

National Alzheimer's Project Act (NAPA)

The information that follows was included as an attachment to an email submitted by the public.

For more information about NAPA, visit the NAPA website at:

<http://aspe.hhs.gov/national-alzheimers-project-act>

DOWN SYNDROME

News

REMEMBERING BILL

By Mary Hogan, Eliot, ME

He was the youngest of the nine of us. Each would probably remember him a little differently. Most of us smile a soft warm smile when we think of him. Since his death, many of us often greet one another with “his words,” the special way he said “Hello,” and quickly let you know he missed you and that he couldn’t wait to see you again — soon, very soon. Our stories and memories are different and in some ways they are the same. Maybe that is how it is when you look back on something special in your life.

My brother, Bill, died on February 25, 2010, in a hospital in Middletown, NY. He was 49 years old. He had Down syndrome. That part of Bill’s life seemed to be just incidental in many ways. He also had Alzheimer disease. That part of Bill’s life was his greatest challenge. Lots of people came that last day — to sing to him, tell him stories, rub his head and say thanks. And then he died. That was not supposed to be the way it happened, but that was the way it did. Somehow we knew that he would die soon. Sometimes we weren’t ready. He was. Mother Nature blanketed the earth with 32 inches of snow that day. It brought our world to a standstill.

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BILL AND HIS SISTERS IN 2008

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Atlanta, Georgia 30338**phone:** 800.232.NDSC **fax:** 770.604.9898**email:** info@ndscenter.org**website:** ndscenter.org**Statement of Policy and Disclaimer:**

This newsletter reports items of interest relating to Down syndrome and will provide a forum for others. The NDSC does not promote or recommend any therapy, treatment, etc. NDSC will not espouse any particular political or religious view. Individuals or organizations referred to are not necessarily endorsed by this publication or its editor. We wish to bring together those interested in Down syndrome and attempt to create an optimistic outlook and attitude.

The editor reserves the right to make corrections as are appropriate and in accord with established editorial practice in material submitted for publication. Submitting an item to the editor to use in *DSN* gives permission to do so.

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Mission

The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

Vision

The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

Remembering Bill

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In early March, after Bill's death, brain donation and cremation, he went home to the small town where we grew up. It was a community that embraced him from the start. It was a community that was there for him at the end. And so, in the midst of our sorrow there was great joy, the joy that my brother gave to many during his life and the joy that he received from those around him. Many people, including his first teacher, came to celebrate his life, tell a story, talk of his smile, relive a moment in time and let us know how Bill touched their lives. He was a good man who had a good life.

Bill was born on April 30, 1960. He came home after my parents made a conscious choice to bring him home. He learned to do things he wasn't supposed to be able to learn to do. He grew and changed and somehow thrived in our big family that was so often chaotic and disorganized. There were expectations that Bill would fit in, that he would behave and that we would take care of him. All of those things happened. Little kids sometimes took on big responsibilities. It did not seem to matter then, as Bill made us laugh and seemed to teach us lessons of love, tolerance and patience. In 1968, our father died. Bill seemed to become the glue that held much of this big family together.

At our mom's insistence, Bill entered the local elementary school and

attended kindergarten for two years, long before mainstreaming was even considered. He was described as a playful student who brought lessons about acceptance. He headed off to a Board of Cooperative Educational Services (BOCES) program for the remainder of his school career. He loved school, but hated to get up each day for that more than one hour drive in the little yellow bus to his school program. He acquired basic reading skills, learned to be a good swimmer, loved music, dancing and cheating at backgammon. With each passing year or two, one more of us would head out the door to college and begin our own lives, leaving one less person to assume responsibilities around the house and help with Bill. Eventually, over the course of many years, it was Bill and Mom. They enjoyed life together, for the most part, as they shared this big house in this little town.

Bill learned to bowl, with our mother as his demanding coach. She expected him to do and be his best. On the other hand, she was often ferociously protective. Bill maintained a paper route in our neighborhood but often preferred an abbreviated work week. He frequently insisted that he needed a day off to "sleep in" until 10:30, so Mom and her long-time companion traveled the neighborhood in her old Mercedes, stuffing those

mailboxes on many a Sunday morning. Nonetheless, Bill loved payday! Mom cooked dinner; Bill told her that the milk was good! It was their story.

Bill went to work at the local florist where he enjoyed a very special relationship with his boss and co-workers. In March, his boss talked of the special people who come into one's life. He told of the goodness in Bill's heart, his quick wit and flirtatious nature. He told of Bill's trips through the village after working, visiting with shopkeepers who became his good friends and guardians. His boss told of the day that he and Bill would meet in heaven and drive around in an old red truck, whistle at the girls and fix the flowers at the Pearly Gates.

Despite the richness of life, Bill faced many medical challenges. He had chronic ear infections and gastric issues. He had a very high tolerance for pain, so often it was hard to know that he was experiencing difficulties. He faced his first surgeries as a young man for hernia repairs, ear infections and for gastric complications. Many more unanticipated medical issues lay ahead for Bill.

