TRANSITIONING TO MIDDLE SCHOOL

By Jann Logue, Washington, IL

Editor’s note: Last fall, Down Syndrome News (Vol. 32, No. 6, 2009) asked for ideas on making a smooth and successful transition from elementary to middle school. We heard from several of you and common themes are in the sidebar on page 4. Thanks to paraprofessional Jann Logue for sharing her thoughtful ideas on a successful transition she helped orchestrate.

I had the privilege of assisting a student with Down syndrome from his kindergarten year through eighth grade. Throughout our journey, we had many ups and downs and learned invaluable lessons along the way. I think we did our part in helping our school district think more inclusively. Along the way, he and I forged a lifelong friendship because of our shared experiences. He is, undoubtedly, the best teacher I have ever had.

Our elementary school goes through fifth grade and then we transition to sixth grade in the middle school building. I share a few tips that made our journey smoother. We did most of these things (and some became obvious to me during the process).

The first thing is communication between fifth and sixth grade teachers. Teachers know what information is important to share and they respect each others’ opinions. Ideally, this should begin in the middle of the fifth grade year.

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CALLING SELF-ADVOCATE PRESENTERS

Here is your opportunity to take a leadership role as a workshop presenter in the Youth & Adult NDSC Conference at Walt Disney World, FL, July 16-18, 2010.

Workshops are presented three times to about 25-30 people each time. Keep in mind convention planners look for submissions that are interactive, fun, and will be of interest to both guys and gals of various ages and abilities.

To submit your idea simply:

1. Think of a topic others will enjoy like art, cooking, hobbies, dance, sports, volunteering, communications or independent living. These are just a few suggestions. The possibilities are endless! (Find more on the NDSC website, ndsccenter.org.)

2. Find a support person who can help you with your presentation.

3. Complete a Y&A Workshop Proposal Form and send it in.

For a list of possible workshop topics and a copy of a Y&A Workshop Proposal Form go to the NDSC website. Click on the “Self-Advocates” tab and then “Be a Presenter.” Or, call the NDSC Center at 1-800-232-6372.

Please send your completed form OR a typed page with your workshop title, main points, and activities, as well as your contact information including address, phone, and email, along with the signature of your support person to:

Y&A Speakers
NDSC Center
1370 Center Dr. #102
Atlanta, GA 30338
info@ndsccenter.org

GRETA FOYE PRESENTING HER COOKING WORKSHOP AT THE NDSC YOUTH & ADULT CONFERENCE IN 2009.
Transitioning to Middle School
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It sounds early — but it’s not. Sixth grade teachers will have many questions they only feel comfortable asking fifth grade teachers.

As an aide, one thing I did was to put together a binder showing examples of the student’s writing, coloring and work. I included many photos of his classroom interactions that demonstrated how he was included. We also made a video to show he speaks and interacts; his sense of humor and interests; and accommodations, including a slant board and voice amplification system. We all worry about change and the unknown — this helps teachers know what to expect.

Taking it one step further, we invited the sixth grade teachers over to the elementary school to observe the action. These introductions really helped initiate a teacher/student relationship so that the sixth grade teachers weren’t total strangers to the student. In turn, the teachers liked observing the student in his fifth grade environment to think about how their rooms would suit his needs. Again, this spurred many questions and emphasized the importance of communication.

After the sixth grade teachers observed at the elementary school, we took a trip over to the middle school to see how things worked there. We toured the building and pointed out restrooms, lockers and the gym. We even ate lunch there — going through the lunch line with other middle school students. The most important thing we did was to spend time hanging out with other students. Here again, through conversations and games, the seeds for relationships with children just one year older were planted.

Another vital part of the transition was pre-planning the student’s day. In our sixth grade, students go to different rooms and teachers for each subject. We came up with a “circle of friends” that were the most supportive and helpful with our student. We made sure that eight to 10 of these students were in each class. This helped immensely with both communicating needs and modeling appropriate behavior.

Because both schools are in the same district, I also accompanied the student as his aide in the middle school. This helped to alleviate the many worries of both the student and teachers. There are some things you just don’t remember to talk about no matter how many meetings you have. So, by traveling along, I could address a myriad of little issues when they arose. If it’s possible, this was probably the key to a smooth transition.

