Humans were created to be the ruling population on the earth. They are highly intelligent and yet many are prone to make some very ignorant assumptions about others of their kind. People with disabilities are probably the biggest victims of this misguided behavior. Somehow, mankind has been taught throughout history to view their peers with any type of disability, especially those physical in nature, as having minimal intelligence and unable to contribute much to society.

It is true that some individuals with physical disabilities have mental challenges, but “mental challenges” is not a label that means no intelligence. It just means a person’s mind may function a bit slower or differently than others. As McGinn Morgan says, “I’ve been in a lot of situations where people think I’m stupid because I’m a slow learner. I was in English class at Cuyamaca College once, and the professor called on other students in the classroom. I could tell he purposely did not want to call on me.”

Those not in that category fight the daily battle of proving to the rest of the world that the limitations of their bodies does not relate to the capabilities of their minds. Appearances can be very deceiving, especially for people like Rebecca Kingsley, who has cerebral palsy. “If I walk, my disability is somewhat more prominent. And people assume I have a cognitive disability, rather than a physical disability,” she says.

Katie Griffith is another such fighter with cerebral palsy, making it necessary for her to use a power chair. Looking back on her high school years, she recalls a discouraging comment from one teacher who said, “You can’t go to college, Honey. Think about it. Are you going to be in Special Education classes there? They don’t have Special Education in college.”

Katie can still laugh at that silly assumption to this day. She has received her A.A. degree in Biblical Studies and is beginning to take classes to count towards earning a B.A. degree in Social Work. If Katie does need extra help in any of her classes, all colleges, community or otherwise, offer some type of services for students with disabilities, which usually includes tutoring.

The misconceptions that the disability community faces does not, unfortunately, stop with academic success. People tend to assume those with disabilities will not be able to live on their own, hold down jobs, or lead overall fulfilling lives. However, people are being proven wrong more and more in recent times.

Christopher Pirino is a perfect example. He explains his experience this way; “Some of the misconceptions people had of me were (continued on page 7)
Here’s My Health Care Story
What’s Yours?
By Katie Griffith

My name is Katie Griffith. I’m from Gilbert, AZ. I am an outgoing 22-year-old woman with cerebral palsy and attend Rio Salado College. My other activities include being a member of the Youth Action Council of Arizona (YAC-AZ) and working with the Set Yourself Free project to identify physicians willing and able to serve people with special needs.

From my own experience as a person with special health care needs, I have found it very difficult to find a physician that I like and one that is comfortable working with me. Many physicians that I have gone to visit seem to be afraid to work with me because maybe they do not have enough knowledge about my disability.

The physicians that I have seen so far seem very nervous to talk to me and ask me questions during my visits. They usually ask my parents the questions instead of me because they must not think I can answer for myself. Some of the questions they have asked are: Why are you here today? How many days have you been sick? These questions are questions I can answer on my own. There are times when they ask me questions that make me feel very uncomfortable talking about in front of my parents. I want to be in charge of my own healthcare and have my mom and dad there only when I need them.

Sometimes, when I get blood drawn, they don’t tell me what it is for, but just tell me to pull my arm out. There was also a time when an x-ray technician asked me to hold on to the pole with both hands but I can only use one. One of my arms is not as flexible as the other. The technician tried to force it onto the pole. After so many tries, they ended up using a pillow to support it.

In trying to find interested practices, I have started calling physicians to see if they are willing to answer my survey about accessibility for people with disabilities, their background and experience, and the number of people served with special needs. So far none of the practices have been willing to participate in my survey. The responses I have gotten from office managers are “no”. The Set Yourself Free project wants to list physicians on SWIFT® Resources, a web-based resource directory, so that youth and adults can more easily find their doctors.

So, what is your story? Do you have a physician you would like to recommend to other youth? Have you had trouble finding a physician? We want to hear from you!

Send me an e-mail at katydid51886@aol.com and share your story with me!