When Bill was in his early thirties, he moved on to a group home in a small city near our hometown. This transition was easier for him than it was for our mother. Nonetheless, it was an important move for him as he became more independent, developed friends and had his own life. He continued to enjoy working

As he grew older and enjoyed more frequent haircuts, Bill became convinced that he looked like his hero, Harrison Ford.



in a sheltered shop, his paycheck and a sense of accomplishment. He loved "his staff" at the group home, many of whom worked with Bill for several years. They became his second family. As he grew older and enjoyed more frequent haircuts, he became convinced that he looked like his hero, Harrison Ford. On more than one occasion when flying independently to see family in Boston, he introduced himself to the flight attendants as the well-known actor. With delight, they confirmed his resemblance!

Bill eventually experienced severe bilateral hearing losses that required hearing aids. Over time he also developed a cholesteatoma, a destructive inner ear growth that required more surgery and eventually eliminated his ability to wear a hearing device in one ear. He grieved the reduced contact that he had with the outside world, anxiously asking when he would hear "better." His gastric issues complicated his life as he

experienced severe hypoglycemic episodes. His diet needed to be carefully observed to ensure that he maintained good health. Each new medical wrinkle required advocacy for Bill, to make sure that recommendations were followed, that he would be safe and well cared for, that complications would be avoided. Unbeknownst to us, in the midst of all the known factors that he faced, he had developed osteoporosis.

In 1997, our mother died unexpectedly. Because Bill had already made the move to a group home, the trauma of that loss was more tolerable for him. He had settled into his life in his group home and had a built in support system. He maintained close contact with his extended family and visited regularly, something he loved greatly. Though many siblings helped with Bill's visitations, one sibling became his primary

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Remembering Bill

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advocate, a role assumed until his death. In 1998, while vacationing with family, Bill fell and fractured his hip. Despite immediate and on-going medical attention, the fracture went undiagnosed for six weeks. One cannot help but ask how this happened as he repeatedly was taken for medical care at our insistence; but, it happened. The keen observations of a physical therapist prompted a diagnosis and eventual surgery requiring a partial hip replacement. Bill experienced his first stay in rehab. The family rallied and was a presence during rehab to ensure that his needs did not go unnoticed.

During those next few years Bill faced surgery for continued ear difficulties and a bowel prolapse. He developed a serious bone infection in his lower spine that made it very difficult for him to walk. He was hospitalized, stabilized and returned to rehab for treatment of his infection and physical therapy. He faced all of this with relentless good humor and few complaints as he worked hard to get back “in the game.” When he was back on his feet, he was thankful for his miracle. Advocacy again was the operative word, with the one family member willingly assuming the bulk of the responsibility. Over time it became harder for the family team to rally. As siblings aged and family demands and Bill’s needs increased,

the team sometimes tired. We were blessed to have reinforcements waiting in the wings ready to help. One loving husband and three family friends emerged to periodically help maintain the “we” in the team.

The diagnosis of Alzheimer disease in 2006 seemed unreal, a brief notation in a medical record made by a neurologist who did not really know Bill. It did not seem to relate to who he was in that moment in time. Gradually, over the next two years it became more apparent that diagnosis was correct. Bill began to have difficulty remembering the steps of his job and initiating self-help skills. The losses eventually became more pervasive and the changes far more noticeable. Familiar tasks became impossible to complete as interest in once favorite activities waned.

As Bill faced more debilitating changes due to Alzheimer disease, the need for advocacy greatly increased. His life at the group home was threatened as he was the first resident to face life-altering changes. We advocated for him to “age-in-place” as long as possible. We worked to make sure that he, his housemates and the staff were all safe; we worked to help his mates understand the changes, though we could hardly understand them ourselves. We worked to make sure that he was not marginalized in the medical community as he presented with problems that were not due to Alzheimer disease, but were often readily attributed to the disease. We



BILL HOGAN

were tenacious warriors in his defense. There was no choice. Though hard to locate, outreach to a family who had lost a son with DS to the complications of Alzheimer disease proved to be a godsend. They could provide support that only those who had endured the experience could offer.

In July of 2009, Bill began to deteriorate more rapidly and exhibit more challenging behaviors. Safety issues became a concern. Eight months before the end of his life, he left his old group home and second family and moved to a new group home that could better meet his physical needs. It was traumatic for Bill. It was traumatic for all of us. Though it was a difficult start in his new setting, he was blessed with a caring, attentive staff who worked hard to help him with all of his daily challenges. They learned his story; they came to recognize that we would support both them and him. They came to understand his losses and treated him in a very gentle, loving manner. He became a

part of their family and they became part of ours. We faced the end of his life together. It came quickly on that snowy winter day.

Over time, April 30th seemed to become a national holiday for many in our family. Bill typically began planning for his birthday shortly after we had celebrated Christmas. We listened for months to his litany of ideas and plans on how to celebrate the day. Sensing that changes were in the wind, we celebrated his life in grand style in 2007, with the birthday of all birthdays. He was born knowing how to celebrate. He had cause to celebrate. Life was generally good to Bill, but mostly he was good at life! In 2010, we buried Bill on what would have been his 50th birthday. It was a beautiful spring day and a simple celebration with an Irish prayer, a James Taylor tune and a homily about a man and his community.

Mark Twain was once quoted as saying, "Let us live so that when we come to die, even the undertaker will be sorry." Bill's was a life well-lived. We bid him adieu and can almost hear him signing off with his favorite, "Too-da-doo." Toodle loo to you, too, Bill. See you on the other side.

