The greatest vision on the face of this planet lies not in our eyes but in our minds. It is only through education that this vision can be obtained and be used to improve our future. Believe it or not, education does not reach everyone by one method of teaching. There are those who need to be taught differently. There is no better example of this than the movie, “Educating Peter.” This remarkable documentary, which won an Academy Award in 1993, tells the story of how a boy with Down syndrome proved that he was able to learn along with the other students in Gilbert Lycos Elementary School in Blacksburg, Virginia.

During his first week of school Peter was seen as a taciturn character, with thick glasses and in a state of continual perplexity. Every day he peered around the classroom, lost in thought, and had difficulty grasping the material. However, the real trouble was that his peers kept their distance from him, not knowing who he was and why he was in their class. On top of this social segregation, Peter had trouble expressing himself and had a tendency to push and strike his peers for the sake of attention. Mrs. Stalling, his third grade teacher, noticed Peter’s troubles and, undertook the difficult task of helping Peter fit in. Approaching the issue with perseverance and patience, she made Peter a part of the class and encouraged her class to cooperate. When Peter pushed someone or attempted a risky escapade, she reprimanded him. When he did something right, she cheered him on.

continued on page 10

Eighty percent of people with autism are males, which begs the question: is autism an extreme reflection of the male attitude and brain? This is a new theory that stems from the notion that women are naturally more attuned to emotions, while men are prone to more tangible things. It seems that the average male, when compared to the average female, is less capable of reading and understanding an individual’s emotions. However, males are often more capable of comprehending the mechanics of a concrete device or system. It is from this premise that a new theory concerning the origins of autism has arisen. Autism hinderers a person’s social skills, which makes it even more difficult for someone with autism to analyze feelings and decide what is appropriate behavior. These characteristics are strikingly similar to the difficulties with which the average male struggles. An individual with autism often has an astounding grasp of concrete things, such as phone numbers, dates and details.

continued on page 10

Features

3 People First Language
4 A Teachers Perspective
5 A Man on a Mission
6 Runaway Train
8 Dealing With Deafness
9 Entering the World of Sound
11 On the Outside Looking In
12 Living in the Real World
13 Why I Can't Read
14 Life With Ambrose
15 A Mother’s Love
16 Learning to Live Without

Poetry

4 Hands
5 A World Apart
12 The Girl
The world of disability advocacy is one that is often overlooked by the American public. With the passage of the Americans with Disabilities Act in 1990, many heralded it as a complete victory in the last battle for full citizenship and full protection under the law. Though the ADA made huge strides towards tearing down the walls of ignorance that have interfered with the lives of those with a disability, there is still a great deal to be done. Legislation can smooth the way but positive attitudes and knowledge of disabilities will enable us all to live in an inclusive world.

In its eighth year of existence, the Disabilities Awareness Newsletter continues to promote the ideals that serve as the bedrock for disability advocacy. The Newsletter’s purpose is to advocate for students with disabilities while raising awareness in America’s schools about the harmful names and detrimental attitudes that can stigmatize and devalue an individual’s life. By featuring articles covering a vast expanse of topics, this year’s Newsletter continues to try educating students about disabilities. In working with one of the youngest staffs we have ever had, it was the mission of the Editorial Board to mold these young writers into weathered advocates. In the years to come, these individuals will provide the backbone of the Newsletter, and continue to contribute to the disability advocacy movement into the 21st century.
In school, teachers who see students as people first have higher expectations for their students than teachers who focus only on the disabilities of their students. I know because I have been in both types of classes.

Over the years, people with disabilities have been called a number of names like retard, invalid, and dumb. You can still hear these terms being used today. The better way to refer to people with disabilities is to use people first language. People first language puts the person first and the disability second – an easy concept when you think about it.

People with disabilities are people! They happen to have a diagnosis that gives them a label. If people are only called by their label, it limits their opportunity to be seen as a human being with potential. My name is Sarah, but if you only knew me as “Cri-du-chat syndrome,” chances are you would have a negative view of me. My friends who happen to have autism or Down syndrome are frequently bullied because other students have learned the general characteristics of these disabilities, and use these characteristics to tease them. They don’t know that autism and Down syndrome are different in every person. They see the label and never get to know the real Jonathan or the real Steve. The most common name for people with disabilities is retard. They get called that even if they don’t have mental retardation. People with disabilities have real names, not just labels.

In school, teachers who see students as people first have higher expectations for their students than teachers who focus only on the disabilities of their students. I know because I have been in both types of classes.

When teachers only see disabilities, I hate school and rarely learn anything. I have been fortunate to have had some great teachers who get to know the whole me. Disabilities are just a part of who I am; they are not the whole me. The best teachers work with my abilities, and those are the years I love school. Students benefit when teachers see them as learners and not as disabilities.

