I was a weakling; especially since Jen, my best friend, began to diet with me and worked through it and has a lot to show for it. I'm lucky to be alive because of what I did to my body by not eating. And each time I open a magazine or talk with a friend, all I think of is weight and it makes me uncomfortable.

Tim: Social interactions can end in tears due to my sporadic emotions, which can become very aggravating. Trying to talk about a simple subject like the weather, can create extremely awkward moments for me and the person I am talking to. At first, I felt like I didn't have control over many important parts of my life. Simple things such as my emotions, my legs, and even my job seem to be ruled by my disability instead of me. I used to be assistant manager of a large company, but because of my disability, I was no longer able to continue my work. Leaving a job that I had once loved was emotional and depressing, yet in order to earn a living I decided to get a job at a local grocery store.

How has your disability made you feel different from other people?

Jason: Everyone seems to be so relaxed in class; most of them don't even pay attention. They have freedom. They can play video games all night and they still do well in school. I work so hard, but I am always behind. I always need help and I've known for years that the tortoise never really wins; the hare is always ahead.

Bill: My mannerisms aren't considered normal; I learned that at a young age. When I was a kid, people would tell me right then and there that I was different. My teachers taught me that I was different. They treated me differently from other students. It was assumed that I wasn't as capable and I believed them. I was usually separated from my classmates. They told me that I was merely a distraction in the classroom. It wasn't until recently that I realized that what they told me at that age might not be the truth.

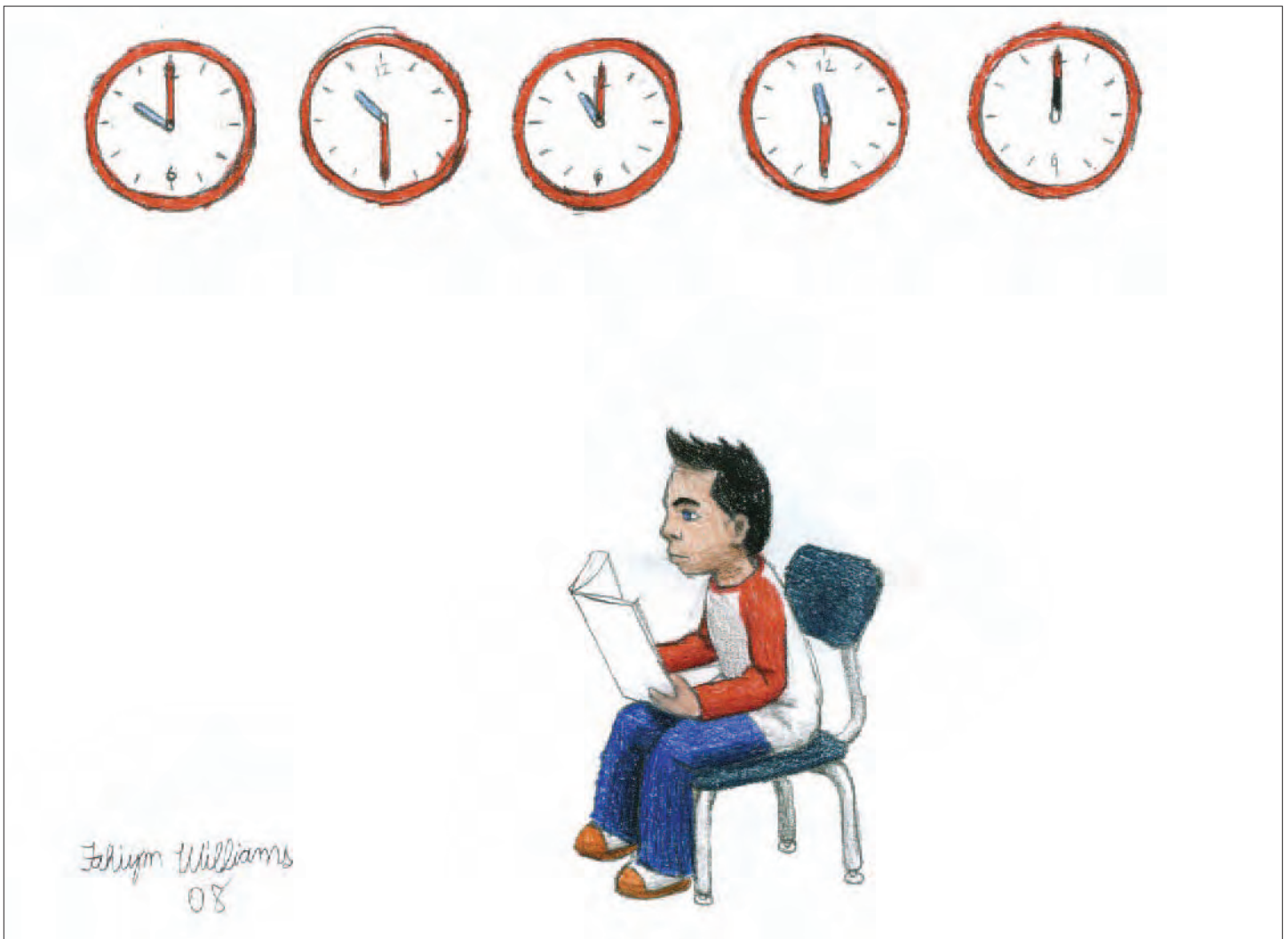
Sara: A lot of people look at me and often times small

children will point at me. I know that they are staring at my bones through my thin skin. People think that I am doing this all for attention but they don't understand how bad this hurts me and how troubled I have become. Strangers approach on the streets suggesting that I just eat a ho-ho and gain weight but it's not as easy as that for me and they don't know that; they can't feel it rotting deep in the confines of their malodorous gut, but I can.

Tim: I often feel out of place when I am out in public. People always act as if they pity me and although I appreciate their kindness and empathy, I feel like I've lost some of my dignity. I feel as if people see my disability and not me. Running used to be a huge part of my life and every Sunday, I would run at least four miles with a group of my closest friends. Now I think my friends feel like they can't talk about running in front of me, because I now use a wheelchair and I'm unable to participate in running. I also am reminded of my differences when I see young kids looking at me wondering why I'm in a wheelchair or why I have frequent muscle spasms.

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JASON



Does a brunette ever apologize to her employer for not being a blonde?