Editor's note: This article first appeared in the December 2010 issue of the American Association on Intellectual and Developmental Disabilities (AAIDD) Gerontology Division Newsletter with permission given to reprint in DSN.

Potpourri

Parents wanted for research study on language ability

Dr. Lizbeth Finestack, a professor in Speech-Language-Hearing Sciences at the University of Minnesota, Twin Cities, is working with Valerie Schmidt, a Masters' student in Speech-Language Pathology, to conduct an online survey of parents of children with Down syndrome (DS). The survey results will help researchers better understand parental views of their child's language abilities and speech and language needs. Through this survey, further research can be promoted in the language areas that concern parents most. Findings will also help educate other speech-language pathologists as to how to better serve children with DS and their families.

Parents of children with DS are invited to participate. This survey takes about 30 minutes to complete, and is completely anonymous. The information collected from this survey will be used for this research only.

To complete the survey, go to the study website at <https://survey.cla.umn.edu/66546>. To find out more about the study, please email or call Liza Finestack, Ph.D., CCC-SLP: finestack@umn.edu; 612-624-6090.

What Do You Want to Share?

D.S. Headline News is written by and for self-advocates (people with Down syndrome). You have important things to share, so write an article that will be printed in *D.S. Headline News*. People all over the country will read it! Send your article by **May 10** to:

D.S. Headline News
National Down Syndrome Congress
1370 Center Dr., #102
Atlanta, GA 30338
or Julie@ndsccenter.org

Don't forget to send your name, age, address, phone number and a photo of yourself to go with your article!

Acceptance

By Emily Simino, Age 15, Brentwood, CA

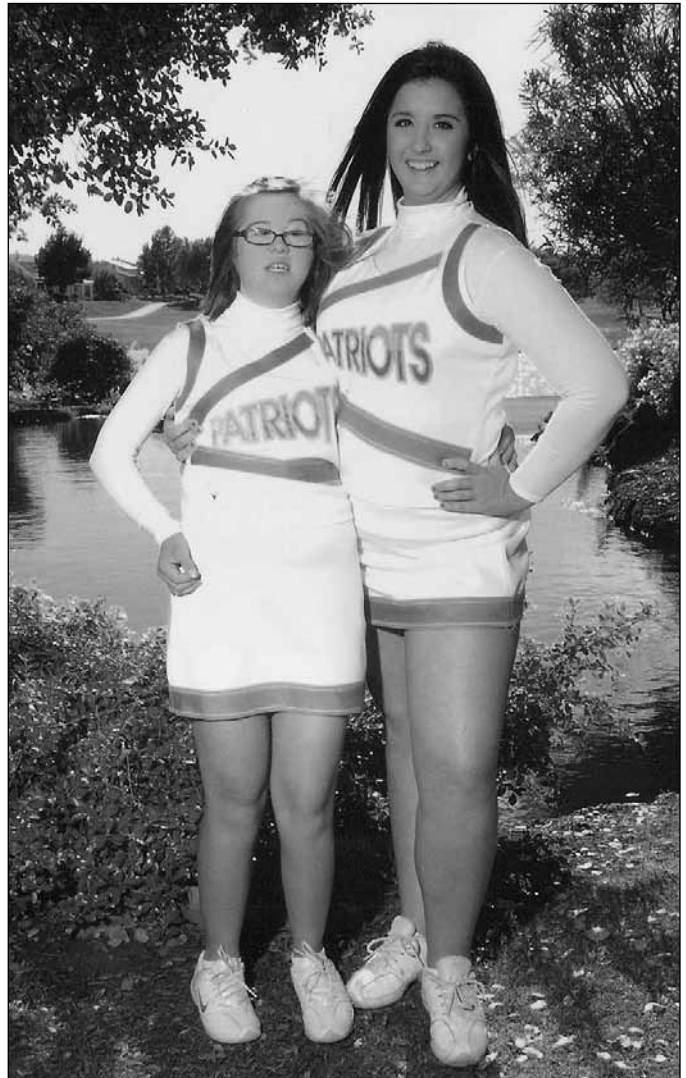
Many girls dream of being a cheerleader and inspiring others by promoting school spirit. Wearing the illustrious uniform clearly identifies one as belonging to something bigger than oneself. It's the ultimate desire so many teenage girls strive for — “acceptance.” This character-building experience can take on a different role. Ironically, cheerleaders may be thought of as self-absorbed, catty girls who measure value on looks and popularity. Constantly judging others harshly, they are reminded of their own mortality by researching each other's “Facebook status.” In reality, they all are searching for their own acceptance.

High school is difficult. Students are judgmental, teachers are overwhelmed, classes are overcrowded and campuses are dangerous. Acceptance is something that so many of us strive for and struggle with throughout high school and beyond. One does not need to climb Mt. Diablo or run a 10K to recognize the satisfaction of achieving a goal. Recently, my friend Emily has taught me a great deal about acceptance.

Emily McDaniel and I have been friends since fifth grade, but never had a class together. We hang out with the same group of friends, but we're not best friends. We love to swim, shop, bowl and dance together. We love cupcakes, pajamas and talking on the phone until all hours of the night.

Emily has always wanted to be a cheerleader. As a freshman at Heritage High School, she expected nothing less. Her concerned parents clearly understood it's difficult to be accepted in such a competitive arena, but they wanted to support Emily's dream.