Words paint pictures of people. The pictures can be positive or negative based on the image the words create. People first language helps society see the person, not just the disability. When you don’t know how to refer to a person, simply use the label that everyone likes – his or her own name.
Every wrinkle, every line,  
God carved them into me.  
Every fold is a sign  
God left for me to see.  
Every hangnail, all spots dry,  
God placed them all right there  
Every little hair is God  
Showing how he cares.  
Every instance I can’t hear,  
God knew better for me.  
Every silent prayer is more dear,  
God gave me blessings, not a disability.  
If you ever forget what’s true,  
Or if someone starts to tease,  
Look at your hands, God made you,  
How do you question a masterpiece?

I wrote this poem from my grandmother’s perspective because she is going deaf.
A Man on a Mission:

In Step With Michael Volkman

BY RORY HARTE

Michael Volkman is an advocate for people with disabilities who writes a column for the Times Union newspaper in Albany, New York. He is one of a handful of columnists across the country who writes about these issues.

In 1999, Michael Volkman, then President of the New York Capital District Center for Independence, attended an Independent Living conference in Louisville, Kentucky. The Independent Living movement is based on the belief that people with disabilities should have the same civil and personal rights as those without disabilities. These rights include the opportunity to choose how and where to live and work. These activists also suggest that our society should be repaired in order to include all people, rather than expecting that people with disabilities will be fixed.

Volkman came home from this conference with renewed energy and asked himself what he could do in his own community to further advocate for the rights of people with disabilities. He decided to use his skill as a writer to achieve this goal. The Times Union agreed to publish his columns in September 1999. He found the Times Union easy to work with and described his editor as “tough but fair.” Volkman wrote about such topics as: “Airlines Don’t Do Enough for Disabled,” “What Bush Should Do To Help the Disabled,” and “Disability Activism Is Good News.”

Volkman states that he is proud of each article he wrote. His goal is to use his columns “to convert one person at a time,” and he is trying to reach everyone. He wants to “let people with disabilities know they are not alone.” He also wants people without disabilities to be exposed to his ideas and those of other advocates.

Volkman says that the media presents people with disabilities in a stereotypical manner. One presentation is “the pity stereotype” - the person with the disability who is in need of help from others. The other stereotype is “the overachiever” - the person with a disability who appears to be superhuman. Volkman was inspired to be a freelance writer to help eliminate these stereotypes in the media. He wants people with disabilities to be presented just like everyone else, not specifically as a person with a disability.

The columns that appear once a month in the Times Union reflect Mr. Volkman’s strong views. He has received a considerable amount of feedback regarding his articles and has been stopped in the street, received e-mails and been interviewed. Mr. Volkman challenges his readers to think about their own prejudices and political views. He reminds his readers that we all may experience a disability at some time in our lives. When asked how people with disabilities could increase their political clout, Volkman replied: “There are three things every person with a disability can do - advocacy, advocacy, advocacy.” Michael Volkman is certainly making his contribution.

A World Apart

BY IGOR MANELIS

A World Apart
A world apart
is the disabled man,
who cannot enjoy the same things
all others can.
Why? he asks,
did this happen to me?
Why? he asks,
Am I not free?
Free from the bondage
of the wheelchair;
or from the loneliness
of the hospital bed.
Free from those looks
that burn through one’s soul
that communicates so clearly:
“you are not whole.”
Yet, it is the soul
that is to be judged.
Not our facades
that cover it up.
Runaway Train

BY SAMANTHA PACK AND JAMIE FUTTERMAN

You seem to have a choice. Option A: You can choose to be extremely inspired and have new, innovative ideas for an indefinite period of time, but you may be severely depressed the rest of time. Option B: You can avoid severe depression, anxiety attacks and feelings of worthlessness, but you will not be as creative. In fact, you may feel rather dull. So, what’s it going to be?

People who have bipolar disorder, have a very important and difficult decision to make at a time when they may be least able to make it. The decision of whether or not to take medication rests almost entirely with the person who has the disorder and who may be experiencing a mood swing which affects the ability to make the decision. Other factors make the decision difficult as well.

Bipolar disorder is a condition characterized by extreme changes in mood. Mood swings range from extreme happiness and energy, called mania, to deep depression. This disorder is thought to be a hereditary condition caused by an imbalance of chemicals in the brain, and more than 2.5 million people are diagnosed with it every year. It typically begins in adolescence. Contrary to popular belief, it is nothing that the individual can simply grow out of or control. Symptoms of the manic stage of bipolar disorder may include excessive energy, imprudent spending of money, risk-taking, heightened creativity, and general impulsiveness. Conversely, the depressive stage is characterized by a lack of interest in familiar people and activities, a loss or gain of weight, fatigue, difficulty concentrating, and, in extreme cases, suicidal ideation.