Fabio Botarelli interviews Rich Donovan

The American educational system is increasingly aware that students with disabilities need and deserve the resources and accommodations to keep pace with the rest of their peers. What is often ignored is the sad reality that of the 22 million working age Americans with disabilities covered by the Americans with Disabilities Act, only 38% hold a steady job, compared with 78% of non-disabled employees. Simply put, Americans with disabilities are often second class citizens in the workforce and their means of employment is limited to the menial tasks that plague other minority groups.

This was an obstacle that beset Rich Donovan, a former Merrill Lynch trader with cerebral palsy, when he was

I am motivated to prove myself every day, to appreciate what I am good at and to see my abilities as a reflection of myself.

applying for a job after he graduated from Columbia University. Cerebral Palsy is a disability that can limit speech and movement, yet Mr. Donovan's mental gifts and determination were so apparent that from 2001 until 2008, he was a successful portfolio manager of Lynch's New York propriety trading team focusing on global macro strategies.

In 2006, Donovan founded Limeconnect, a company that matches candidates with disabilities and private recruiters from major corporations that include Goldman Sachs, PepsiCo and Google. How Mr. Donovan was able to lift the bar is an extraordinary accomplishment, yet after interviewing him it soon became clear to me why this man, who could only shake my hand with three fingers when I met him, could firmly grasp a concrete understanding of himself and the world.

1) How did your disability affect the way you learned?

In my generation there were no computers and I couldn't write, so I needed to have someone write for me on a daily basis, including on exams. If I didn't communicate properly to my note taker, I would be marked off for the mistakes that I made. But in mathematics I was able to formulate concepts in my head and solve convoluted patterns with an aggressive drive that I show with everything else in life.

2) Who were some of the mentors that inspired you?

My first mentor was my father. As an engineer he taught me to think of everything as a process. He said that no matter how much you change during your journey in life, never change who you are. Then there was Ronald Reagan. Reagan was able to convince people that free enterprise is not a demon but a positive force in society and while orchestrating this positive message he always did it with a smile on his face. With disabilities it's no different; disability has to be presented in a positive light because no one can relate to negativity. Once that message has been presented, people without disabilities can learn to embrace it and people with disabilities will be inspired to pursue their passions. Jack Welch, the former manager of General Electric, always said "let results speak for themselves and always search for an objective solution." The man was a realist, he told things the way they were.

3) How did you sell yourself successfully at Merrill Lynch?

I was very aggressive. I sold my skills and I never apologized for having a disability. Does a brunette ever apologize to her employer for not being a blond? The point is to be honest with yourself so that you can put yourself in the best life possible. If you know who you are you can sell yourself at any level.

4) What do you think is one of the main problems with how society views disability?

The current problem is that "disability" is seen as a liability that should only be talked about in the doctor's office, but 99% of life happens outside of that office. A person with a disability does not just go from point A to point B. A person with a disability gets to there at a different rate through different means. He or she may go from point A to point Z before backtracking to point B. Your employer does not care how you get there, what matters is that you got there and you are thriving. Therefore it is important to take risks.

5) How does your company help candidates with disabilities get recruited?

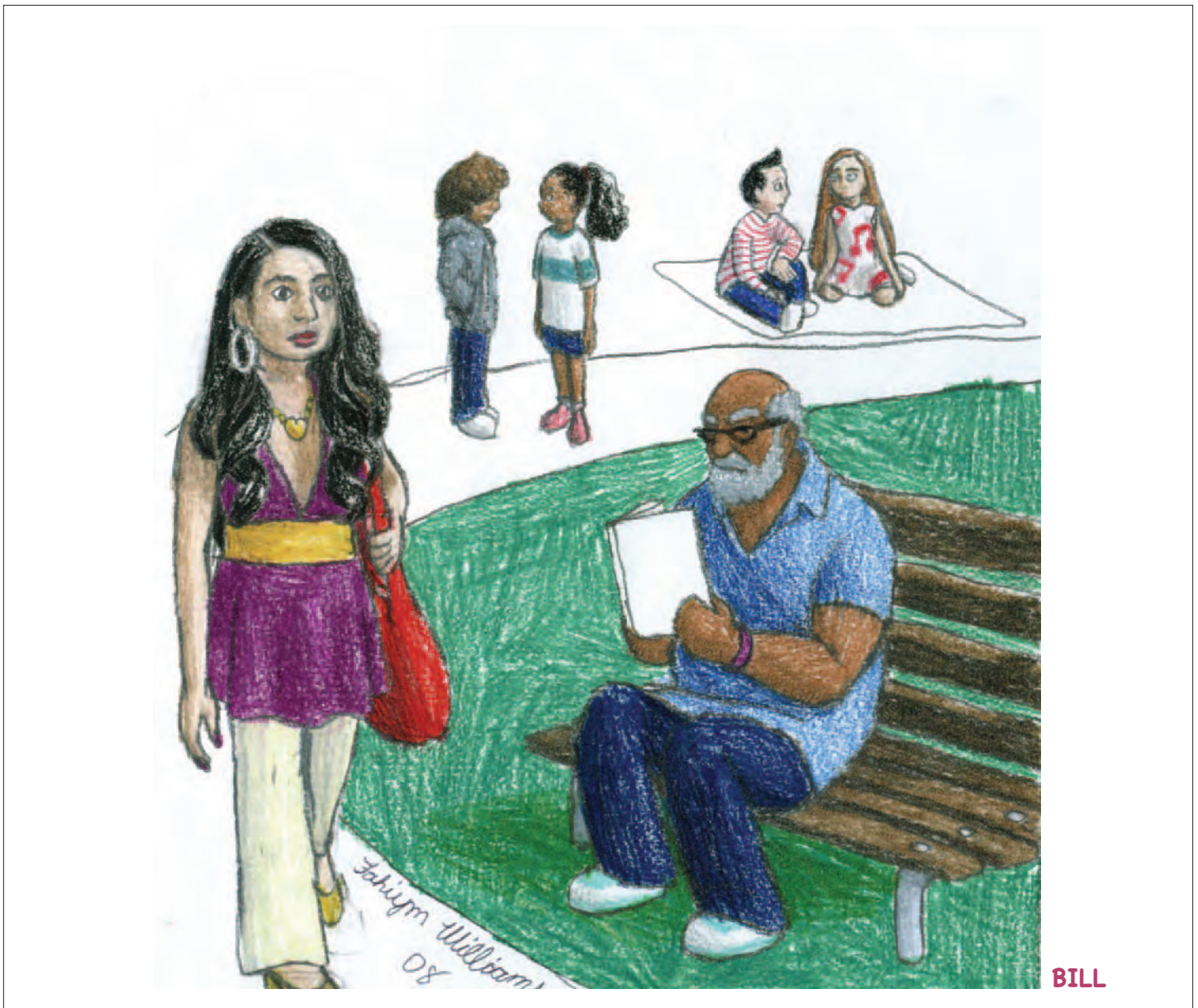
We represent individuals with disabilities by setting them up with recruiters from top corporations. What happens is that these individuals are nervous because their recruiters know about their disabilities and it is the first time in their lives they find themselves competing against the rest of the world at a top level. But after I tell these people to be themselves and sell their skills they end up impressing their recruiters to no end. All of a sudden the frowns turn into smiles because it is in those minutes that these individuals know that they deserve to be given a chance.

