

DOWN SYNDROME

News

WITH A LITTLE HELP FROM HER FRIENDS

By Jan Tobin, Arlington, MA

Throughout her life, my daughter, Kate Bartlett, had the opportunity to be educated in regular education classes. The benefits to Kate, who has Down syndrome (DS), are both obvious and great. At age 25, Kate is an articulate, socially appropriate college student and part-time employee. She works hard and learns by observing and absorbing everything around her.

As her parents, we knew a typical educational experience and social life were important to Kate's development. We gently coaxed the school system to include Kate in regular education classes, insisted it was worthwhile to let her try and promised we would help at home with school work and assist in class when it was necessary. From time to time, a few administrators and teachers resisted, but Kate's motivation and ability quickly won over most of them. This successful experience required Kate's hard work and determination with much support from her family and teachers. Less obvious was the tremendous

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KATE AND BEST FRIEND ERIN

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With a Little Help From Her Friends

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peer support her classmates provided.

We readily admit that we worked as hard on Kate’s social life as we did on her academics. During Kate’s early school years, she easily made friends and was invited for play dates. We frequently invited her friends to our home. Kate and her younger brother also played youth soccer, with my husband or I

sometimes involved as coaches. Kate was also a member of a Brownie and then a Girl Scout troop. Each year, I met with the group leaders and offered assistance when needed.

These activities helped expand Kate’s circle of friends — and support. When there were problems, it was often her peers that noticed and found solutions. For instance:

- At a first grade recess, the boys were throwing a football around and Kate asked if she could join them. A couple of the boys rolled their eyes but Tyler stepped up and said, “Let’s let her play, Kate has a good arm.” Kate played.
- Kate’s fourth grade teacher had a restroom sign-out sheet and required each student to look at the analog clock and record the time they left the classroom. Kate couldn’t read an analog clock. When she looked confused, the student who sat at the closest desk would whisper the time to Kate. Problem solved.

- In fifth grade gym class, relay races were all the rage. After one race, one young man screamed at Kate that it was her fault their team lost the race. Kate was shaken, then reported to me that the rest of the team yelled back at him that it was not her fault and reported the incident to the classroom teacher, who spoke with the young man.

With fewer activities, middle school was a social challenge. Kate no longer had the interest, skill or ability to play soccer at a competitive level. In general, the girls were no longer interested in Scouts and her Girl Scout troop disbanded. Kate still interacted with her best friend, Erin, whom she’d known since third grade, and a few others. She clearly didn’t have a very active social life outside of our family.

To keep Kate connected in high school, we sought out groups like the swim team and chorus and continued expanding her circle of friends. Both were quite successful.

Kate asked the swim coach if she could practice with the swim team and he encouraged her to attend the team’s first meet. Kate thought she was there to support the team, but the coach and team captains had a different idea. As we sat in the stands — thrilled that Kate was included — we watched as the captains walked Kate over to get in

Less obvious, but just as important, are the benefits that including Kate brought to her classmates.

place for the freestyle relay race. It was overwhelming to listen to the crowd cheer harder for Kate than for any other swimmer.

At that first meet, Kate did not jump off the starting platform, but went in from the side of the pool. When it was her turn to swim in the relay at the next meet, two senior girls stood on either side and put out a hand to help her up on the starting platform. From then on, Kate dove off the platform — with a little help from her friends.

Every year, the chorus and orchestra took a bus trip to perform at other high schools. In Kate's four years, the chorus traveled to Quebec, the Hudson River Valley and Charleston, SC. The trip to Quebec went off without a hitch because Erin still lived in town. After Erin moved away, we worried about what would happen on the other trips. Lo and behold, not a problem. Each time, Kate was invited to room and hang with a group of girls. Kate *loved* chorus. We loved the

wonderfully kind chorus members and faculty.

Because Kate had always been included in regular education classes, most students knew or knew of Kate. With a little help from her peers, high school events like dances, plays and sporting events also provided for a more active social life.

Proms and dances are stressful, even for students who do not have disabilities. Erin took care of Kate's dress, hair and make-up and went with her to the freshman dance. Erin always did (and still does today) a superb job of including Kate and subtly coaching her interactions.