In consultation with doctors, individuals with bipolar disorder must consider their personal health history, current medications and previous responses to medications of any type. Taking medications may mean living through a period of adjustment of dosages, lifestyle, sleep patterns, and diet. Constant monitoring and sticking to a consistent routine become the cornerstones of daily life.

If an individual with bipolar disorder makes a decision to take medication, mood stabilizers are the most common form. They work by affecting certain chemical messengers in the brain, stabilizing mood swings and mediating between the two severe stages of bipolar disorder. The calming effects of mood stabilizers may be accompanied by a flat, lifeless personality. Drowsiness, weakness, even nausea and weight gain are some of the possible side effects of the medication. Oftentimes, people with bipolar disorder who have been on medication for a period of time decide to discontinue it because they long for higher levels of energy and the creative ideas they used to have. They can’t tolerate the side effects of the medications and end up choosing not to take them. By doing so, they risk a return to a state of depression, which often escalates with age and sometimes leads to more serious behaviors.

Dr. Gianni Faedda, a psychiatrist who directs the Lucio Bini Mood Disorder Center in New York City, offers valuable insight into this particular problem and others that people with bipolar disorder face. Dr. Faedda compares bipolar disorder to an engine in which one of the cylinders is broken; “If you keep on running it [the engine], a lot of things will get out of tune.” When asked about treatment and medication for bipolar patients, Dr Faedda explains that many doctors “...are more reluctant to treat a mental illness than a physical one.” Even though, in his opinion, bipolar disorder “is no different from a physical illness – the patients suffer just as much pain and have to go through just as much.” This general unwillingness makes the choice about whether or not to take medication even more complicated. Also, doctors and patients often come into conflict over the issue of medication – many refuse to take medication because they enjoy the mania stages they experience, and don’t want to risk losing their creativity. Dr. Faedda has had experience with this; “Patients just love it. They enjoy the mania. It’s incredible to them!” Moreover, it can be hard to draw the line between what is called “functional mania” and harmful mania. Sometimes, as Dr. Faedda notes, patients will “...produce more, think more, and create more than they normally would if they were not in that state [mania].” It is only when patients reach a manic stage during which they are harming themselves or others that doctors consider medication. It is difficult to predict how much “creativity” is too much.

Medications don’t cure illness. They only help deal with the symptoms. Even if medication seems like a good option for an individual with bipolar disorder, other forms of treatment are likely needed as well. Medication is one of many options that can be considered. Behavior therapy, social skills training, psycho-
Across
3. Setting __________ expectations for students with disabilities will help them have a bright future.
4. Mary was featured in “TIME” magazine and a guest on __________ street.
6. Dyslexia means __________ language.
8. Bipolar disorder is a condition characterized by __________ changes in mood.
9. Hypo-mania in children is reminiscent of _________.
11. A hearing aid __________ sound.
12. ________ percent of people with autism are males.
15. Asperger syndrome is characterized by an inability to ___________, uncoordinated motor movements and unusual interests.
16. Michael Volkman writes a column for the ________ Union newspaper.
17. Down syndrome is usually caused by an error in cell division called _____________.

Down
1. ____________ implant is a device that provides stimulation directly to the auditory nerve.
2. ____________ is a chronic autoimmune disease of the connective tissue.
5. Extra time for work, a tape recorder and oral instead of written tests are all examples of _________.
10. ____________ means paralyzed from the chest down.
13. Rheumatoid arthritis is a serious ________ of the lining of the joints.
14. ____________ first language puts the person first and the disability second.

Runaway Train (continued)
therapy, individual and group therapies ought to be explored first or in combination with medications. There is no one answer for individuals with bipolar disorder. They face the unique challenges of taking medication, seeking other services and learning to live with a disability as difficult as this one can be.
I imagine asking these questions and being ignored. How would you feel? Hurt? Angry? Frustrated? Before jumping to any conclusions, stop and think. Maybe that person is deaf. Maybe that person didn’t respond to you because he or she couldn’t hear you.

Two inventions that have greatly improved the hearing abilities of deaf people are cochlear implants and hearing aids. Though both have been revolutionary devices, there are significant differences between the two. A cochlear implant is an electronic device designed to help individuals who are severely hearing impaired or deaf, and gain little or no benefit from hearing aids. A hearing aid can only amplify sounds. Users of hearing aids and cochlear implants need excessive speech therapy for long periods of time. In addition, constant tune-ups of the processors in cochlear implants are necessary.