6) How did your disability help you succeed?

Whenever I walk into a room people underestimate me. They see me as an awkward person who needs help. But when I get the highest score on a test everyone says “Holy Moly, did he just do that?” You get some added leverage. You have the element of surprise at your command and when people don’t expect something of you and you prove them wrong they start to expect even more extraordinary things from you. In turn, they give you responsibilities. I am motivated to prove myself every day, to appreciate what I am good at and to see my abilities as a reflection of myself. So that if I ever think about putting aside for tomorrow what I could do today, I tell myself this is not the time to delay.

7) What if your disability was not as obvious and you had the opportunity to hide it?

In time disability is going to be cool because my company makes it cool. If you don’t have a disability there is no way my company can help you. Eventually Americans with disabilities will enjoy the benefits that we are now giving to minorities and women. But on a personal note, it would be safe to just tell your closest friends and your teachers so that you get the right accommodations. You could also have a little fun with some “shock value” by working hard and outperforming everyone on an exam and then tell them that you have a disability. Just remember to keep a touch of modesty. After that people are going to seek help from you because people like to study or work with the person who promises results. But like I said it all depends on how well you know yourself.



BILL

Four Pairs of Moccasins...

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What annoys you most about what people without disabilities think about people with disabilities?

Jason: Everyone feels sorry for me and always offers so much help. It doesn't make me feel better; it makes me feel worse. I want to help others for once. I don't always want to be the person being helped. I love math and I feel so angry when people try to help me with a subject I am very good at. Just because I have dyslexia doesn't mean I need help with absolutely everything. Sometimes when I am asked to read in class I begin to stumble over words and become confused, instead of letting me work out my own problems other students will blurt out the words before I have even begun to try to figure them out. I always feel so annoyed and frustrated by this kind of help.

Bill: The most annoying thing that I can think of about people without disabilities, and their opinion(s) about people with disabilities would have to be that they believe that we're not worth getting to know. They think that we're just a bunch of people who are stupid, uninteresting annoyances. They don't think much of us.

Sara: It bears repeating that most people don't know anything about eating disorders and offer advice that is silly or hurtful. Some of them, those with a few extra pounds on, even say they wish they were me!

Tim: I hate it when people try too hard to make me feel included; if I want to do or say something I can speak up for myself. Sometimes people act overly sensitive around me as if I'm going to have a break down if one wrong word is said. Sometimes people don't talk to people

who have a disability because they are afraid of doing or saying something offensive. Friends I had before the accident now act as if I'm a different person because of my disability. What they don't realize is that I'm still the same Tim I've always been. And lastly, I hate it when people say I look healthy or good, when clearly I'm not.

Why do some people make fun of people with disabilities?

Jason: I see people smirking and giggling over my troubles with reading, my dyslexia. My teacher says that they are just insecure and nervous about making mistakes themselves. A lot of people are just bullies and will push around and bully anyone, with a disability or not. They always pick on people who seem to have weaknesses and this seems to make them feel better.

Bill: I'm not exactly certain about that one. Heck, I'm just as guilty for making fun of people myself. Disabilities are different and it's a whole lot easier to crack a joke at someone's expense than to actually take the time to understand the other guy's side of the story. I do know, however, that as long as it's okay to be the brunt of the joke, people with disabilities will never be able to fully achieve total acceptance in the world.

Sara: Many people ridicule others with disabilities simply because they don't understand the person's disability. Other times, less often, people who are uncomfortable with their disability will poke fun of themselves; apparently trying to 'make light of the situation.' Acting that way about your own disability encourages others to demean you as well. It's not that you can't laugh at yourself once in a while but if you only "play the clown" about your disability, you're setting the stage for others to do the same.



BILL



Tim: People may laugh at me or make fun of me because I'm an easy target. Sometimes my muscle spasms cause me to knock over things when I'm at work at the grocery store. People also make fun of me because I have random bursts of crying or laughing during inappropriate times. Sometimes children laugh at me when they see my younger sister helping me in and out of the car. The reason why people make fun of me is because they believe I am not "normal".

How have you modified your activities, goals, dreams, and hopes because of your disability?

Jason: I try to make up for my dyslexia through sports. Coaches sometimes tell me I am too competitive, but recently I have developed a love for running. I like being able to run so fast I leave everyone behind. At the end of the race I hope to feel the weight of a gold medal around my neck. Dyslexia has given me the fuel and running has become my main physical activity. I substitute running fast for reading fast. When I won the 800 meter race, one kid

said that people always said I was slow, but that now he realizes I am fast at other things.

Bill: When I was younger, I honestly believed that I was doing the best I could with what life had given me or you could call it what life forced on me. In those days, goals, dreams and hopes were way beyond me. I survived and I coped, but I didn't dream. However, looking back at my experience, there is a lot that I wished that I had tried. My life could have been a lot more than simply coping. I could have had hopes and goals.

Sara: I recovered from anorexia nervosa fourteen years ago; I can't imagine what I was ever thinking when I was that young. Unfortunately, the permanent damage my body underwent from months of near-starvation has left me unable to carry a child. I realize that I've lost one of the most important gifts that life offers. But I have modified my dreams and my name is now slowly surfacing on the (so-far 2 year) adoption waiting list.