For me, finding out that we both made the JV Cheer team was a dream come true. Life works in mysterious ways, and we should never forget that there is a plan for



EMILY AND EMILY

each of us. Little did I know at the time, Emily's presence on this team would be life-changing for everyone who took the time to get to know her.

You see, Emily has the ability to soften the hardest of hearts and recognize the very best in everyone. She measures one's value by the size of a smile and the sound of a laugh. Despite Emily's own daily challenges with “Up syndrome,” she exemplifies what a true cheerleader should strive to be. Emily radiates an inspiring awareness of the world and I find myself looking at life through her eyes. She has taught me (and

hopefully our fellow teammates), to suspend judgment and love unconditionally.

Behind every successful person, there is a support team. Emily has many “real life” cheerleaders that support her every day, including her mom, dad and older sister, Katie. In Emily’s eyes, being a cheerleader is just part of going to high school — as it was for Katie. Emily doesn’t realize the behind-the-scenes activity that took place. Heritage High is part of a school district that doesn’t seem to value this opportunity. Do they underestimate the positive impact? Do the “big shots” in their cozy offices even know what takes place on campus? To date, the district has never had a student with special needs be part of a cheer team. Emily’s mom, Michelle, is a seasoned parent who was all-too-familiar with what she was up against. Michelle made it happen without involving the “big shots.” For that reason, Emily — and hopefully other students — will have the opportunity to shine.

Our coach, Shannon, does not make a distinction between team members. When the coach makes us run because we are not listening, we all run — including Emily. When a girl talks back to our coach, Emily is quick to call her out — and we all run. When we practice our cheers, Emily shakes her booty with the rest of the team. Her spirit outshines any synchronized routine any day. Understanding the commitment, Emily never misses practice, takes great pride in her uniform and looks forward to “game days,” when she proudly shows everyone she is a member of the Heritage High School JV Cheer team.

Emily’s typical day is in a classroom of her “peers.” I often wonder why I don’t see her around campus. Is it really the best thing for her? Does that mean that I am *not* her peer, even though we are friends? Why don’t I see her at lunch? Why does Emily have to stay with her “peers” while our team hangs out together? Why does Emily miss out on campus activities — even though she is part of the cheer team?

I then realized the magnitude of it all. When Emily wears her uniform, she is no longer considered special, slow or whatever label people give her. She is a cheerleader! That really is the only label I can think of that truly describes my friend and it is her ticket out of the segregated environment where everybody makes decisions for her. It is Emily’s time to shine and show everyone that she is also a student at this school. As a cheerleader, Emily is accepted and respected as a significant member of our team.

To me, the uniform has become a symbol of acceptance. Each time I put mine on, I think of Emily. She reminds us all of the importance of teamwork, respect and school pride; and to always give 100% and take nothing for granted. Emily’s presence on this team has influenced all who opened their hearts to her message. So, it’s not hard to get fired up on game days knowing that this is the time for Emily to shine. She shows the whole school that she belongs, is accepted and that we are all in this together. It is a great life lesson, and that is why I need to share Emily’s lesson with everyone.

NEW MEMBER JOINS NDSC BOARD

Claire Odermann has been appointed to fill an open position on the NDSC Board of Directors. Claire lives in Monument, CO, where she owns a private music studio for piano and voice instruction. She has been an educator for over 18 years serving many students with Down syndrome (DS) and other special abilities. Claire’s very special connection to a young man with DS led her to join the Youth & Adult Conference Team in 2005. This is her first term.



“Why Are We Even Doing This?”

A Commentary on Including Students with Disabilities in General Education Contexts

By Stan Weser, Florida Inclusion Network, Ft. Myers, FL

At last summer’s NDSC convention, I was part of a workshop panel on *Facilitating Success for All in Inclusive General Education Classes*. During a discussion about what parents can do to push inclusion for their children when meeting resistance from school staff, a slightly exasperated parent in the audience asked, “Why are we even doing this?”

In my work at the Florida Inclusion Network, I see benefits every day of including students with disabilities in general education classrooms. I’m also aware that despite decades of research documenting the benefits of inclusion — for those who have disabilities and those who don’t — parents still have questions about whether inclusion is worth the effort. If you find yourself asking whether or not inclusion is worth it, I’d like to offer the following encouragement.

WHAT DOES THE RESEARCH SAY ABOUT INCLUSION?

A number of studies over the years have reported the various benefits of inclusive education. In 1996, the National Down Syndrome Society published a research report on the inclusion of children with Down syndrome (DS) in general education

classes. After analyzing and comparing extensive parent and teacher questionnaires, this study found that, “with proper support and adequate communication between parents, teachers, and professionals, inclusion is a favorable educational placement for children with DS.” The study also found that the learning characteristics of students with disabilities were more similar to their peers without disabilities than they were different.

Moreover, teachers reported positive experiences with students with DS. They described their students as “eager to learn, especially when encouraged, and reported personal satisfaction in terms of their professional achievements.” (Wolpert, G. 1996).

An analysis by Baker, Wang and Walberg in 1994 concluded that “special-needs students educated in regular classes do better academically and socially than comparable students in non-inclusive settings.”

Education Week conducted a survey that reported the performance scores of students with disabilities were typically 30-40% below those of students without disabilities

(*Quality Counts 2004*). The survey also found that the longer these students received so-called special instruction, the steeper their academic decline, resulting in inordinately high dropout and low graduation rates.