The sophomore dance was a bit more challenging since Erin no longer lived in town. Kate's two high-school aged cousins, Holly and Julie, escorted her to the dance and did a great job facilitating. This is the dance where she met Nolan — but more on him later. Kate found groups of girls to go with to her junior and senior semi-formals.

Kate was supposed to attend the junior prom with a friend — who cancelled just two days before the dance. When Kate reported this to me, I told her we would make some phone calls. Kate responded that she'd already taken care of it and had asked Nolan, a senior and captain of the school's hockey and baseball teams, to take her.

I was worried. Had Kate elbowed her way to the senior athletes' lunch table to sit with Nolan at the

expense of being a laughing stock? Were three successful years of high school undone in one lunch period?

Nope. When the phone rang that night, it was Nolan's mother, Mary. Nolan wanted to take Kate to the prom and asked Mary to make sure it was okay with us. We had no doubt that such a sensitive and confident young man would ensure

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KATE AND NOLAN

With a Little Help From Her Friends

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Kate had a great time at the prom. Remembering that phone call still brings tears to my eyes.

However, that was not the end of the story. On the day of the prom, Kate went to the school office, tried to buy Nolan a ticket and was told that it was not possible. No explanation provided. Kate returned to the lunchroom and burst into tears. Nolan wasn't in school that day, but friends, cousins and people she really didn't know tried to console her. Some even called and left messages for us.

I did speak to the house dean that time and politely explained it was an unusual situation. Nolan was setting a great example for everyone and should be allowed to go to the prom. According to the house dean, students had been in and out of his office all afternoon. A dozen or so had even offered to give up their tickets to Nolan. As the dean thought about this, he changed his mind and handed me a ticket for Nolan.

For her senior year, Kate asked Sean, a classmate who had graduated the year before and was in college locally, to go to the prom. A friend since preschool, he graciously accepted her invitation.

It's clear that Kate had a fun and successful school experience both academically and socially. A number of school friends are still in Kate's life: Erin, of course; Corey; Maureen; Jessica and Becky. Despite their busy lives — they work, some are married and one has a baby — they still make time for Kate.

Less obvious, but just as important, are the benefits that including Kate brought to her classmates. They were great kids, who are becoming wonderful adults. I like to think that the experience of going to school with, supporting and standing up for Kate made them a little more empathetic, understanding and tolerant. The kind of people who offer help to those they meet in life. The kind of people we'd all like to count as our friends.

From Our

STEVE GRABEN of Springfield, IL, writes:

When my youngest daughter, Camille, was diagnosed at birth with Down syndrome (DS) I was upset. An old friend, whose child with DS had been born a few months earlier, tried to console me with all that our children could do. I explained, "I don't care about the DS. She's my third girl — I wanted a boy."



Our family loves water. We live on one lake and own another. While the rest of us would water ski, Camille was content to ride in the boat or an inner tube until the summer she was 12 and learned to ride a bike without training wheels at a *Lose the Training Wheels* summer camp. Camille decided that she wanted to learn to ski like the rest of the family.

Camille was on the boom, a training device which sticks out of the side of the boat and allows the skier to steady herself on the water. The instructor is just a few feet away from the skier, which allows coaching. Camille popped right up each time with great form. My driver suggested it must be due to all

Readers...

of the observing she'd done of the rest of us. We added a five-foot handle to the boom, which forced Camille to balance right from the start. Again, she did great.

After a short break, Camille got in the water and grabbed the end of the 75-foot ski rope. I slipped into the water with her to steady her. On just the third try, Camille went 100 feet. That year, our Christmas card photo featured all five family members skiing!

That was two years ago, Camille is now a hot dog, skiing in and out of the wake, waving to the crowd and playing around. Next summer, it's time to drop a ski and ski slalom!

Editor's note: If interested in water ski lessons, contact Steve at llds@comcast.net.

SUSAN RACKERBY
of Simi Valley, CA, writes:

My 27-year-old son, Michael Ponce, attends a day activity program in our community. Sometimes, Michael brings a lunch from home. When he does, I make his sandwich and leave it in the refrigerator before I go to work. Michael gets himself up and ready and adds other items such as a drink, pudding or fruit to his lunch.