(continued on page 6)
On August 25, 2008, I began my first night of school in the Master’s evening program for social work at Arizona State University (ASU) West. Having a disability, I knew that the next few years would be challenging but not impossible. ASU provides students with accommodations necessary to participate fully in class in a fair and equal manner. Due to the fact I have quadriplegia with paralysis from the shoulders down, the accommodations I received were extensive. Through the Disability Resource Center, along with services from Vocational Rehabilitation, I was provided with a note taking assistant, an accessible classroom, and a test taking scribe for any midterms and finals scheduled by the professors as my accommodation.

That first night as I arrived at 6:30 p.m. the campus seemed desolate – there were just a few students having dinner in the cafeteria and empty administrative buildings throughout the campus. I made my way to my classroom on the second floor of the Sands building. Fewer than ten minutes into the professor’s introduction, the building fire alarm began to sound. Students initially looked around perplexed, but soon calmly filed out of the classroom and proceeded to exit the building. I and another student who uses a wheelchair also proceeded to exit the building by heading towards the elevators.

To our surprise, the building elevators were shut down. As this was our only way to exit the building, we were struck with the prospect of no way out. There were no areas of refuge designated in the building to shelter us as we waited for emergency personnel. As we sat there, a small group including the class professor and several other students approached us to determine our plan. With no other option available, we indicated we could do nothing but wait for help. Fearing that no help would come, the group stayed with us to assist if an evacuation became necessary.

For fifteen minutes the fire alarm rang. The building was completely evacuated, except for our small group on the second floor. Periodically, we would look around the building to search for the cause of the fire alarm or emergency personnel assigned to answer the alarm. However, in the end, emergency personnel never arrived and the cause for the alarm was never determined. Fortunately, the alarm was false and did not result in harm to any students. However, this is not the first time that a fire alarm has been activated on an ASU campus. On November 1, 2007, a fire broke out on the second floor of the Memorial Union building at the ASU Main campus in Tempe. Five thousand students were evacuated from the building, including four students in wheelchairs. In total, it took sixty firefighters twenty minutes to extinguish the flames and to carry the four students in wheelchairs up a flight of stairs and out to safety. According to one of the students who was rescued, the nearest exits in the basement were not wheelchair accessible.

The current evacuation plan for ASU is vague and generalized. It does not take into consideration various types of disabilities or the various types of assistance people might need. Neither does the plan address training in assisting people with disabilities during an emergency or after evacuation. No universal plan is provided for all campus buildings, but rather, each building manager is responsible for creating and implementing their own evacuation plans. Furthermore, the guidelines that are in place are not being implemented properly by school faculty.

Yes, a working fire alarm system and elevators programmed to shut down upon its activation are standard emergency system features. But without a coordinated emergency plan (continued on page 7)
Interview with Author Brooke Brown

By Katie Griffith

Author Brooke Brown is an honors graduate of Arizona State University with her Bachelor’s in Journalism. Yet, she hopes to become a well-known Christian fiction author rather than be buried in the newsroom. The Little Butterfly Girl is her first published work and she is also the editor of this newsletter.

Q: When did you first begin writing?
A: I started writing with a passion in fourth grade. Thanks to my teacher, Mrs. Jones, I discovered that a few carefully chosen words could breathe life into the pictures in my head.

Q: How did you decide you wanted to become a writer?
A: I don’t believe “becoming” a writer is a conscious decision that I had to make. Writing was a way for me to experience all the things that were and are still physically difficult for me. So, the words just flowed through me like a natural river.

Q: How long did you have to go to school to become a writer?
A: I went to school for four and a half years to earn my Journalism degree, but again, I am one of many authors who will say as long as one enjoys creating a good story, one may call themselves a writer. It doesn’t matter if someone is published and well known or attending a special writing program in school.

Q: What is the hardest thing about writing?
A: The hardest thing about writing for me is just the physical act of typing. If I could move faster, I would write every day for hours. There are so many characters in my head waiting for me to introduce them to the world. Their chattering keeps me up at night.