“If children with disabilities are to acquire the skills and behaviors they will need to function in the ‘real world,’ they must be instructed in the various environments which are part of that reality, and they must learn to interact with the many persons (handicapped and nonhandicapped) who live, work, and recreate in those environments” (Meyer, 1987).

DOES INCLUSION AFFECT THE LEARNING OF STUDENTS WITHOUT DISABILITIES?

Research by Hollowood et al., (1995) found that inclusion was not detrimental to students without disabilities. In fact, a national study of inclusive education conducted in 1995 by the National Center on Educational Restructuring and Inclusion (NCERI) reported academic, behavioral and social benefits for students with and without disabilities.

HOW WILL MY CHILD MAKE FRIENDS IN INCLUSIVE SETTINGS?

“Interactions with others enrich our lives and give us the chance to develop friendships and critical personal relationships which we all enjoy across our lifespan. We typically regard these interactions, relationships, and friendships as central to our personal well being. It is time for children with disabilities to share these experiences, so that these individuals will no longer be isolated from what is perhaps the most essential component of what we elusively refer to as ‘quality of life’” (Meyer, 1987).

“Students cannot learn social skills without opportunities to make friends, they cannot learn communication skills without interacting and working with classmates, and they cannot learn competencies related to behavior if they are not allowed to solve problems and work through difficulties with others in authentic environments” (Kluth, 2005). For students with disabilities, the **most** natural environment is the general education classroom and other school or after-school settings where peers without disabilities learn and socialize.

WHAT DO PARENTS SAY ABOUT INCLUSION?

Peck, Staub, Galluci, and Schwartz (2004) found that “inclusion is *likely* to be of substantial benefit to children without disabilities.” Survey results generally indicated that parents felt that being in an inclusive classroom was good for their child, particularly in terms of their child’s increased appreciation of the needs of other children and increased acceptance of differences in appearance and behavior among other children. Half of the parents responding to the survey also indicated that they believed the overall emotional climate of the classroom had improved when children with severe disabilities were included.

Survey responses indicated that:

- 78% of parents of children without disabilities indicated they believed their child’s progress had not been affected by their enrollment in a class with a child who had a severe disability.
- 15% of parents believed their child’s progress had increased.
- 67% reported that their child’s appreciation of the needs of other children had increased.
- 65% reported that their child’s acceptance of “differences among people in terms of behavior and appearance” had increased.

- 29% of responding parents perceived that their child’s positive feelings about herself or himself had increased since participating in an inclusive classroom,

Asked to indicate the overall impact of their child’s participation in relationships with peers with severe disabilities:

- 87% of these parents of children without disabilities indicated the impact had been positive.
- 12% of responding parents evaluated the impact of these relationships as “neutral.”
- 1% characterized them as negative.

WHAT CAN I DO?

While I hope I’ve provided convincing evidence that the benefits of inclusion are worth the effort, I’m also aware that in communicating with the school staff to make inclusion a reality for your child may pose a challenge. If so, here are some suggestions from The Florida Inclusion Network’s publication *Communication Tips for Families of Children with Disabilities*:

- Provide information to school staff about your child’s strengths, talents, interests and gifts. Creating a Student Profile will assist the school team to better

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“Why Are We Even Doing This?”

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design an effective educational program for your child. This reinforces the “Individual” in IEP.

- Clearly express your family’s future dreams for your child. When the team knows of your hopes and dreams, it helps them stay focused on your child as they plan for how to best include him or her. It also helps them to maintain the presumption of competence.
- Voice your concern for all children’s needs, not just those of your child. This helps inform school staff of your understanding of the difficulties they face in meeting the needs of all their students and reinforces your willingness to assist them in their critical work.
- Ask to be part of the decisions that school staff make about your child. When the school staff understands your desire and willingness to be a crucial part of your child’s team, they become

more attentive to the importance of these decisions in your child’s future.

- Gather and share information about the Individuals with Disabilities Education Act (IDEA) of 2004 and the No Child Left Behind Act (NCLB). Letting the school know that you are an informed parent willing to assist in bringing them current, relevant information helps to clarify the lens through which they filter data about your child.

More tips are available at www.floridainclusionnetwork.com.

Author’s note: Special thanks to Vicki Barnitt, Florida Inclusion Network Product Development Office, for her invaluable input to this article; to Vicki and Dr. Diane Ryndak, University of Florida for their mentoring and to Cheryl Liles, Director of the Florida Inclusion Network for her steadfast support for our work.

References

Baker, E.T., Wang, M.C., and Walberg, H. J. (1994). The effects of inclusion on learning. *Educational Leadership*, 52 (4), 33-35.

Education Week (January 8, 2004). Quality Counts 2004: Count Me In. *Education Week*, XXIII, No. 17, 1-153.

Florida Inclusion Network. *Communication Tips for Families of Children with Disabilities* [On-line] Available: http://www.floridainclusionnetwork.com/Research_Centers/CRSRL/Florida_Inclusion_Network/Products/Family_Fact_Folios.aspx

Hollowood, T. M., Salisbury, C. L., Rainforth, B., and Palombaro, M. M. (1995). Use of instructional time in classrooms serving students with and without severe disabilities. *Exceptional Children*, 61, 242-253.