There have been some recent staffing changes and Michael does not always readily adapt to change, so I have been getting some phone calls about compliance



**MICHAEL
AND
FIANCÉE
KRISTINA**

issues. Well, one day I got a phone call at lunchtime and a program staff member told me they were having a problem with Michael. When I asked what was going on this time she said "He brought a wine cooler to have with his lunch and he won't give it up!"

When I stopped laughing (which I know she didn't appreciate), I explained that the wine coolers were Michael's, bought for him and his fiancée, Kristina, to drink at home. Michael must have just innocently picked it up instead of a Gatorade. The staff person put Michael on the phone so I could explain that the wine coolers were just for at home and he needed to save it and all was well.

When I relate this story to people who know Michael, everyone says they want him making their lunches. I think we all need to remember to laugh sometimes!

The NDSC Silent Auction Is Back

This year's NDSC convention in San Antonio will mark the return of a silent auction during the Friday evening reception. Please think about contributing an item or volunteering to help. Watch for more information in the next *Down Syndrome News*. In the meantime, contact Silent Auction Chair Martine Hobson at mhobson584@aol.com with any questions, ideas or potential items to donate.

EVERYDAY MATH

By Dana Halle, Newport Beach, CA

Many parents think math just involves numbers and calculations. But basic math involves much more, including sizes, shapes, colors, measurements, time, place and money. These basic concepts provide a necessary backdrop for using numbers and helping children process, organize and communicate about math.

At a very young age, children carry out routines, play games and face choices involving math. For younger children, math might be *more* Goldfish or *no* broccoli. Math language helps describe a *round* ball or a *yellow* butterfly. Math may be *five more* minutes, *yesterday's* movie or *tomorrow's* birthday party. Math also is keeping score during a game; helping cook, shop or sort laundry; and choosing an outfit that “matches.” As our children grow, math skills more directly relate to practical success. Math becomes waking up in time for school, tracking homework dates and bringing enough money to buy popcorn at the movies. Math matters, because math concepts help our children understand their

world and prepare for greater independence.

While research regarding the math capabilities of children with Down syndrome (DS) lags behind research in some other areas (such as literacy skills), present data suggests that early introduction of math to children with DS may enhance their ability to comprehend math concepts later in life.¹

Evidence suggests:²

- Children with DS master the early steps in counting the same way as other children, but at a slower pace.
- Instruction will be more effective if math tasks are broken down into smaller steps, taught with more repetition and made highly visual.
- Parents should use math language early and often.
- Parents can help compensate for challenges; for instance, choose larger objects to count when using manipulatives; support handwriting challenges by offering alternatives (computer,

stamps, number cards, dictation); provide visual supports (number lines, times tables, calendars).

- Math achievement varies widely among children with DS.
- Multi-sensory math programs — like Numicon³ — work well to support early learners because they provide concrete number images.
- Children with DS sometimes have difficulty generalizing math knowledge (information learned in one setting or used in one way may not transfer to other settings or other applications), so parents should help their children understand how to apply math skills in everyday situations. Make math meaningful.

As with early literacy instruction, parents can play an important role in introducing and reinforcing math concepts. Some parents avoid math instruction, fearful it will be too complex or unsure of where to begin. Cast aside any bad memories of high school geometry and you may find it simple and fun to work with your child on math at home!

1 Bird, Gillian and Buckley, Sue, *Number Skills Development for Infants with Down Syndrome (0-5)* (Down Syndrome Education Intl. 2001). Free to download at <http://www.down-syndrome.org/information/number/early/>.

2 Bird, Gillian and Buckley, Sue, *Number Skills for Individuals Down Syndrome — An Overview* (Down Syndrome Education Intl. 2001). Free to download at <http://www.down-syndrome.org/information/number/overview/>.

3 Numicon is a multisensory program that supports learning of math concepts. It is distributed in the U.S. by DownsEd USA (<http://store.downsedusa.org/>).



USING A NUMBER LINE TO COUNT GOLDFISH

Down Syndrome Foundation of Orange County has a number of free online resources available. Register for free access to The Learning Program™ materials to download math worksheets at www.dsfo.org. Email info@dsfo.org to request an Everyday Math activity handout, Early Number Cheat Sheet or list of math-related resources.