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No Miracle Diet

Neil Botticelli

There was a rig, some foreign tubular instrumentation, wired throughout my nasal cavity and then extending down to my stomach. I knew of its existence even before I opened my eyes; before I saw the blue-uniformed figure standing in front of me. I attempted to reach for, and remove, the yellow toxic tube from my nose although I could not free my arm from the alligator's sudden grip. I sank into the bed. I peered up and became frightened by the blue figure's seemingly calm stare. I screeched a tune which vibrated the machines around me.

I woke up some days later, restrained to a hospital bed without knowledge of what had happened or how I'd gotten there. When I asked her, the nurse seemed surprised at my inconsistent memory and began reading from her clipboard, asking simple questions like "What's your name?" and, "what color is this?" The odd questions continued. "Do you know the date?" the lady in blue asked. "December 11th, isn't it?" I asked back; she drew her brown eyes up from the clipboard, gazing into my own with a cold stare. The nurse paused while she marked her paperwork. My voice shook violently as I repeated my question. "It is the twelfth, isn't it?" I anxiously asked. As she began stepping backwards from the room, the nurse told me quietly that the doctor would be in shortly.

I've always taken pride in caring for my body and appearance although some say that same pride is what pushed me into this disorder in the first place. You've got to try to understand. Prior to the past eight months, I had never taken, or even considered, such drastic weight-loss measures.

As a matter of fact, I'd always thought that eating disorders were 'fake' disabilities; I'd just always thought that people claiming to have eating disorders were looking for attention or for pity or for something. I'd known a girl with bulimia some years back; the last thing I ever said to her was, "eat a ho-ho." Her name was Angela, and she died a few months later. I wish, for the life of me, that I could take those last words back. I had never known that eating disorders are real, and I couldn't have ever imagined the pain Angela must've experienced; until the day when I almost died from anorexia nervosa.

It began the fourteenth day of this past July, according to my nutrition journal, the first day of the Dr. Smith's miracle diet. The diet was supposed to be a team effort between my girlfriend Jen and myself. We were trying the team-support method; both of us had a food journal to

monitor nutritional intake and we'd agreed to call each other for support. It only took about a week before Jen phoned me to explain being seduced by some chocolate cake. I tried toning Jen's guilt down, "It's okay though," I told her, "Because now I don't have to feel so bad when I cheat." Honestly, though, I had no intentions of cheating; in one week I dropped six pounds, every one of which made a noticeable difference.

The thought of Jen with her chocolate cake upset me; she could have had the same results as me if only she kept her commitments. I wanted to lose an extra few pounds to make Jen jealous. "When she sees me, Jen's going to wish that she never bit into that cake," I remember saying to myself. I decided that I'd reduce my entire daily values by seven percent. The frustration came about six days later, when I made my weekly average and found that, in the past seven days, I'd lost almost four pounds; only two-thirds of the week prior.

I phoned Jen, curious of her results. "You've got to try this new soy-bread," Jen told me, "It's carb-free; I've been eating it all week, it's not too bad." I wasn't really paying her much attention; instead I was re-calculating the figures in my journal. "So what was your total for last week?" I asked. Jen's voice shot up enthusiastically, "I dropped six and a half pounds! After eating that cake I was a bit nervous; but it worked out, I guess." And then Jen went on, asking, "How about you, Sara, what was your total?"

"Uh," my brain froze for a moment, "Seven pounds!" I said, trying to sound enthusiastic. "Whoa, you go girl!" shouted Jen. I wrapped the conversation up by congratulating her and told her we'd go out for lunch or a walk soon.

I couldn't figure out how Jen and her chocolate cake managed to lose more than me. I opened my journal and made some revisions for the following week, subtracting a whole ten percent per daily value. I had also decided to begin a yoga-style workout regimen to help eat away some calories.

When I phoned Jen, at the end of that week, I learned that she had, again, lost more than me; she dropped another six and one-half pounds where as I had lost only four and one-half. "So

whatever happened to lunch last week?" Jen asked, "We should go out tonight, I heard there's going to be a concert at the Riverside." I came up with an excuse quickly, "I'm actually babysitting my nephew tonight," I told her. I was afraid, if Jen saw me, she would suspect I'd lied to her.

I realized that, after just one month on the Smith

*"I'd always thought
that eating disorders were
'fake' disabilities"*

SARAH



Miracle Diet, I was almost ten pounds heavier than Jen. I felt awful for lying to her, but I really couldn't stop myself. "It's been awhile," claimed Jen, during our weekly phone call, "you need to stop being busy and make time to enjoy life!" she suggested. I agreed with her, ending the call with another lie. This week I was eleven pounds heavier than Jen. Unacceptable!

August the eighth was my last entry in the journal, I didn't need it anymore. To 'cut corners' I decided to fast for a week or so. My logic: if eating light doesn't do it, then eating nothing will. I missed going out for walks, and having the occasional lunch with Jen but I couldn't let her know I had lied.

My stomach, for the first few days, was all cramped up; painfully requesting to be filled. After ten days without food, I was finally beginning to show some progress. Six pounds were gone for good and the digits on the scale were finally becoming visible.

Just as I was approaching my goal, weird things began to happen. I came home after an intense yoga workout and noticed that my house had been broken into; oddly,

though, nothing was missing. My dishes were disorganized and my furniture was even moved. Cups and plates were placed randomly throughout the kitchen; the sofa and television had been rearranged. And then the phone rang.

"Hello," I demanded. "Sara!" the voice said, "I've been trying to get a hold of you for weeks!" It was Jen. "How are you?" she asked. I held a stern voice as I asked, "Were you in my house today?" Jen is the only person in the world with a key to my house. "No, silly; I work all day every Thursday." Jen claimed, "I just got out a few..."

I didn't let her finish, I knew she was lying to me. "Don't lie to me, I know you were here!" I shouted through the line. "Don't ever touch my stuff again, not ever!" I screamed. "But, Sara," began Jen, with a falsified tone of confusion, "what do you mean, I was..."

Her excuses were making me angry and I interrupted her again, "You were nothing, Jen," I told her, "I want my key back immediately and don't ever call here again!" I yelled, as I smashed the phone back on the receiver, ending the call and finally eliminating that pest.

By October I was skinny but not skinny enough. I'd lost

Continued on page 18

Blogging toward disability awareness

When editorial board members met in March 2008, our writing coach, Tom Corrado, suggested we try some exercises in flash fiction. Tom has worked with us over the years, tried to help us hone our writing skills, encouraged us to learn from one another in our group editing sessions, and is always the first to congratulate us on a job well done. Still, he never fails to find ways to challenge us to become better communicators and to try to engage our readers in new ways.