Q: What is your biggest accomplishment since you became a writer?
A: Honestly, any time I finish a whole story and someone is moved by it — that is my greatest accomplishment.

Q: Were family and friends supportive of your writing?
A: My family and friends are very enthusiastic about my writing. They are all waiting on pins and needles for my book. There are even a couple who are willing to help me type.

Q: How did you decide what your first book was going to be about?
A: Bridget’s story was not planned out, at least not very much. A vision of Bridget came into my head. I talked with her a little bit and went from there.

Q: How did you decide the title of your first book, The Little Butterfly Girl?
A: Bridget was not overly dramatic so I went for a title that simply told her reader who she was.

Q: What is the biggest obstacle you had to overcome to be a writer?
A: Well, even though the publication process is grueling and not always edifying, I guess I would say my biggest obstacle is gathering the endurance I need to sit at my computer and type for blocks of time.

Q: Do you plan to write another book?
A: Yes, I am actually working on two new ones right now.

Q: Do you know what the next book will be about?
A: As far as the sequel to The Little Butterfly Girl, I’ll just say Bridget and Jeremy learn a lot of lessons in junior high.
Two Book Reviews: The Little Butterfly Girl

This book was a very wonderful book. When I first started reading it I could not put it down. It took me to a whole different world when I read it. I could relate to Bridget and how she felt because I felt that way too — sad because I could not do things like other kids on the playground because of my disability which happens to be cerebral palsy, just like Bridget’s. It made me feel many emotions. I wish I could be a butterfly like Bridget! Most of all being a Christian myself, it made me think about what I have to look forward to in heaven! I may not be a butterfly but I will be able to walk and run like everyone else in heaven! I would recommend this book to any of my friends. It is one of my favorite Christian books! I can’t wait to read the next one! Two thumbs up!  

~ Katie Griffith

Bridget Saunders in Brooke Brown’s The Little Butterfly Girl delights in fairy tales. A reader cannot help but suspect the same is true of the author. The Little Butterfly Girl is a beautifully woven fairy tale, dancing with ethereal ease between the grounded world and a world inhabited by wonder and fantasy – fantasy, however, not purely imagined, but rather issuing from a place of solid faith such that the boundaries of the two worlds are happily blurred.

Ms. Brown writes of a loving girl who through her gift of imagination and spirituality profoundly enhances the lives of those around her. While using a wheelchair to get around, her unbound creativity and generosity confer remarkable agility of spirit. The book chronicles several extraordinary days in the life of its young protagonist in which she truly lives Jesus’ spoken words, “I tell you, you can pray for anything, and if you believe that you’ve received it, it will be yours” (Mark 11:24). Her Father summons her to a secret island, one materialized from her dreams, to fulfill her greatest wish – that is to fly. A nod to her love of butterflies, she is transformed into a beautifully colored butterfly and appointed a guardian angel to gently guide her as she employs her newly gifted powers, done so true to Bridget’s nature in the service of others.

The Little Butterfly Girl, nominated for the 2009 Schneider Family Book Award (see box below), shows us a place where imagination, faith, and the spirit of caring overshadow the limitations of the physical world. Beyond crafting a beautiful and inspiring fairy tale, Ms. Brown relates Bridget’s disability as a gift to others, as “a tool you can use to share your faith...” Her physical disability influences not only the shaping of her creative mind, but in strengthening her faith, also fosters her capacity to deeply connect with and help others.  

~ Laura Schweers

About the Schneider Family Book Award

This award, administered by the American Library Association and donated by Dr. Katherine Schneider, honors an author or illustrator for a book that embodies an artistic expression of the disability experience for child and adolescent audiences. The book must emphasize the artistic expression of the disability experience for children and/or adolescent audiences and must portray some aspect of living with a disability or that of a friend or family member, whether the disability is physical, mental or emotional.