To read more about math research or for ideas on working with your child at any age, visit www.downsed.org and review DownsEd International's Number Skills series. DownsEd is in the process of developing math materials for its *See and Learn* series. *See and Learn Language and Reading* materials are available now at www.seeandlearn.org. *See and Learn Speech* materials are expected later this year.

Where to begin? As with most instruction, consider your child's **age** and **experience**.

Activities should be age appropriate. Parents will have more success working with their children when they match age with activity. If you can slow down your three-year-old for a few minutes, try play-based math activities with books, music, toys, food or objects that interest your child. Point out colors or shapes in a book. Sing a counting song. Identify “big” and “little” toys or count and sort blocks. Similarly, as your child's attention span increases, work with your four- or five-year-old at a desk or table to prepare for the kindergarten learning environment. Children

may not even notice they are “working” if exposed to math activities during snack time or right after a meal (*we can make a pattern of grapes and Goldfish or let's see if we can match these cards to our number line before we clear the table*).

Once children start elementary school and grow accustomed to structured learning, parents can vary between table-top and play-based activities. Take math lessons “off the page” and parents make math more meaningful and provide an incentive to complete homework (*once we finish this worksheet, let's use our fractions to bake cookies or when we're done with our addition homework, should we play Sum Swamp?*⁴).

Base activities on your child's math experience. At-home instruction allows you to support learning at your child's exact math level. If your child lacks prior exposure to math, take the initiative to introduce it. Use simple math language, label colors and shapes, sing counting songs or perform simple counting tasks. A child with some math knowledge might start work at home sorting by color or shape, counting with support to five or 10 or identifying numerals.

Once children start school, at-home math support becomes more structured — and, in some ways,

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4 Sum Swamp is a fun addition and subtraction game available on www.amazon.com.

Everyday Math

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easier. Meet with teachers and review the “math standards” for your state (usually available online through your department of education) to learn what is being taught in the classroom, and reinforce those lessons at home. Parents can also lay the foundation for upcoming math topics.

Parents working at home with newer learners might focus on:

PRENUMBER CONCEPTS:

1. Sorting (grouping objects based on similarities — color, shape, type, size)
2. Ordering (comparing items based on differences)

3. Patterning (repeating sets of shapes or numbers)

EARLY NUMBER CONCEPTS:

1. Rote counting (child learns names of the number words in the correct order — “one, two, three,” etc.)
2. Counting with meaning (traditional counting of objects)
3. Number symbol recognition (knowing that the word “five” looks like “5”)

Parents working at home with older learners might focus on:

1. Skip counting (counting by 2s, 5s or 10s)
2. Operations (addition, subtraction, multiplication)
3. Time

4. Money
5. Fractions
6. Measurement

Activities should make math meaningful. As a parent, you have an opportunity not available to teachers — the resources and flexibility to create teachable moments that put math in context. When teaching money concepts, go to the store and make a purchase. Teach fractions by cutting a pizza in halves, quarters, sixths and eighths before eating it. At home, sorting laundry or emptying the dishwasher becomes a math task. During simple everyday activities, math makes more sense.

Math is every day, everywhere. Working on math concepts at home helps pave the way to math success in school and independence in life. Best of luck and enjoy this opportunity to connect with your child through math!

Editor’s note: Dana Halle, J.D., is the parent of 12-year-old Nick, who has DS; executive director of Down Syndrome Foundation of Orange County; and developer of The Learning Program™, a nationally-recognized program that delivers evidence-based educational support to children, parents and teachers. Halle also is vice-president of Down Syndrome Education USA, a U.S. non-profit affiliated with Down Syndrome Education International (DownsEd), a recognized world leader in scientific research into early intervention, education and cognitive development for children with DS.



PRACTICE MATH WHILE COOKING

CAUSE FOR

Celebration!

A feature celebrating personal triumphs.

DSN invites readers to share their own cause for celebration — first steps, first tantrum-free haircut, successful toenail clipping or keeping glasses on a nose instead of watching them fly across a room. The event doesn't have to be momentous for anyone other than your family, but other readers are likely to relate and share your joy. Submitting something doesn't guarantee it will be included, but we know that you want to celebrate — and we want to hear about it. Send it to Julie@ndscenter.org with the subject title: Cause for Celebration!