Flash fiction or micro fiction is simply a style of writing that forces the writer to say a lot in a small amount of space. It is sometimes limited to a specific word count but it's always shorter (and less daunting) than the usual writing assignments our English teachers give us. Pressed for time at our writing workshops it appealed to us to try this new approach.

Practicing writing flash fiction pieces started us thinking about how to interest our readers in improving their understanding of disabilities through short, written pieces that popped off the page and grabbed their attention. Getting high school students to read about disabilities is, after all, a heavy lift. We might reach our goal of bringing students with disabilities and students without disabilities closer together if we connected them through a hypothetical blog we called eBility. Each of us got an opportunity to respond to some blogger's questions. Here's how it turned out:

Our E-Bility blog

My friend wants me to try down hill skiing but I'm a little scared. What should I do?

Go skiing. If you don't like it, go to the lodge and have some hot cocoa instead.

I think anyone is scared of anything that's new. I say "try it."

With the courage and support of a friend, you can accomplish the unimaginable.

I think you should just try it once and see how you like it.

If you don't want to, I understand.

Try it!

Try down hill skiing because you will like it. Have confidence in yourself. Know that you tried something new!

You only live once. If you can do it, do it!

I think you're justified in being scared. But if it works out, you'll be justified to challenge yourself further.

I have a hard time studying for tests and next week I have a real important test that I don't want to fail. When I try to study I get distracted a lot – can you suggest some tips or strategies I could use?

Maybe setting aside some shorter periods of study time each day at the same time...a fifteen minute session on Mondays at 4:00 and another one later in the day.

Find a way to center yourself. If you find yourself in such a situation, seek a place of comfort if you want results.

Get help from your parents. Ask them to tell your siblings to keep it down or stay after school with a teacher and study there.

Avoid distraction. Try a little harder. Use a graphic organizer to keep you focused.

Put yourself in an environment where you know you can focus the best. If that means locking yourself in your room or using a study room at the library, then go for it. After that, all you can do is buckle down and try your best.

Turn off the TV and tell your little brother to go outside. Close your bedroom door and relax. Study for 20 minutes and then reward yourself and watch some TV. Do this for a

few days and you'll be fine.

I suggest changing the scenery a bit. Try studying at the mall or at a bookstore. From personal experience I found that not only was it easier to concentrate but the results of studying in different places are interesting.

My friends and I went out for pizza last night. It was a lot of fun but there was so much noise in the pizza place that I had a tough time hearing what everyone was saying, even when they were talking to me! (Yes, I was wearing my hearing aids!) I decided that I would play along, so I made believe I was following the conversations. I laughed when everyone else laughed, etc. I felt like a phony! Am I?

No, everyone wants to join in even if they can't for one reason or another. Maybe next time explain that it's too loud. You are not a phony!

Absolutely not! You cannot call yourself a phony because of a small misunderstanding like that. I believe there are many different ways of hearing or being heard.

I don't think you're a phony. There are some things in life you can't control!

Well, yes, not to be rude, but you were pretending. There is nothing wrong with a hearing aid. We all have different strengths and weaknesses. Speak up!

No, you're not a phony. Next time you are with your friends in a noisy place you should tell them you can't hear. If they're true friends, they'll understand and go elsewhere.

PSH! No!

You have a right to talk to and hear from your friends. Have some confidence!

No! You're doing what every one does – adapting in some social Darwinism sort of way. It's all the same – pretending to hear your friends' conversation or pretending to agree with what they are saying.

No, you're not a phony! You were in an awkward position and did what was right at the time. Next time get pizza delivery at someone's house!

There's a new kid in class who wears really thick glasses. He can't see very well. He sits in the front row in all of his classes so that he can see the board. He told me that he likes to play chess, and asked if I liked to play. I like chess a lot, but this kid is weird. I think I'd feel funny playing him in chess. What should do?

I think you should challenge him to a game. It's always great to meet new friends and sometimes the weird ones are the most interesting (in my experience).

How is it weird for a kid to wear glasses? Chess is chess – whether you're playing with your best friend or a total stranger. Sitting in the front row is not weird either. If you think it is, maybe you're the weird one!

Thick glasses are hip! Stop being square. Play chess. Try it out. See how you feel AFTER you get to know him.

I am in chess club too and I love it. Play chess with him. Think of him as weird in a good way!

Try to understand that he can't help his visual problems and try to ignore it. Play chess with him!

“Just because he can't communicate the way you do doesn't mean he has nothing to say! He just says it differently.”

You shouldn't judge a book by its cover or a person by his eye wear! He probably doesn't have too many friends because he's new. Give him a chance! He could be a great guy.

Go play chess with him and see how it goes. He's new. Give him a chance.

Play! It makes someone feel good about himself knowing that there's a person who wants to connect with him. It doesn't take a heart of gold! Just try it.

Everyone should try something new. Even if you think you might feel awkward, just try it. It can't hurt. Play chess. You only think he's weird because you don't understand. What is strange or foreign to us sometimes makes us afraid.

I hate reading! I have 150 pages to read by Monday. I'm a junior in high school and all I want to do is pass English, get out of here, and start my life. Any ideas?

Try a book on tape!

Reading can become quite tedious when it involves a grade. Knowing what your goal is – that's what you should focus on.

Just read a little bit at a time and you should be fine!

We all have different things that we don't like to do but we just have to try hard to get through them. Maybe you could find a friend in your English class and read aloud to each other to get through parts of it.

You have to read to succeed in life! Start anew!

Deal with it or it will only get worse. Just do it. Spread it out. Pace yourself. If you want to get out of high school, you have to read your way out.



Personally, I love reading. If all English class was reading, then it would be a blast! I understand reading may be hard for some so go to sparknotes.com and read the summary of the book. Then, go back and read the actual book so you understand it better.

Reading and writing are SO critical for your future! Talk with your English teacher and get some suggestions.

My cousin uses little pictures to communicate. He can't say ONE word! If I want to talk to him, I have to use his pictures. I hate it! I try to keep it simple. I really can't talk about stuff I'm interested in. So I mostly just sit in silence when I see him. What could a kid like that have to say anyway!

Just because he can't communicate the way you do doesn't mean he has nothing to say! He just says it differently.

I'm not sure what he would say with pictures but "listen" to him.