New social situations often present challenges for someone with a cochlear implant. Most people have to learn how to be friends with someone who is different from them. They have to understand the disability and know how to be comfortable with it, but not make it the total focus of their friendship. This takes work on both sides. Attending a regular school may be difficult for someone with an implant. Students with a cochlear implant may have trouble understanding the teacher because of background noise from a large public school classroom. In addition, they may be unable to take notes and listen to the teacher at the same time. While they can get help to stay in a regular education classroom, they might find it easier to eliminate some of the stimulation found in large classes.

You may think that people who are hearing impaired might despair about dealing with the difficulties their disability presents. My experience has been that the opposite happens. I have found that people who are deaf are usually very strong. While they are making new friends they are also educating people about how to treat people who are deaf with respect. In school, they get help from an oral interpreter who explains things to them and takes notes from the teacher.

When my hearing loss was diagnosed at two years old, I was fitted with very powerful hearing aids. Extensive speech therapy was not successful because my hearing loss was too great. I was implanted at age three and immediately began to hear. However, because I had not ever heard any sounds, I needed extensive training to help me recognize these sounds and eventually learn to speak. This process continues today. I still receive speech therapy and will continue to for the foreseeable future.

I have been attending a private bilingual mainstream school since nursery school and use the services of an oral interpreter to help me take notes and understand my teachers. I am presently in eleventh grade and plan to study psychology in college.

Every day I have to tell people not to treat me differently because of my deafness. My father always says, “Be stubborn.” He is right. Persistence is one way of achieving a successful life. Although my disability has made me strong, it is very hard to be strong everyday. All those therapy sessions take me away from the things and people that I enjoy. Sometimes I cry because I feel my life is made difficult by deafness. However, I always try to refocus on the positive side. If I don’t do that, I couldn’t survive at all. Given all these pressures, I am living proof that you can still be a great kid living with a cochlear implant and enjoy life to the max!
Thirty years ago the likelihood that a person with profound hearing loss could gain any ability to hear was doubtful. Then, in 1985, the prospect became an attainable reality when a device was invented to aid those individuals unable to perceive sound waves. This remarkable invention was the cochlear implant.

According to the American Speech-Language-Hearing Association a cochlear implant is a device that provides stimulation directly to the auditory nerve, bypassing damaged hair cells in the cochlea that prevent sound from reaching the nerve.

Hearing individuals have ideal pathways for sound to pass through the outer portion of the ear and into the inner ear. People who are deaf have damaged hair cells within the inner ear or cochlea, which inhibits sound from reaching the auditory nerve. In order to compensate for the biological flaw, an implant was designed to bypass the obstruction.

The implant is unique in that it sidesteps the external and middle ears by means of electrode electrical stimulation, which allows impulses of nerve fibers (from the eighth cranial nerve) to be carried to the brain. The device has microphones to collect the sound, speech processors or tiny computer chips for interpreting and converting sound into digital signals, and transmitters which receive the signals and send them to an implanted receiver. The cochlear implant allows for the sensation of sound, but not for a quick fix to hearing loss or damage. Obviously, this process isn’t as simple as pressing a button in the inner ear to suddenly enable sound perception. It is complicated and may not have the desired effects or produce any sound at all.

The National Institute on Deafness and Other Communication Disorders reports that roughly 14,000 adults and children have received cochlear implants in the United States, and more than 30,000 individuals have received cochlear implants throughout the entire world. Although the price of implanting the device reaches close to $40,000, this medical procedure is considered one of the most cost-effective treatments available.

The cochlear implant is the first instrument that allows for the partial recovery of a damaged sensory organ. For the first time in history, a technology exists that allows auditory perception for people who are profoundly deaf. In a once silent existence, they can now perceive sound.

Cochlear implant surgery is not without risks. They include:

- Short-term dizziness
- A ringing sensation in the ears (tinnitus)
- Numbness behind the ears near the incision
- An alteration in the way things taste
- The possibility of developing infection, such as meningitis, and
- The risk of device failure, which would require additional surgery to correct the malfunction.

For more information on cochlear implants, or other assisted hearing devices, please visit http://www.asha.org or http://www.cochlearamericas.com.
The girls in the class had a spellbinding effect on Peter, often assuming the role of little mothers. By the end of December, Peter was making the sound of a motorboat every day in class, which was his way of expressing his gratitude. The new friendships Peter made delighted his parents. From here Mrs. Stalling took a bolder stop – upgrading Peter’s academics. It wasn’t that Peter wasn’t bright, he just needed work comprehending what each task demanded. Once Peter understood the question, he could do incredible things. Each task was a bit challenging - teaching Peter how to read, write and identify specific objects - but the fact that Peter tried was the most important aspect of it all. With the combined efforts of Peter, Mrs. Stalling’s perseverance, and the encouragement of his peers, Peter proved that he was able to learn along with his nondisabled peers.