**Kristen Faulkner of Pfafftown, NC,
shares this long-awaited moment:**

Ethan has never been a fan of teeth brushing and attempts typically brought on head thrashing, back arching, biting and crying. We struggled with the responsibility of good oral hygiene and concern about inflicting trauma on Ethan by trying to enter his mouth. Multiple therapists advised us not to force teeth brushing if it caused such a traumatic response.

The semi-annual visit to the pediatric dentist required Ethan to be placed in a “papoose” so that the dentist could examine Ethan’s teeth and gums. When we left the dentist’s office, Ethan was always sweaty with broken blood vessels all over his face from his intense crying.

We had begun wondering if brushing Ethan’s teeth would ever be done without a fight or struggle. Then, after almost 10 years of trying, it finally happened — Ethan allowed us to brush his teeth! We were thrilled to be able to brush Ethan’s teeth without inflicting a

traumatic experience upon our son — or us.

Just as we celebrated when Ethan began to walk, we celebrate this great leap forward. A seemingly tiny accomplishment for some, this is a giant step on Ethan’s climb to the top of his personal Mt. Everest.



**Nicos and Renee Vekiarides of Natick, MA,
share this recent cause for celebration:**

Our seven-year-old daughter, Anna, is fully included in a first grade general education classroom and gets a homework packet every week. Anna and her classmates are supposed to memorize a four-line poem, draw a picture about the poem and then present it to the entire class at the end of the week. We weren’t sure how this was going to play out with Anna, but we gave it our best shot. Every night, we sat down with Anna and worked on memorizing the poem. By Thursday night, she had it down. We proudly emailed a video of Anna reciting the poem to her teacher, who was thrilled!



In class the next morning, one by one the other children in the class got up and recited the poem. When it was Anna’s turn, she froze. This wasn’t entirely unexpected, as Anna’s personality is tentative by nature. So, her teacher took Anna and two peers out into the hall where Anna successfully recited the memorized poem. This pattern continued for several months and was, in itself, all cause for celebration. Then, in January, Anna was able to stand up in front of the entire class and recite the whole poem while holding a good friend’s hand. At this point, she has done it two weeks in a row and has a huge sense of accomplishment, which is recognized by and shared with the whole class!

Why I Chose Special Education

By Norma Z. Smith, Baltimore, MD

Editor's note: Last summer, this essay arrived in the mail along with a short note explaining that Mrs. Smith, now 91 years old, had found it when destroying old school materials. She wrote the essay in 1973 for a college course, Introduction to Special Education, and thought it might be of interest to Down Syndrome News readers.

Society — and some language — has changed a great deal in the last 40 years, but many of the experiences, struggles and possibilities this mother writes about will likely resonate with parents today.

When thinking about the past, I must report that originally I did not choose special education but over two decades ago special education chose me. At that time, the birth of my second child abruptly changed my dreams and goals for my family and my future nursing plans. Here-to-fore, my plans had not included using my nursing skills working with children with cognitive disabilities. Yet only a few years ago, when I had the opportunity to redirect my career, I chose to continue nursing within the confines of special education.

During the years of the Depression a nursing education offered one of the few hopes of higher education to a small town girl. Training in a large medical center, surgical nursing became my foremost interest and in this field I began to specialize. The war intervened and then marriage, so that another aspiration ensued. My children would be prepared and able to secure the college education and other amenities that I so far had been unable to obtain.

My first daughter, a promising child, showed evidence of fulfilling my dream. But my second daughter's birth shattered the dream and in a short time made me realize that I had to learn a whole new set of values. I had become one of the Unfortunate — the parent of a child with a cognitive disability. In this crisis I had the unfailing support of my husband, without which I doubt if the following events could have happened.

The need for securing special education for our daughter came to the forefront when she was not allowed to continue in a summer Bible school. At that time we began

in earnest to look for a school which would accept her. Correspondence and visits brought us back to Baltimore where she was placed in a special school setting. At this time, we were indeed fortunate as any children with her type of disability were not accepted in any school due to lack of classrooms, limited number of teachers, transportation problems and lack of community support.