Kluth, Paula. (2005). *Is This Inclusion? Questioning Removal, Rejection and Exclusion*. [On-line] Available: <http://paulakluth.com/articles/exclusion.html>

Meyer, Luanna H., (1987). *Why Integration?* [On-line]. Available: <http://www.mnddc.org/parallels2/pdf/80s/83/83-WIN-SUN.pdf>

National Down Syndrome Society, Elementary & Secondary Education – What is Inclusion? *Education, Development, and Community Life* [On-line] p.4. Available: http://www.ndss.org/index.php?option=com_content&view=article&id=58&Itemid=83&limitstart=3

National Study on Inclusion: Overview & Summary Report. *National Center on Educational Restructuring and Inclusion Bulletin*, v2 n2 Fall 1995 Record Details - ED389143

Peck, Staub, Galluci, and Schwartz (2004) *Research & Practice for Persons with Severe Disabilities*, 29, (2), 135–143

Wolpert, G. (1996). *The Educational Challenges Inclusion Study*. New York, NY: National Down Syndrome Society.

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The Broward Gold Coast DS Organization hosted a *Just Dance!* event on February 19, 2011, with music, costume characters and a visit from NDSC Board Member and self-advocate Patricia Moody who sang and signed in ASL. For information about bringing a *Just Dance!* to your school or community, contact the NDSC at 1-800-232-NDSC or info@ndsccenter.org.

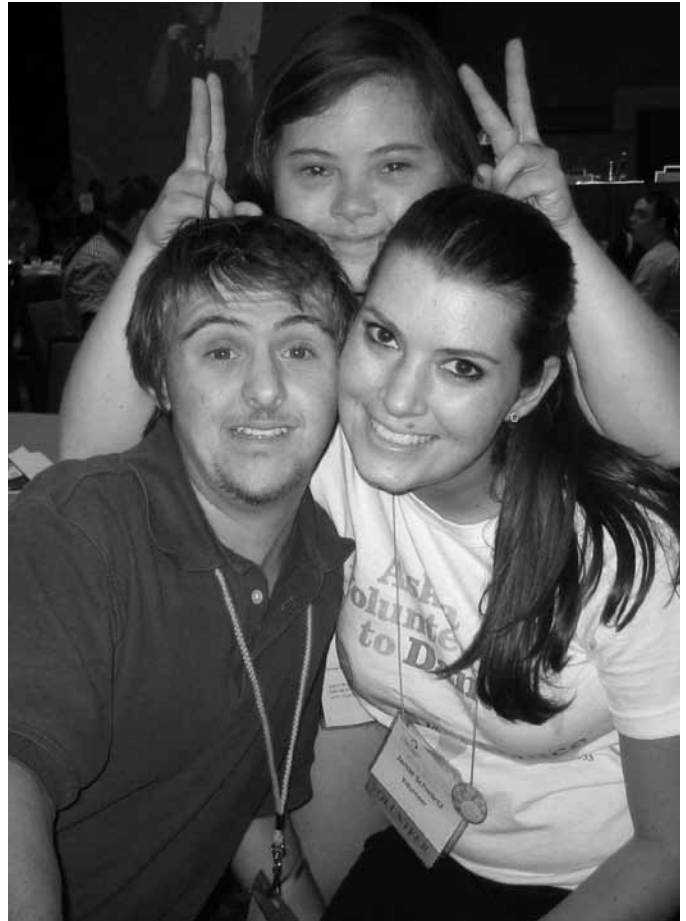
An Unforgettable Experience with the NDSC

By Jamie Schwartz, Orlando, FL

We all have life experiences which hold special places in our hearts. These life-changing moments often occur at unexpected times, as was the case for me last summer at the 2010 NDSC Convention. It was one of the best weekends of my life.

As a graduate speech-language pathology (SLP) student at the University of Central Florida, I enrolled in an augmentative and alternative communication class. Because I'm busy with both courses and clinical work, I surveyed the course requirements and saw that my classmates and I would provide communication supports for self-advocates attending the NDSC convention at Walt Disney World®. At the time, I anticipated it would just be one of the many course requirements along with exams, readings, labs, and writing assignments. After working with my professor, Dr. Jennifer Kent-Walsh, and staff from the DSA of Central Florida, the Florida Alliance for Assistive Services and Technology (FAAST), Atlantic Region Assistive Technology Demonstration Center and the NDSC to prepare for this experience, I felt ready to complete the class assignment. However, within minutes of meeting my six self-advocate partners for the weekend, I knew this service-learning "project" would be a life-altering experience. It was clear to me that I would be learning much more than how to support the communication needs of individuals with Down syndrome (DS).

On the first day of the convention in the huge ballroom that was the center of the action, I found myself in the midst of several hundred enthusiastic self-advocates who appeared to be greeting old friends and welcoming new friends with open arms as the Chris Burke Band got the party going. Since I had studied various forms of communication all semester, participating in interactive



JAMIE SCHWARTZ WITH TWO OF HER CONVENTION PARTNERS

songs that incorporated sign language was very fun. I realized that, as professionals, we need to think outside the box and ensure our clients are able to communicate in fun and engaging activities that are meaningful to them — like singing and dancing to music with friends! The supportive and non-judgmental atmosphere at the convention was obvious from this very first activity. Although I am a terrible dancer, it was liberating to have people I just met ask me to dance and realize they were not going to judge me for my questionable dancing

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An Unforgettable Experience

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skills. Instead, they complimented me on my efforts! Similar compliments were shared among everyone throughout the weekend, which really lifted up everyone.