He is showing you that he wants to communicate with you even though he has a hard time doing it.

What he has to say may surprise you? He probably goes through a lot of hard times with his disability. Listen up.

I'm sure he has a lot to say and I suggest you let him say it! Come on. Is it really that difficult for you?

I think you should try. My mother communicates with so many people with different disabilities and she has learned a lot. A lot more than you have to say apparently!

Everyone has something to say. Maybe he's a great artist!

My brother returned home from Iraq where he was wounded. He seems angry most of the time. He doesn't seem like my brother anymore. Help!

TBI can drastically change the moods and personalities of the people affected. Your brother may never be the same and that is a hard adjustment for you. Get used to it and try to understand.

Do you really think that being angry with him will make him snap out of it?

He's not angry at you! He's just mad because he has TBI and he has to do things differently now and it's hard.

Give him support and a little space. He's been through a lot but he'll come along.

Try to expose the positive factors of having a brother. He's the same underneath it all. Pay attention to the fact that he's home!

Take one day at a time. Maybe just like him as a brother who has been sorely missed and altered. There are no easy answers.

Make him a photo album of memories of you and him before he went to Iraq. Maybe it will remind him of some good times.

I'm a freshman in college. I sometimes hear voices, and have strange thoughts. I'm afraid to go to the health center and tell them, because they might have me expelled. What should I do?

Seek the advice of a medical professional. Your records are confidential meaning that no one will know. There are diagnoses that you need a specialist to help you cope with. You obviously have some serious issues. If you don't get help soon you might do something because of your illness and that would get you expelled. Who knows? The health center may have the answers for you!

Continued on page 16

The transition from school to work

Not a one act play

At the March 2008 writing workshop, editorial board members learned more about transition planning, a process available to students with disabilities that enables them to play an important role in planning for their adult lives. Through the transition planning process, students, parents, school district staff, vocational counselors, and people from the business community get together on a regular basis to brain storm ideas, discuss possibilities, identify strengths and interests, and evaluate and assess possible routes to achieving the student's adult goals. Planning encompasses continuing education or training, employment, living arrangements, and social and recreational options.

The movement from high school to adult life takes careful thought on the part of many individuals. Students need to know how to advocate for themselves, talk about how their disability might affect their adult lives and begin to learn how to make decisions for themselves. Transition planning takes time.

Editorial board members participated in a mock transition planning meeting. Given the bare bones of a script, eight students gave an entertaining and educational performance.

Check out the script with discussion points if you want to learn more about how to prepare for a meeting yourself at www.nysut.org/connect.



Struggle Leads to Glory

Jose R. Pororreal, Jr.
Eleventh grade
Greenburgh Eleven School
Dobbs Ferry

I am lost in a place called Life.
Confusion clouds my vision and thoughts.
Hate and anger run through my blood at a rapid pace.
I am impatient for what is to come.
Struggle leads to glory.

I am cluttered with pain and disaster.
I feel unwelcome and disturbed.
Rage passes through my body like thunder.
I am disabled
To accept and understand myself.
Sometimes I lose hope but still I try.
Struggle leads to glory.

With encouragement
I will overcome obstacles thrown my way.
Everyone struggles.
Struggle leads to glory.

**THANK YOU TO NYSUT,
OUR NEW SPONSOR.**

*YOUR SUPPORT ALLOWS US TO CONTINUE
THIS NEWSLETTER AND THEREBY PROMOTE
AWARENESS AND UNDERSTANDING AMONG
THE YOUNG PEOPLE OF NEW YORK.*

nysut
A Union of Professionals

Blogging...

Continued from page 14



If they expel you because you do the responsible thing, then go elsewhere for an education!

Sometimes what you think may happen may not be what really happens. Maybe the school's health center will help you.

Why would they expel you? Why wouldn't they give you help?

Get help from someone outside of school if you're worried about being expelled.

If you are worried, then definitely get help. They won't expel, they'll help. Mental illness is not that unusual and they have experience with helping people like you.

I went to the mall with my new friend. He has CP. When I introduced him to a group of my friends, I noticed that some of them were making fun of him. What should I have done?

You should have explained to your friends making fun of him what CP is and informed them. I think that is a better response than getting angry with them.

You should have stood up for your new friend. It's not his fault he has CP.

Tell them to knock it off and then walk away because they are not your friends!

Take your friends aside as soon as possible and tell them that CP is not a laughing matter. He's just like them.

Step up to the plate and defend him! You have that responsibility!

Do what you would like him to do for you if the situation was reversed! Stick up for him.

Subtly make comments about some cool or interesting things about your friend to help them see that laughing at him is rude.

There's this kid in my class who always looks sad. I wonder what he's thinking about. I bet it's bad. I wonder if he is going to shoot somebody or blow up the school.

Sadness is a normal human emotion. Everybody has been sad at one point or another. Be a friend. Tell him a joke. Listen to him.

This is a bit of a leap but there is always a way to learn more about a person and what he's thinking. Talk to him.

Talk to a teacher. Talk to him.

Get to know him. If he doesn't have many friends, give him one. Make him happy.

Try talking to him. Being friendly to him might make him happier.

Ask him what's bothering him and be nice to him. If there's something on his mind, ask if you can help.

If he's depressed, get to the source. Ask him about himself.

Depression is more common than you know. Don't be afraid. Help him by being a friend and talking to him.

Authors: Neil Boticelli, Fabio Botarelli, Austin Crittenden, Shane Crittenden, Bridget Ford, Cassie Ford, Mitchell Goliber, Rory Harte, Alexis Kim, Valoree Lisi, Robbie McNary, Joseph Montemaugh, Stephen Schubmehl

Looking for additional information on disabilities?

Tourette syndrome

www.tsa-usa.org

www.tourettesyndrome.net

www.ninds.nih.gov/disorder/tourette

<http://faculty.washington.edu/chudler/ts.htm>

Anorexia Nervosa

www.nationaleatingdisorders.org

www.nami.org/helpline/anorexia.htm

Traumatic Brain Injury

www.ninds.nih.gov/disorders/tbi/tbi.htm

www.cdc.gov/ncipc/tbi/factsheets

Reading Disability

www.ncid.org/content/view

www.ldanatl.org

Four Pairs of Moccasins...