For more information about the Schneider Family Book Award, go to http://www.ala.org/ala/awardsgrants/awardsrecords/schneideraward/schneiderfamily.cfm.
Meeting Happy Tails

By George Garcia

Saturday, April 18, 2009, YAC-AZ members listen attentively as Joyce Weber, cofounder of Happy Tails, addresses the youth group. By her side is a puppy in training named Ace. Joyce begins the presentation by going through the history of the use of service dogs. After a short history and explanation of disability law, a trainer who accompanied Joyce proceeds to show the YAC-AZ members the limited commands Ace has learned in his brief time with Happy Tails.

Founded in 1995, Happy Tails is a nonprofit organization that helps people with physical disabilities and/or those who are deaf and hard of hearing find and train dogs to be service animals, free of charge. While Happy Tails does not charge for its services, it does require a commitment from those who choose to get a service animal. In order to properly train a service animal, Happy Tails requires its members to meet once a week for 15 months.

Service animals can be of great use to people with disabilities. There are several types of service animals that can be specifically trained according to the needs of their owners. In general, the Americans with Disabilities Act defines a service animal as an animal that is “individually trained to perform tasks for people with disabilities such as guiding people who are blind, alerting people who are deaf, pulling wheelchairs, alerting and protecting a person who is having a seizure, or performing other special tasks. Service animals are working animals, not pets.”

A service animal may provide assistance in helping a person with a disability live a much more independent life. However, many people with disabilities may feel that their service animal is not welcomed in public. Seeing that a service animal is not viewed as a pet, under the Americans with Disabilities Act, “businesses and organizations that serve the public must allow people with disabilities to bring their service animals into all areas of the facility where customers are normally allowed to go. This federal law applies to all businesses open to the public, including restaurants, hotels, taxis and shuttles, grocery and department stores, hospitals and medical offices, theaters, health clubs, parks and zoos.”

To learn more about Happy Tails and for information on how to obtain a service dog, please contact Joyce Weber:

jandrweber@aol.com
623-580-0946
that I would not graduate from high school or go on to college. To others’ surprise I went to a junior college and took child care classes, which made me happy. Also, many people gave me a hard time about believing I could drive. I proved them wrong and got my driver’s license and have driven for over a year. I think the biggest misconception is that I would live in a group home forever and could not live independently. In early 2005, I made a plan to get more than one job to make more money, so I could rent a place. Now I am happy that I live on my own and have great quality of life.”

These sentiments echo the underlying goal of the majority of the disabled community – to lead fulfilling lives in which their accomplishments are respected and remembered just as much as those of their able-bodied counter parts. Achieving this goal must begin with one very important step: speaking up for oneself. George Garcia is a young man with a firm grasp of this skill. “I have found that people judge those who do not speak up for themselves. By taking the lead in any situation and being the first to speak, I take away the opportunity for people to judge me based on my disability,” he observes.

George’s is one voice that is difficult to ignore. He holds various leadership roles within the disabled community of Arizona and refuses to let anyone he meets think that his quadriplegic body is any indication of the power his mind possesses.

Everyone has heard the age-old adage, “don’t judge a book by its cover.” The same principle applies to the human body. Flesh and bone just make up the perishable container that holds one’s spirit. Would Einstein still be revered today if he were judged only on his disheveled clothes and unkempt hair when he was alive?

If there is one misconception people with disabilities want their able-bodied peers to understand, it is beautifully summed up in the words of Rachel Loria: “Hey you out there, I may not be the one I seem. It might just be the way you look at me.”

that considers the needs of all its students, ASU shows that it does not value the safety of its students equally. As a self-advocate, I felt unable to attend a school that jeopardizes the safety of students with disabilities. To address the issue, I wrote to ASU’s President, Michael Crow, stating my disappointment with the university’s reaction to the alarm and that a revision to the evacuation plan was warranted.

His initial response was to send me a cut-and-paste link to the campus’ current emergency guidelines. Feeling that ASU did not consider the problem serious, I contacted the local media to voice my concerns. After appearing on the six o’clock news for CBS, I immediately received a response from President Crow and the dean of the social work program. Additionally, I heard from the director of the Disability Resource Center (DRC), ASU West Campus, who requested a meeting to address my concerns. The focus of the discussion was on updating current evacuation procedures to include guidelines that take into consideration all types of disabilities.