I first became an active PTA worker, then a substitute aide, and finally was offered a part-time nursing position. This was most acceptable as I could work in nursing and still be home with the children when they were not in school.

As I continued working, my admiration for the teachers grew and my interest in all kinds of cognitive disabilities increased. The children captivated me and my personal experiences aided me in becoming a parent advocate. I was able to give insight into the family problems to the staff; and, in turn, I learned better ways to handle my own children, thus helping to make our family happier.

It gradually became evident to me that a special kind of person is needed to be a special education teacher to children with cognitive disabilities. ...This kind of teacher is one whom I delight in knowing and working with, and one I believe is not found in many other fields.

MRS. NORMA Z. SMITH, 91, PICTURED WITH HER DAUGHTER JUDITH ANN, 63, IN 2010.



It gradually became evident to me that a special kind of person is needed to be a special education teacher to children with cognitive disabilities. A teacher who can be content with a very slow progress, one who can laugh with the child or at himself, one who can tolerate lapses in behavior and one who can see beyond the immediate situation. A teacher who can be firm but just and one who can believe the child will succeed in some way to be a useful and happier person. This kind of teacher is one whom I delight in knowing and working with, and one I believe is not found in many other fields.

Too, the children want to come to school; they express their pleasure and say without guile how they feel toward me. They demand without knowing it, maximum performance in one's work, which is another reason to choose special education. The challenge of teaching simple

tasks to these children, tasks another child can learn so easily, makes the work very fascinating.

Being an advocate for the children and their families fulfills a desire to teach about and seek acceptance of people with disabilities. Believing in and knowing what they can accomplish makes effective most any method one uses. The sense of accomplishment is great when another person, through one's own efforts, expresses a desire to work with these children.

However, one can become too ingrown, too set in one's own ways, so the diversification is needed for good mental health. A parent who works in this field and goes home to the same problems can become "saturated" to the point that effectiveness is lost. Knowing this, I accepted another position, one which includes cognitive disabilities but also encompasses behavior, learning, language, hearing,

orthopedic and other physical problems. The longer I work in this field, the more I become entranced by its many facets.

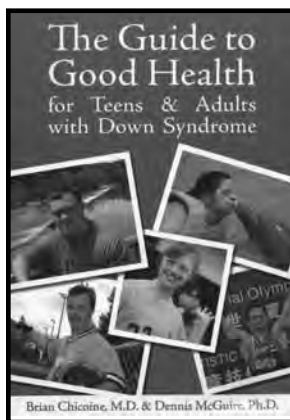
In my present position, I am responsible for orienting new nurses and nursing students to the special schools and the nursing services offered there. I also am involved in evaluating old programs, in implementing and planning new ones and at times give direct care to the children. This all gives me much personal satisfaction and hopefully in some way benefits my co-workers, the children and their families.

No longer do I consider myself unfortunate. Our daughter has become a contributing member of society and a respected member of our family. Thus, I have turned to special education to use my experiences because it has more meaning to me than any other field I know.

Resources: Book Reviews

THE GUIDE TO GOOD HEALTH FOR TEENS & ADULTS WITH DOWN SYNDROME

by *Brian Chicoine, M.D. & Dennis McGuire, Ph.D.*
(Woodbine House, 6510 Bells Mill Rd.,
Bethesda, MD 20817, www.woodbinehouse.com),
2010, (392 pp.), paperback, \$29.95



Chicoine and McGuire are directors of the Adult Down Syndrome Center of Lutheran General Hospital in Park Ridge, IL. Since the Center opened in 1992, the two have seen more than 4,000 patients, aged 12 to 80+. In 2006, they published the popular *Mental Wellness in Adults with*

Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges. They believe (and frequently make the case) that there is a strong link between mental and physical health for their patients. Their second book provides excellent information on both maintaining good physical health and providing appropriate care to diagnose and treat health problems.

I think my favorite line in this book comes from the section on treating sleep apnea with a CPAP (continuous positive airway pressure) machine. As many parents can attest, getting accurate information is one challenge; getting your child — no matter what age — to comply with the prescribed treatment is another. Drs. Chicoine and McGuire know that, so they offer a number of suggestions to encourage the use of the mask, including “Watch the movie *Top Gun* in which Tom Cruise is a fighter pilot who (of course)

wears a mask while flying. (‘If it is good for Tom Cruise, it is good for me.’)” That’s the kind of wisdom that only comes from experience!