My group attended a trio of spectacular workshops led by self-advocates where I noticed a recurring pattern of extremely positive attitudes and optimistic mindsets. We all tried new activities and strategies, such as making sushi and employing specific communication strategies, and the facilitators and self-advocates supported each other. Everyone was accepted, regardless of whom they were, what they looked like or where they came from with a consistent message that you can do whatever you set your mind to do. Throughout the weekend, the sincerity behind the interactions made it impossible to leave a session without feeling like you could take on the world if you were willing to try.

My experience at the 2010 NDSC Convention had a profound effect on my approach to clinical work and an even more meaningful effect on my outlook on life and my interactions with others. Although many people would say that I have always been an enthusiastic and energetic person, I can honestly say I have a new “spark” and pep in my step! I know that experience taught me far more than what I needed to know to meet my course objectives. Many individuals thanked me for helping that weekend, but I am grateful for the opportunity to play a small part in such a positive experience. At the conclusion of this wonderful journey, I made plans to attend the 2011 NDSC Convention and many more. I hope you will consider joining me and so many others this year in San Antonio, TX. I guarantee you will end up with many memories that will forever have special places in *your* hearts!

Editor's note: To find out more or to volunteer for the San Antonio convention, visit www.ndsccenter.org and click on the “Volunteer” link.

Treasures from the Heart Silent Auction

By Martine Hobson, Chair,
Silent Auction Committee

As you may have heard, the NDSC Silent Auction will return to the NDSC Convention this year in San Antonio. With a theme of **Treasures from the Heart** from Deep in the Heart, it promises to be a fantastic addition to an exciting weekend. The silent auction will be Friday night, August 5, from 8 to 10 p.m.

The Silent Auction Committee would like your help in making this event a success. Please consider donating an item from your parent group, business or family. You might make a gift basket around a specific theme, such as reading, children, relaxation, cooking or showcasing your home state or community. You could also donate a gift certificate, piece of artwork or craft, sports collectibles or toys. Items created by self-advocates (original artwork, photography, jewelry) are especially popular. The sky's the limit! **And** the proceeds from this event target NDSC programs that promote independence and self-advocacy skills for people with Down syndrome.

Thank you in advance for your support for the 2011 silent auction. We look forward to seeing you in San Antonio!

Kendra Scott Jewelry Sales Benefit NDSC

Jewelry designer Kendra Scott has teamed up with Issie, a self-advocate who loves to draw hearts, to create the Issie Heart Collection. A portion of proceeds from the jewelry sales will benefit the NDSC. Take a look and order at www.kendrascott.com.

National Down Syndrome Congress Convention

FRIDAY THROUGH SUNDAY, AUGUST 5-7, 2011



SILENT AUCTION

Treasures from the Heart Silent Auction & Reception

Friday, August 5

8 to 10 p.m.

JW Marriott Hill Country Resort

Grand Oaks Ballroom Foyer

Looking for a fun and easy way to help support programs which promote independence and self-advocacy skills for people with Down syndrome? If so, please consider donating an item for this year's silent auction, to be held during Friday night's reception. In the past, individuals, families, affiliates, and businesses have all contributed to support this worthy cause. Tax-deductible donations range from gift certificates, artwork, crafts, sports collectibles, and toys, to gift baskets with themes such as reading, kids, relaxation, cooking or showcasing your hometown or region.

Silent Auction Donation Form

Name: _____

Organization Name (if applicable): _____

Address: _____

Phone: _____ Email: _____

Brief Description of Donated Item: _____

Estimated Value: _____

Please Check One:

I'll bring the item(s) to the convention by noon on Friday

I'll ship in advance to: DSA of San Antonio
2800 NW Loop 410
San Antonio, TX 78230

Return no later than July 15, 2011, to:

NDSC, ATTN: Martine Hobson

1370 Center Drive, Suite 102

Atlanta, GA 30338

1-800-232-6372 Fax 1-770-604-9898

Direct: 1-901-262-0473

Email: mhobson584@aol.com



Resources: Book Reviews

BIENESTAR MENTAL EN LOS ADULTOS CON SÍNDROME DE DOWN: UNA GUÍA PARA COMPRENDER Y EVALUAR SUS CUALIDADES Y PROBLEMAS EMOCIONALES Y CONDUCTUALES

by *Dennis McGuire, Ph.D. & Brian Chicoine, M.D.*
(Woodbine House, 6150 Bells Mill Rd., Bethesda, MD 20817, 1-800-843-7323, www.woodbinehouse.com), 2011, (441 pp.), paperback, \$29.95

Carentes de antecedentes inmediatos, y conscientes de que su empresa era eminentemente creadora, el equipo liderado por un trabajador social clínico, el Dr. McGuire, y un médico internista, el Dr. Chicoine, se dedicó a analizar exhaustivamente cada caso que acudía a su centro de adultos para seguirlo de cerca y poder establecer cuánto había de problema físico, cuánto de problema conductual y qué estrecha correlación podría establecerse entre ambos. De este modo, la experiencia acumulada en el análisis caso por caso, se fue destilando con exquisito rigor en la elaboración de criterios y categorías fielmente compilados y reflejados en este libro.