Continued from page 9

Tim: After my accident I had to accept that I'd never be able to run again. At first I was depressed that I could no longer exercise the way I wanted to, but I changed my attitude and tried weight lifting. My life long goal was to be the CEO of the company I used to work at, but now that goal is no longer realistic because of my TBI. My new goal is to learn to accept my disability. Although I still suffer from bouts of depression, I am trying to be more optimistic about my situation.

What are some things that you've done that would surprise people who don't have a disability?

Jason: I made a video game that was a spin off of a short story project we were assigned in school. It was really difficult to write the story but my mom rewarded me by encouraging me to create the game and by paying a tutor to help me with the reading part of the game. Everyone was really surprised by the complexity of it.

Bill: I'm not sure if there is anything that would surprise anyone. I kind of live by routine. The only thing that really comes to mind is me singing in the choir. There I don't have to worry about screwing anything up. You never hear one voice, just the entire choir. However, for someone who's considered himself a wallflower, I guess it's surprising to be standing up there belting out a song.

Sara: Most of my friends were extremely surprised to hear of my nearly fatal disorder; Jen was astonished that I had become anorexic; she almost didn't believe me at first. Jen told me that with my diet journals, filled with Dr. Smith's nutrition info, and with my sincere dedication to living a healthy lifestyle, it should have been near impossible to become ill with anorexia. Many of my friends and family questioned this as well and it's honestly so hard to explain to them that I don't know how it happened. I guess the most surprising thing about my disability is that I have it.

Tim: Although my life seemed like it was over after my accident, I changed my attitude and began to appreciate my accomplishments. Determination that I didn't know I had drove me to start lifting weights for my upper body. I realized my sister and her husband began respecting me more which helped motivate me to lift even more. Eventually I entered a Wheel Chair Warrior competition. Although I didn't win, I felt proud and respected. When people learn I accomplished this with my disability, they act very surprised. Learning to accept my disability, allowed me to accomplish many goals.

Is there anything else you'd like to tell us about yourself or about people with disabilities?

Jason: I may be seen as a loner, however, that does not mean I don't want to be accepted. I know by now that I am different, always looking from the outside in. Having a

disability can be lonely but I have grown as a person and I have discovered how to show people the other sides of me.

Bill: I'm not one to speak on behalf of others. All I can do is speak for myself. I'm not afraid to tell people about my disability anymore. At my age, there are a lot more important things to worry about. I don't care if anyone thinks I am odd anymore. I have Tourette's. I'm 72 years old. I can't move as well as I used to. I can't stay up past 9:00 PM anymore. My eyesight is going. I'm pretty much like everyone else my age now.

Sara: I want everyone to know that recovering from anorexia is far more difficult than picking up a ho-ho; it almost cost me my life before I was able to begin recovering. I want all of you to think about me and remember that somehow, in the midst of confused starvation, I honestly thought that my life wasn't worth that ho-ho; and so my friend, remember my story and be aware that you, too, could have a disability that you never thought you'd have.

Tim: Although my life has drastically changed, I now realize that living with a disability is different than many may perceive. There is a misconception that people with a disability have no control over their lives. I have learned that although I have a disability, my disability doesn't totally control me. I could have let my Traumatic Brain Injury ruin my life, but I decided to be optimistic, change my goals, and not let my disability define me.

Authors: Neil Boticelli, Fabio Botarelli, Austin Crittenden, Shane Crittenden, Bridget Ford, Cassie Ford, Mitchell Goliber, Rory Harte, Alexis Kim, Valoree Lisi, Shane Messmer

A DISCLAIMER: Most of the editorial board members have been working on the newsletter for many years. They have participated in presentations to the group by people with disabilities and they have taken part in activities designed to teach them more about disabilities. They have read and researched and held discussions about disability. As the result of their experiences on the editorial board they are committed as a group, and as individuals, to helping others better understand disabilities. Many of the board members have disabilities themselves or have siblings and friends with disabilities. As editorial board members, they promote positive attitudes and "people first" language. They know that simulating a disability is not the same thing as actually having that disability and they don't speak for all people with disabilities or for any individual person with a disability. By taking part in this writing exercise they hoped to learn more themselves and to help others learn more about how walking in someone else's moccasins can enhance understanding and improve the way we relate to the diverse group of people who make up our world.

No miracle diet...

Continued from page 11

fifty pounds. I tried eating a little although the feeling of food, as it hit my stomach, made me nauseous; each time I tried, I threw-up.

I began to notice absurd patterns I'd never observed before: at about the same time, every day, a mysterious man would stop and tamper with all the mailboxes. The telephone would ring with random voices, imposters and stalkers, sometimes speaking foreign languages. And then I heard the footsteps upstairs and I realized the crazies were intruding so I put my shoes on and ran, as fast as I could, from my own home.

The chaos, outside, had gotten out of control; I was quick to notice the Earth's abnormal rotation. I watched the sun rise above my head and set below the horizon, in about an hour. I looked down at myself and realized there was fat consuming me; it was under my skin and in my veins. And when I tried shaking it off, my skin flapped and sagged and began dripping from my bones which terrified me and so I ran and I screamed for someone's help but it didn't come fast enough because I fell on the ground and the fat began eating my body whole and then I was reduced only to a skeleton.

I woke restrained to a hospital bed without knowledge of what had happened or how I'd gotten here. After speaking with the doctor, I learned that I was in recovery. The doctor spoke very sternly, "Sara, you've suffered trauma and muscle degradation," he began, "and unfortunately, one of your kidneys and both of your ovaries have failed due to nutritional deprivation." I was confused, "Nutritional deprivation?" I asked, "How?" The doctor looked up to my eyes, "Sara," he began, "today is the seventh of February; the police found records in a journal in your apartment which indicate that you stopped eating months ago." I met the doctors stare with dismay. "You've been very weak and nearly unconscious for a long time," the doctor said, "Is there anyone you would like to call?"

I picked up the phone and dialed Jen. "Jen, this is Sara," I began, although I was interrupted immediately, "Why are you calling me?" Jen asked, in an anxious tone, "I don't have anything of yours and I certainly don't want anything to do with you!" she screamed, "Just leave me alone, Sara."

And then Jen disconnected the call with a loud click. I didn't know how I lost my best friend. I remembered what the doctor told me. And I realized I'd never be able to carry a child. And so I lifted the sheets. And I realized the doctor was not lying. I couldn't understand why I wasn't dead. Because I was only bones covered in thin skin.