This book is written for parents, caregivers and medical professionals who see people with DS in their practices. All will be able to put it to good use in their care. **JA**

MANAGING MY MONEY: BANKING AND BUDGETING BASICS

by *Natalie Hale*
(Woodbine House, 6510 Bells Mill Rd.,
Bethesda, MD 20817, www.woodbinehouse.com),
2010, (144 pp.), paperback with CD-ROM, \$34.95

Knowing how to manage money is a life skill which goes beyond being able to identify coins and bills. This colorful workbook has three sections



with 33 lessons that explain how to keep records of money spent and received, develop a budget on a limited income and manage a checking account. The workbook is designed to be used by a teacher and a student working together and the lessons are organized with the teacher plan on one page and the activity on the opposite page. The lessons are broken down into precise steps with clear and simple language and can be repeated as often as necessary until the student understands the concept and is ready to move to the next lesson. Additional worksheets and forms are included on the CD-ROM and can be printed out for future use. **JA**

MANAGING A SPECIAL NEEDS TRUST: A GUIDE FOR TRUSTEES

by Barbara D. Jackins, Esq., Richard S. Blank, Esq.,
Ken W. Shulman, Esq. and Harriet H. Onello, Esq.
(DisABILITIESBOOKS, Inc., 33 Pond Ave. #919,
Brookline, MA 02445, www.DisABILITIESBOOKS.
com), 2010, (242 pp.), paperback, \$29.95



A special needs trust allows families to set aside assets for a family member with a disability without compromising eligibility for federal programs such as Supplemental Security Income (SSI), Medicaid and other government benefits. A trustee manages the trust and needs to know such things as allowable expenditures, what records to

keep, how to make investments and file taxes and how to find professional help when necessary. This book was first published in Massachusetts in 2005, but this version is updated so it covers all 50 states.

Future planning can be both complex and emotional and this reference guide will be very helpful in answering a myriad of questions. **JA**

Reminder for board and suggested award nominations

Recent issues of *DSN* have included detailed calls for nominations for 1) the NDSC Board of Directors and 2) the NDSC Annual Awards, which will be presented at the NDSC annual convention in San Antonio, TX. Details for both nominations are available on the NDSC website, ndscenter.org.

The deadline to submit an award nomination for consideration is Tuesday, March 1, 2011.

The deadline to nominate a candidate for the NDSC Board of Directors is Friday, April 15, 2011.

What Do You Want to Share?

D.S. Headline News is written by and for 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 to:

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

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

School Tips for Parents

Editor's note: Thanks to The Advocacy Center in Rochester, NY, for permission to reprint these tips from its newsletter, The Bridge, Vol. XVIII, Issue 3.

Get to know other parents

- Get to know the parents in your child's class.
- Get to know a variety of parents – not just those whose children have disabilities. Other parents are invaluable resources, both for the factual information they have to share and the understanding and insight they bring to your situation.
- Be a source of information and support to another parent.

For children who have communication difficulties

- Use a daily communication notebook that will travel back and forth to school. Both you and your child's teacher or aide can bridge the communication gap.
- Use a picture symbol communication chart to help your child assess his or her own day.
- Arrange for regular team meetings.
- Email the teacher with questions or concerns as they come up

Advocate

- Learn the appropriate wording to use when advocating.
- Clearly identify and state the problem.
- Consider the school or agency's viewpoint.

- Consider alternatives.
- Take action and follow through.
- Include your child in team meetings when appropriate.

To facilitate your child's success, be informed

- Visit your school's website. Depending on your school, you may find morning announcements, schedules, forms, the school newsletter, policies and contact information.
- Visit classroom web pages where teachers may introduce themselves, explain expectations and post photos and homework assignments.
- Attend PTA meetings. If you can't attend meetings, offer to volunteer for a one-time event — this will keep you in the loop.
- Attend open houses and walk around to notice both the physical environment and the cultural climate. Try to imagine what your child sees as he or she navigates the building.