En la primera parte se aborda la explicación de las características propias de los adolescentes y adultos con síndrome de Down, a lo largo de capítulos que exponen temas tan apremiantes como:

- Apoyo de la comunidad y la familia.
- Soliloquios y amigos imaginarios.
- Problemas relacionados con la comunicación.
- Puntos fuertes y débiles de la memoria.

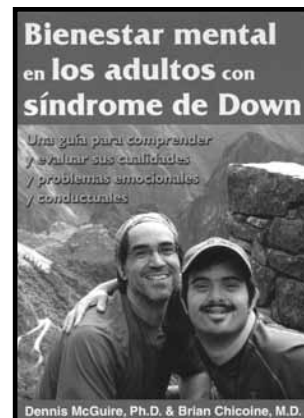
- Desarrollo emocional.
- Tendencias a la repetición y la monotonía.
- Autoestima e imagen de uno mismo.
- Temas relacionados con las diversas etapas de la vida.

La segunda parte aborda de forma sistemática la patología conductual y mental que en ocasiones aparece a lo largo de la vida, con capítulos dedicados a:

- Depresión y otros trastornos del estado de ánimo.
- Ansiedad.
- Psicosis.
- Trastornos obsesivo-compulsivos.
- Tics y otros movimientos repetitivos.
- Trastornos por déficit de atención con hiperactividad y otros temas relacionados con el control de impulsos.
- Autismo.
- Enfermedad de Alzheimer.

Para cada situación, los autores describen los signos problemáticos, el proceso diagnóstico y un abanico de opciones terapéuticas, como asesoramiento, terapia conductual y medicación.

Editor's note: A review of this book appeared in English in Down Syndrome News, Vol. 29, No. 6.



Resources

Development News

By John Kupris, NDSC Development Director

CREATING YOUR LEGACY AT THE NDSC

In 1994, Ms. Dolly Riedel celebrated a signature event when she became the first person to create a major legacy for the NDSC. Her estate gift of \$752,451.56 established an endowment for the NDSC, which formed the NDSC Foundation on December 30, 1994. Dolly's generous gift has ensured the NDSC is able to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome (DS). Dolly shared NDSC's vision of working to create a world with equal rights and opportunities for people with DS.

The NDSC Heritage Society honors Dolly Riedel and all other legacy donors to the NDSC and NDSC Foundation who make planned gifts that will benefit and strengthen our programs and membership into the future. Although there are many

financial and tax benefits that accrue to the legacy donor and NDSC Heritage Society members, the greatest benefit of all is the satisfaction of creating a gift to support the NDSC's mission.

Dolly Riedel truly created a legacy for a greater purpose — and you can, too. The NDSC invites you to create a lasting and meaningful legacy to help fulfill our mission and to live it out fully today and into the future. A legacy gift provides support for all people with Down syndrome.

Leaving a legacy to the NDSC can be accomplished without involving NDSC staff. However, the NDSC offers to collaborate with you and your advisors (tax, legal and/or financial) as you create your values-based gift through your estate plan. Your charitable goal may reflect an important milestone in your life,

memorialize a loved one who has guided you, express your hope for the future, or any number of other personal objectives or reasons. Working with the NDSC, your gift can be tailored to achieve your individual dreams and to complement your other financial and estate planning objectives.

An advantage to working with the NDSC staff is assurance that your charitable designation is understood and your wishes can be achieved. It also allows the NDSC to express its gratitude for your legacy!

Benefactors who plan legacy gifts with the NDSC will find the process satisfying and a reason for donors, family, advisors, NDSC members and others to celebrate.

For more information on giving to the NDSC, please contact me at John@ndsccenter.org.

Create a lasting and meaningful legacy to help fulfill our mission and to live it out fully today and into the future.

Down Syndrome News is a benefit of your annual membership in the National Down Syndrome Congress. To renew or join today, visit ndscenter.org or call 1-800-232-NDSC (6372).



1370 CENTER DRIVE, SUITE 102
ATLANTA, GEORGIA 30338

[NDSCENTER.ORG](http://ndscenter.org)

DOWN SYNDROME *News*

A newsletter published throughout the year
by the National Down Syndrome Congress.

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Now is the time to register for this year's NDSC Convention at the JW Marriott Hill Country Resort in San Antonio, TX, August 5–7, 2011! Convention brochures are in the mail and online registration is in progress at www.ndscenter.org. Register by Friday, June 24, and save money by taking advantage of the “early bird” general convention registration discounts.

We hope you join us at this year's largest annual gathering of self-advocates, families and professionals as we come together to learn, grow, celebrate, connect, share — and dance!

La convención anual del NDSC se lleva a cabo del 5 al 7 de agosto del 2011 en el hotel JW Marriott en San Antonio, Texas. ¡Ahorre dinero! Llene su inscripción electrónica antes del 15 de julio en el sitio de internet www.ndscenter.org. El folleto de la convención ya fue enviado por correo a los miembros del NDSC.

Esperamos verlo en la reunión más grande de jóvenes y adultos con síndrome de Down, sus familias y los profesionales que los apoyan. Todos juntos vienen a aprender, celebrar, intercambiar, compartir y bailar.



**39th Annual
NDSC Convention
August 5 – 7, 2011
San Antonio, Texas**