During those last few days of the school year Peter had outbursts, usually taking place at the end of the day when he was tired. Peter was apprehensive to part from a class that loved him so much, many of whom he would affectionately hug. One of Peter’s friends said that he had many friends, yet they didn’t have the same compassion and loving nature as his best friend Peter. Unfortunately, the time came when Peter had to say goodbye to his third grade class. Due to his effort and improvement over the year, Peter was one of the few children who won the “Teachers Special Award”. After singing the national anthem with his best friend in the hallway, Peter hugged his friend and left the building.

There was a long summer to look forward to, not to mention a new year. This time, however, Peter would be ready. He not only grew as a learner, but he taught his classmates and his teacher something special about human nature. Peter taught the class a valuable lesson in tolerance, and showed them that a student’s potential is not hindered by a disability.

Children are like seeds in the learning environment; it takes time and energy before an individual’s potential can be fully achieved. Had Peter’s teacher not employed such an aggressive teaching method, he would still be chained to his disability. We have only begun to understand and explore the many ways of teaching, and we owe a great deal to the perseverance of students with disabilities. One day, Peter may find himself preaching to a new generation that will have the power to coalesce our much-segregated educational system.

A Guy Thing

concerning his surroundings. This too is characteristic of the typical male, and has led some to the conclusion that autism is in fact the male psyche at some extreme level.

This theory embraces the idea that individuals with autism can improve and develop their social skills. Just as men and women, with the appropriate instruction, can hone skills more characteristic of the opposite gender, individuals with autism can learn how to better their social skills and improve their ability to identify emotions. Many programs have been developed to achieve this goal, and in fact have been structured in such a manner that it takes advantage of skills that are symptomatic of autism. Such programs work with memorization and repetition, and have been extremely effective in teaching people with autism. One such program uses a computer to test an individual’s ability to identify emotions by displaying facial expressions. The individual must then correctly identify the emotion corresponding to the specific facial expression depicted on the computer screen. This program tests four hundred and eighteen different and distinct emotions, and has been proven to show success for anyone using the program for at least a ten-week period. This gives new hope to many, and sheds new light on the seemingly mysterious inability of individuals with autism to socialize.

Is it a definitive fact that autism is analogous to an overdeveloped male psyche? Certainly not, but this new theory does present a realistic, factual and reasonable understanding of autism. While it still needs more exploration and backing to ensure its legitimacy, it has a strong foundation and merits serious consideration. In recent years, autism has attracted the attention of serious researchers and, among the numerous explanations that have surfaced, this seems to be one of the most promising. Is autism a guy thing? Maybe not, but for right now it certainly appears that way.
It is not an infrequent sight for a group of girls to be huddled in a corner, quietly gossiping on a playground. Though most observers would glance upon this scene and view it as innocent socialization, Rebecca Heinrich does not. In her new book, Perfect Targets: Asperger Syndrome and Bullying, Heinrich identifies the danger of bullying, particularly when it is directed toward an individual with Asperger Syndrome, and presents a variety of methods to deal with this national epidemic.

Asperger Syndrome is a developmental disorder defined by an inability to socialize, as well as uncoordinated motor movements and unusual interests. While an individual without Asperger Syndrome would be able to join a group or game on a playground with relative ease, an individual with Asperger Syndrome would be baffled as to how to approach peers. Individuals with Asperger Syndrome exhibit a plethora of characteristics, but their behavior is most often controlled by an absence of social skills and a lack of understanding of what is and isn’t socially appropriate. It is these characteristics that make them uniquely prone to bullying, which can come in verbal, physical, or psychological form. Though this unfortunate reality is ignored by many school administrators, it was the focus of Heinrich’s study. She laments, “the more I talked to teachers, parents, and children, I saw this issue was not being dealt with”.

Heinrich, who has both a Masters of Science in Nursing (MSN) and a Masters of Science in Education (MSEd), was able to share her interest in Asperger Syndrome through the Parent Support Network, an organization dedicated to raising awareness and helping parents raise children with learning, emotional, developmental, social, and behavioral disorders. The support she received from this organization allowed her to travel across the country, lecturing about this syndrome, which has, “always been a deep concern”.

The impact of bullying on an adolescent’s development is far reaching and extremely significant. Because of their inability to detect social cues and what is perceived as odd behavior, individuals with Asperger Syndrome are often blamed for provoking the bullies. The result of this daily onslaught, Heinrich claims, is that, “they are so afraid, they are hardly able to learn”. Rather than placing the blame solely on the bully, Heinrich stresses the necessity for adult intervention. In her book, Heinrich provides a variety of coping methods to deal with bullies, but, ultimately, the solution exists in the relationship between teacher and student.