Just in case

- Photocopy your child's schedule and have it with you at all times.
- Keep a list of key school personnel and contact information with you, such as the transportation department, bus numbers, health office, main office and guidance counselor.

Make your child known

Do anything to make your child "real" for school personnel such as using individual portfolios to

introduce your child before school starts, when entering a new classroom or meeting a new bus driver. Teachers may see students daily but never gain the insight that a parent can provide through a portfolio. An IEP or 504 Plan does not reveal who your child is.

Make connections with other students

- Ask your child's teacher to enlist the help of peer mentors or buddies for your child for extra practice in any number of classroom activities.
- Suggest that your child become a peer mentor or buddy to a younger student.
- Remind classroom aides that they are important friendship facilitators.

Middle school and high school students: Get involved outside of class

- Volunteer to help with a school event: hand out programs, serve refreshments, help people locate rooms or hang posters. Get a friend to join you.
- Submit an article or photograph to your school newsletter.
- Submit a photo of you and your friends to the yearbook staff so others can get to know you, too.
- Attend a school sporting event with family or friends and consider trying out for a team.
- Attend a school play and consider auditioning for a future production.

Development News

By John Kupris, NDSC Development Director

The NDSC guides individuals and families to help one another to share a vision of a more inclusive world which recognizes and embraces the value and dignity of people with Down syndrome (DS). For nearly 40 years, the NDSC has worked to realize our founders' dream of creating equal rights and opportunities for all people with DS.

For me, one of the great joys of working in fund development is witnessing the generosity of people who are committed to influencing the world in a powerful way. At the NDSC, your membership and generous gifts support services to individuals with DS, their families and friends. You are not alone in sharing in the work to make this happen, but join with the support of thousands of members like you.

To maintain our service work, we rely on the continued support of people like you — NDSC members and friends. Through the annual fund, special bequests and planned gifts, your donations help us to:

- Promote available and accessible opportunities and/or resources that meet individual and family needs.
- Build a sense of community and fellowship for all people concerned with DS.
- Provide leadership in forming public policy.
- Encourage ethically responsible research related to all aspects of DS.
- Educate professionals, parents, and community in all aspects relating to DS.
- Foster self-advocacy and acknowledge the importance of self-determination for persons with DS.
- Recognize and advance the full range of rights of all people with DS.
- Promote full participation of people with DS in all aspects of community life.
- Recognize the variability of personal needs and respect individual choices.
- Promote policies and practices that sustain cultural and linguistic competency, so that all families feel welcome and have access to useful information and materials.
- Develop and disseminate position statements on major issues related to DS.
- Provide a network for linking state and local groups and affiliates.
- Foster and enhance relationships within the NDSC community and the broader disability community.

The list is long, the tasks are important and the NDSC strives to respond to the changing needs of our members and all individuals with DS in the wider community. The NDSC has earned a reputation for offering support for anyone who contacts us.

One result of investment is excellent service. With your support today, the NDSC will be able to continue offering help and hope — as it already has for so many people.

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

**The NDSC has earned a reputation for offering support
for anyone who contacts us.**

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).



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

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Convención Anual 2011

Agosto 5-7, 2011

**JW Marriott Hill Country Resort,
San Antonio, TX**

La convención anual de NDSC es la reunión más grande de padres, profesionales y personas con síndrome de Down en el mundo. Dada la popularidad de su programa incluyendo la convención para hermanos y ahora también el programa para niños, la convención provee a toda la familia la oportunidad de aprender, crecer, celebrar, conectarse e intercambiar experiencias personales.

La inscripción a dichos eventos abre en marzo, pero le sugerimos reservar el hotel lo más pronto posible llamando al 1-201-403-3434 o en Internet en ndscenter.org/noticias/events.php.



August 5-7, 2011

JW Marriott Hill Country Resort

The NDSC annual convention is the largest annual gathering of parents, professionals and self-advocates with Down syndrome in the world. With the popular Brothers & Sisters Conference and newly added Kids Camp, the convention provides the whole family an opportunity to learn, grow, celebrate, connect and exchange personal experiences.

Event registration opens in March, but make hotel reservations now by calling 1-201-403-3434, or registering online at ndscenter.org/news/events.php.