After much advocating, ASU West has begun to take steps in the right direction. The spring of 2009 saw the placement of fire refuge signs in every building on its campus. The signs designate a central meeting point in which during an emergency people with disabilities may gather to wait for help. As for changes in emergency protocol, the DRC Director is writing new emergency guidelines. I am in constant communication with campus faculty for updates as to whether or not ASU will adopt the new emergency guidelines. Also, I am working closely with disability rights organizations such as the Arizona Bridge to Independent Living and the Statewide Independent Living Council to apply pressure to ensure the safety of every campus visitor.

As leaders and advocates, it is critical that we continue to push for change lest we grow complacent or disillusioned.
community calendar

**Jun 27** [all day]  *“A Time of Service” Kickoff Event* (cost: free)

**Jul 4** [opens at 4pm]  **Tempe 4th** (cost: $5 - $8)

**Jul 24** [11:30am – 1pm]  *Coming Full Circle - Getting Back to the Original Intent of the ADA* (cost: free)

**Sep 21 – 23** [all day]  *Arizona’s Ninth Annual Transition Conference “Celebrate the Journey”* (cost: $110 - $150 for youth / family member)
Radisson Fort McDowell Resort, 10438 N. Fort McDowell Rd. – Scottsdale | 602-542-3855

**Sep 26 – 27** [12pm – 10pm]  **2009 Arizona Arab American Festival** (cost: free)
Murphy Park & The Amphitheater, 5850 W. Glendale Ave. – Glendale  |  602-412-1525 / www.arabamericanfestival.com/

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**A Quick Adventure in the Nation’s Capitol**

*By Brooke Brown*

I attended the Administration on Developmental Disabilities (ADA) South Information Centers TA Institute, March 15-19. The conference was held in Washington, D.C. The trip was very short, but the day before the conference began I did have an opportunity to explore a little bit of the city. My mom, Priscilla Perkins, and I spent the morning wandering the halls of the American History Museum. It was all interesting, however, the first ladies’ exhibit and seeing the first American flag, which inspired Francis Scott Key to write the National Anthem, intrigued me the most. Riding an actual subway for the first time was a rather fun experience because I’ve always loved the elements of big city life. And even though we were too late to see inside the Ford Theater, President Lincoln’s actual custom-made Brooks Brothers coat that he wore on the night he was assassinated was on display in the lobby. The bloodstains on the jacket are still very visible. (Talk about eerie.)

The conference consisted of grantees that all focused their services on youth and emerging leaders with various disabilities. During the afternoon breakout session for youth on Tuesday, I participated in giving a presentation called “Serving on Boards and Committees”. The presentation discussed techniques for and the importance of choosing a board on which to serve that matches one’s personal interests and goals. At the end of the main presentation, I facilitated a game called “On the Boardwalk”. The participating youths were divided into four teams that formed “corporations” on the boardwalk. The teams were asked five critical thinking questions regarding situations that may arise when serving on a board. For each question, one team sat out in order to be the judge. The team that won its round got to move a certain number of spaces on the board.

All teams seem to be enthusiastic about the game and the overall presentation. I felt as though most of the youths left our session with a better understanding of why it is important to serve on a board with a purpose that they feel passionate about. It was nice to be able to present something unique. In my opinion, all future SWI presentations, especially those directed at youth, should try to stray from the basic power point/lecture formats. I think if we make a conscious effort to engage our audiences in a more active capacity, we will see a higher retention of the information we are trying to communicate.

It was refreshing to see that SWI is not alone in its goal to foster powerful leaders who will leave a strong legacy in tomorrow’s world. I hope I am able to attend next year’s conference and see all the progress each grantee makes.

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To receive an electronic copy (PDF) of this newsletter, please send an e-mail message to g.garcia@swifamilies.org with SYF News in the subject line.