“I think there’s a problem with understanding how vulnerable kids with disabilities are,” comments Heinrich. “The missing component exists between kids and teachers...[administrators] must involve the whole school.” Heinrich’s approach differs from conventional methods because she does not hold the student responsible for their own welfare. Her method recognizes that the individuals being bullied have the least amount of power, and thus any solution must involve the cooperation of teachers and administrators.

In her book, Perfect Targets: Asperger Syndrome and Bullying, Rebekah Heinrich exposes the debilitating results of bullying and the struggle that individuals with Asperger Syndrome must face. Rather than placing responsibility in the hands of the afflicted, her method combines the resources of parents, teachers, and students in the battle against this epidemic.

- BY AIDAN HARTE
Living in the Real World  

BY DARIEL NOWAK

Mary is one of 350,000 people in the United States who lives with Down syndrome, a condition usually caused by an error in cell division, called non-disjunction. All people with Down syndrome have one extra chromosome. This extra amount of genetic material alters the course of development and causes characteristics associated with the syndrome.

For many people, living with Down syndrome would be seen as a challenge. Mary and her family never saw it as such. Mary began her schooling in a special education program, segregated from her peers. However, once her family relocated, her parents made the conscious decision to have her included in a regular education classroom. Although her disability set her apart from the rest of the students, Mary was determined to interact and learn the same way as her peers. Mary recalled her middle school years as, “A nightmare! I was made fun of”. The harsh remarks were hard to deal with, but Mary never lost sight of her goals.

Mary remained in regular education classes during her four years in high school. “High school was easier, except for all the homework,” commented Mary. After graduating, she began her work-study program. Here, she gained experience working in a public library and, in the process, built personal relationships with teachers. Mary remained in the work-study program until she was twenty-one.

Currently, Mary is twenty-nine years old, and in a supervised independent living situation. She lives in a house with a woman who does not have a disability. She shops for her own food, cooks for herself, and takes on many typical household chores. Mary works at a local supermarket and recognizes that it is important to work. Like most people, she is sometimes frustrated with her job. “I like independent living, but I don’t like the work,” laments Mary. Someday, Mary hopes to move into her own house and live with a roommate.

Mary has never allowed her disability to get her down. She went through middle and high school with her peers. Although special education laws have been in existence for decades to make it possible for students with disabilities to be educated with their non-disabled peers, Mary’s situation was unique. At the age of eleven she was featured in “TIME” magazine. As a baby, Mary was also a guest on “Sesame Street.” She has worked hard all of her life and continues to do so, proving that Down syndrome is not a barrier in life, just a bump in the road.

For many people, living with Down syndrome would be seen as a challenge. Mary and her family never saw it as such.

"For many people, living with Down syndrome would be seen as a challenge. Mary and her family never saw it as such."

The Girl

BY KATIE

The girl you have all seen, happy as can be
Is not so happy as you can’t see
She is not different, just like you and me
Normal as can be
Or she wishes she could be
She is different not very, mostly like you and me
People make a big deal
At lunch she never finishes her meal
She is happy in class, no one makes fun
The moment the bell rings, down goes the sun
She is not good in school
It is like she is missing a tool
She does not talk much
It is stolen at the touch
She has just enough friends
She prays to God it never ends
The reason I know this
Is deep down inside
We try to keep hidden
So we fit in
For some it is hard to hide
Others it is easy to keep inside
I don’t know about you; but if I were you, I would
Give her a chance
Dyslexia is a word that means “poor language.” It is taken from the Greek words “dys” meaning poor and “lexis” meaning word or language. It is considered a learning disability, and is believed to be inherited.

Kids with dyslexia are often called “lazy” or “slow” and are made to feel stupid even though they have average or above-average IQ’s. A common myth some teachers and even parents believe is that kids with learning disabilities are not trying hard enough and if they only worked harder, they would do better. The truth is that hard work, in itself, won’t take away the disability or even necessarily make a student more academically successful. It is important for all students to take schoolwork seriously and try hard, but it isn’t a cure for a learning disability.

A learning disability is a life long condition. Students need to learn strategies that will help them overcome their disability. We all have to learn to read so that we can succeed in the real world, but students with reading disabilities are not trying hard enough and if they only worked harder, they would do better. The truth is that hard work, in itself, won’t take away the disability or even necessarily make a student more academically successful. It is important for all students to take schoolwork seriously and try hard, but it isn’t a cure for a learning disability.

Since no two people with dyslexia are exactly alike, symptoms vary. Some signs of dyslexia are:

- Reads very slowly and choppy when reading out loud.
- Seems to “zone out” or day dream.
- Can’t read, write or spell at grade level.
- Confuses left/right and over/under.
- Reads things repeatedly and doesn’t understand well.
- Writes short sentences.
- Mispells many words.