So I closed my eyes and thought about Jen and our walks through the park and lunch and the concerts. And that was when I remembered the last thing I ever said to Angela. And a lump grew in my throat and tears exploded from my eyes; and for the first time, I knew that an eating disorder is not a fake disability. Accepting that fact was the most important thing I would ever do.

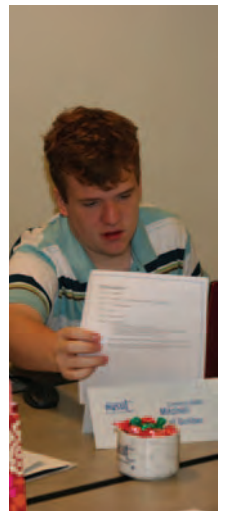
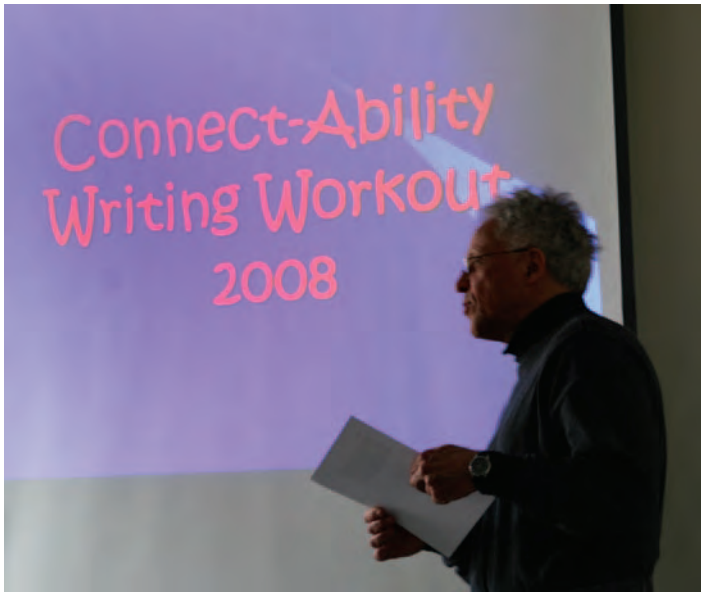
Connect-Ability

- Address your own responsibilities.
- Defend your own opinions.
- Stand for the knowledge you have obtained throughout your youth.
- Use your Ability ... to Connect.

It's hard for me to say

Ashley DeCamp
12th grade
Myers Education Center
Saratoga Springs

It's hard for me to say
But I have a few disabilities of my own.
I never wanted to do anything when I was younger
But sit and cry at home.
I have to live everyday
With bi-polar, ADD and depression,
Sometimes I feel
Like I'm going into recession with my depression.
There is one person
In my life
Who made everything
Seem so right.
My boyfriend Ethan
Made me get over my fears
By having his shoulder there
When I shed my tears.
I'm 19 now
And loving life.
Nothing ever seemed so right.
Living with disabilities
There's no need to feel ashamed.
You and I are just the same.



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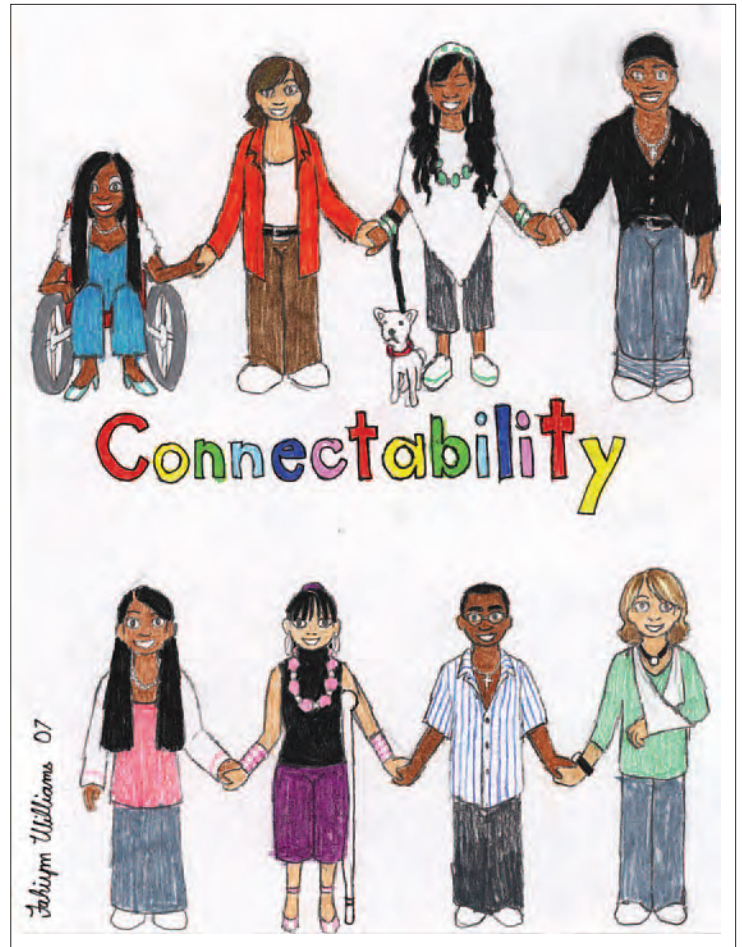
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WE NEED YOUR HELP

We are looking for students in grades 7-12 who are interested in writing essays, fiction or poetry related to disability.

We want this newsletter to connect students with and without disabilities so that we can learn from one another, make friendships and participate in an inclusive environment.

The *Disabilities Awareness Newsletter* has been in existence for 12 years and is sent to high schools across New York state. It is edited by high school students who serve on its editorial board. It is published each year, widely distributed and read by students, teachers and parents across the state.

If you or a student you know would like to learn more about how to participate in this exciting project, contact Terry McSweeney, NYSUT assistant in Educational Services, at (800) 342-9810, ext. 6047 or at tmcsween@nysutmail.org.



Behind the scenes: Neil Boticelli, Writing Coach Thomas Corrado, Austen Crittenden, Shane Crittenden, Bridget Ford, Cassie Ford, Mitchell Goliber, Editor Rory Harte, Alexis Kim, Valoree Lisi, Joseph Montemaugh, Advisor Catharine McHugh and Advisor Terry McSweeney. Not pictured: Art Editor Fahiyim Williams, Fabio Botarelli and Claire Littlefield.

www.nysut.org/connect