They confuse letters like b and d or read words like “rat” for “tar” or “left” for “felt”. They may sound the letters c-a-t, but then say “cold”. To a child with dyslexia, a sentence may look like this: Dyslexia is when you r mdn gets wdrso mixde pu.

Normally a person learns new words by reading. Since children with dyslexia don’t like to read, their vocabulary may not grow as fast as their classmates unless they are read to or listen to books on tape. There are ways to help a child with dyslexia learn. Some may do better in classes that rely on talking and discussion instead of reading, some students may take notes that they can reread later. Because memorizing is hard work, learning spelling words is also hard. Students can spend hours studying a spelling list, get most of the words right on a test the next day, but forget how to spell them the day after that. It seems as if they haven’t done the work at all when really they have worked hard but haven’t been able to retain much of what they learned. This gives rise to the myth that they are “lazy learners.”

Kids with disabilities can be helped to leap over their disability by giving them the tools they need. These are called accommodations. Accommodations are things that can be done in class to help a child learn in a different way. Some accommodations that can help a child with dyslexia learn include: allowing extra time for work, a tape recorder for note taking, and granting the student the right to take oral, instead of written, tests.

Dyslexia can make a student’s ability to learn and keep up with his classmates hard, but it is a disability that can be overcome. If a child is diagnosed at an early age and is taught in a special way, they can be successful in school.
On June 8, 1997, when he was 19 years old, Tom Benjamin was doing routine life guarding drills at a small lake in the Catskill Mountains. As he ran into the lake, he stumbled over a rock and fell headfirst into the shallow water, slamming his head into the hard ground. He ended up breaking his spinal cord between his fourth and fifth cervical vertebrae, which left him a quadriplegic, paralyzed from the chest down with partial movement in his hands. When asked if he realized what had occurred, Benjamin replied, “... I was an EMT, so I knew what had happened and what it meant”.

After the accident, Benjamin took the rest of the school year off for personal reasons and to receive treatment. It took time to realize the implications of his disability. “You realize how you take things for granted, like tying your shoes,” said Benjamin. He also had to pursue an entirely different career than he had originally planned. “... my employment goal was to be an FBI agent, but I realized that goal would be unattainable.” So he decided to attend law school instead of following a career in law enforcement.

At the same time, he also applied for a canine companion through Canine Working Companions, a small organization located near Utica, New York. Six months later, a Labrador retriever, Ambrose, was ready for Benjamin. Before taking Ambrose home, Benjamin had to devote 80-100 hours working with Ambrose, learning to use his commands and developing a bond. The long hours of training are required for many reasons. For one, the companion and the person who will be handling the dog have to connect with one another and get used to each other. Even before this bonding can take place, the person who will eventually own the dog has to learn the specific commands to tell the dog what to do.

Ambrose helps Benjamin with many different things. He is able to pick up pencils, turn lights on and off, and pick up the phone. When Ambrose wears the orange vest, which signifies he is a canine companion, he is trained to ignore everything and everybody but Benjamin. However, when he gets home, he is a “normal dog” who plays fetch and runs around the house. Benjamin and Ambrose do occasionally encounter problems. Some restaurant owners are very skeptical about letting a dog into their building, even though Ambrose is a companion animal.

Benjamin’s outlook is extremely positive. He views everything as an adventure and is extremely happy with life. He tries to live each day to the fullest. For instance, since the accident, Benjamin was presented with the opportunity to go skydiving. He jumped at the opportunity, and really enjoyed it a lot. He has learned to drive a converted van. The van has many modifications. It has a ramp which folds out from the floor of the car and it does not have a driver’s seat. Instead Benjamin centers his wheelchair in front of the driving wheel. Additionally, all of the car’s functions are operated by a system of levers and handles, which are all around the steering wheel. The car is entirely operated by his hands. He doesn’t see this as a barrier, but a challenge. Benjamin said he had always viewed driving the van as a classic arcade game because of all of the levers involved in driving it.

He doesn’t live his life waiting for a cure for his disability. In fact, he is the exact opposite. Unlike others who wait for a way to walk again, Benjamin’s philosophy is simple, “I’m hoping [for a cure], but I’m not living day by day hoping there will be one - whatever happens, happens.” Instead, he makes the most of everything and looks forward to a career in law in which he will be helping others.
When I was young, I remember my mother as being a vivacious and energetic woman. However, as I got older, I noticed that she did not do as many things with me as she used to. Once I noticed this, I felt a little down. I wondered if I had done something wrong. I couldn’t figure it out. The thing that really kept me thinking was when my mother told me she had used a riding lawn mower with my older brother, a long time ago. I thought to myself, “She would never do that with me now.” I got upset just thinking about it. There were many other things along the way that I noticed my mother had stopped doing.

As I grew older, I discovered that my mother had been diagnosed with scleroderma and rheumatoid arthritis. This answered many of my questions. I now know why my mother doesn’t do certain activities with me and why she has pain. The winter is the worst because that is when her joints hurt the most. My mother has to take two shots every week and at least six to seven pills a day.

Scleroderma is a chronic, autoimmune disease of the connective tissue and is a highly individualized disease. The symptoms may either be visible, such as when the skin is affected, or invisible, such as when the internal organs are involved. This is a disease with symptoms ranging from very mild to life-threatening. Scleroderma is not contagious or cancerous. It affects three hundred thousand people in the United States.

The exact causes of scleroderma are unknown. The disease is characterized by an over-production of collagen (an insoluble fibrous protein that makes up most of our connective tissue). Symptoms of scleroderma may include abnormal sensitivity to cold in the extremities, swelling of the hands and feet, pain and stiffness of the joints, kidney, heart and lung dysfunction, joint contractors, and thickening of the skin. As of yet there is no cure, but there are medications available to help control it. The Scleroderma Foundation supports efforts to educate people about this condition.

Living with scleroderma has been difficult for my mother, but this is not the only obstacle she faces. My mother also has rheumatoid arthritis (RA), a serious inflammation of the lining of the joints. Like Scleroderma, RA is also an autoimmune disorder, in which the body attacks joint tissue.

Having a disability (or two) can change your family life and affect your friendships. Many things have changed about my mother, but her unconditional love for me never has. All people, regardless of their disability, need a sense of support and care. I hope that some day a cure is found so that my mother can live a more comfortable life. Until then, it is our responsibility to learn more about disabilities and recognize that people with disabilities are our mothers, fathers, friends and family members. We should do our part to understand that sometimes their behavior toward us may be shaped by their disability. Their disability does not affect what they can do, only how they do it.
Even the most ephemeral look at life reveals that it does not go the way most people intend. Rather than hindering individuals from recognizing their full potential, these life obstacles often evolve into important lessons. Individuals with disabilities are often faced with unique obstacles and, rather than overcoming them, they choose to accept them.

My friend Iggy is one such person. I met Iggy when I was a freshman and he was a senior. I didn’t realize he had a disability because of his general attitude towards it. To everyone, he was just a kid with all of the same qualities they had. He played hockey, practiced karate and succeeded in school. After talking with his parents, I realized what a truly amazing person he is.

Iggy was born with proximal femoral focal deficiency, also known as PFFD. PFFD is a birth defect that affects the end of the thighbone closest to the hip by making it too short or not allowing it to develop completely. Although Iggy had this condition, his parents treated him like any other child. When Iggy was born, his father said, “He might not play football, but he can be great at the piano!” Iggy received his first prosthetic leg when he was one year old and was walking by eighteen months.

As Iggy got older, he kept asking his parents when he was going to grow a leg. His parents were always honest with him, and told him that he was who he was and that he had no limits whatsoever. Although Iggy led a relatively normal life, and was very accepting of his disability, he always wanted a sibling. When Iggy was nine years old, his parents adopted a five-month-old baby girl from South Korea named Carley. Carley was born with a partially developed arm. The umbilical cord had wrapped around her arm causing it to lose circulation. During my interview with Iggy’s mom, Carley ran into the room and sat by her mom. Until she told me about her disability, I didn’t even notice it.

Carley is an accomplished gymnast and horseback rider. Running back into her room, she returned repeatedly with all her trophies and awards. In between, she came out balancing cookies on her one and a half arms. Her vitality and enthusiasm was infectious. Despite their physical differences, Carley and Iggy have had a life very similar to someone without a disability. They have done amazing things. Iggy is a Boy Scout, earning the highest achievement of Eagle Scout. He was selected to be a youth ambassador and traveled to Scandinavia. When he was sixteen, Iggy began playing hockey. He has played on the American Amputee Hockey Association ice hockey team and has traveled all over the world. Iggy recently began college, and is majoring in computer information and technology. He is enjoying college and is involved in many aspects of campus life.

Carley is nine years old and is continuing her gymnastics and horseback riding. Her disability, like Iggy’s, is just another part of her life. Their disabilities are a part of them, a part of who they are. Because they are comfortable with themselves and their disabilities, they have not allowed the stigma that is associated with having a disability to hamper their potential. People with disabilities have learned to do without and they have developed new skills in the process. They become experts in learning unique ways of accomplishing simple daily tasks. They learn to take advantage of modifications and accommodations. Carley and Iggy represent two shining examples of the resilience of the human spirit.