All of the little things need to be pre-planned as well. For easy recognition, we made sure his locker was on an end. We also used a picture schedule until everything became familiar. We brought along things that had made him successful in previous years, such as a communication book. We also planned every new area of his day including lunch routines, recess rules, bus stops and more. It is also a good idea to speak with the entire faculty, including lunch ladies, custodians, bus drivers and recess monitors, to let them know what to expect.

This may seem like a lot, but each piece helped smooth the transition. Middle school is a time for exploring personal interests and making new friends. Every student needs help with transitioning.

That student is now a senior in high school and doing great. I am glad to report he took along many friends from middle school and has made many new ones, too. I stayed at the

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middle school. Teachers here have said they are changed people because of inclusion. It just goes to show that sometimes students are the best teachers of all!

TRANSITION TIPS

• Talk to staff at both the elementary and middle schools about available classroom and teaching options. If possible, set up a time to observe at the middle school.

• Meet with the school team to share what you love about your child, long-term goals and your rationale for what you believe will make your child’s school experience a successful one.

• Share information about your child — how he learns, details about social and physical development, educational expectations and concerns. Encourage questions. Develop a “Student at a Glance” page to highlight IEP goals.

• Have the student visit the school in advance. One student attended three orientation sessions instead of the typical one to increase comfort level. Take the schedule and walk around the building to find classrooms.

• Make an album with photos and information about teachers, office staff and other school personnel that students will meet to use at home over the summer. Use social stories, too.

• Students who need more transition time can visit the new building more often — even daily — during the spring of fifth grade.

CALL FOR NOMINATIONS TO NDSC BOARD

The National Down Syndrome Congress is looking for people who have an interest in serving the Down syndrome community as a member of the NDSC Board of Directors. Board members have the opportunity to shape policy, lead initiatives and make a difference through rewarding work as a team.

Board members typically are elected at the NDSC’s summer annual meeting, which will be Saturday, July 17, 2010, during the NDSC convention in Orlando, FL.

Any NDSC member in good standing is eligible for nomination to the Board of Directors. Self-nominations are welcomed as well as nominations by third parties. The Nominating Committee is chaired by Immediate Past President Richard Robison with representation from the general membership. Members can express interest in learning more about board service without making a commitment to complete and submit an application.

The NDSC seeks wide representation in its board membership and considers factors such as areas of expertise, prior experience on not-for-profit boards, geographical representation, age of person or family member with DS, parent/professional status and ethnic representation. The Nominating Committee would particularly like to hear from diverse individuals and also individuals with backgrounds in accounting and finance, higher education, fundraising and conference program planning.

A Nominee Information Form as well as a description of the board selection process is available on the NDSC website, ndsccenter.org, or by calling the Center at 1-800-232-6372. To submit a name for the Nominating Committee to consider, please send a completed form by mail, fax or email to: Richard Robison, NDSC Center, 1370 Center Dr. #102, Atlanta, GA 30338; 1-770-604-9898; or info@ndsccenter.org.

DEADLINE FOR NOMINATIONS IS THURSDAY, APRIL 15, 2010.
Inclusion Works!

Inspiration and Information to Counter Arguments Against Inclusive Education for Students with Down Syndrome: Part II

By Cheryl M. Jorgensen, Ph.D., Institute on Disability, University of New Hampshire/UCED

Editor’s note: Part 1 appeared in DSN, Vol. 32, #2, 2009. If you weren’t an NDSC member at that time, contact the Center to request a copy.

Sam’s Club recently presented employee Nate Archambeau1 with an award for 12 years of exemplary service. When he graduated from Concord High School in 2001, after being included in general education classes, Nate was one of the first students with developmental disabilities in New Hampshire to march across the stage with his classmates. Two years ago, Nate moved into the townhouse he shares with his brother. Nate was ready years ago, but he had to wait for his dad to be ready to take a chance for Nate to live on his own. Nate belongs to a self-advocacy group and contributes countless hours each year giving speeches and mentoring other young people with disabilities. Nate still is looking for the love of his life.

When Nate was born, his parents were told the same thing that many parents of children with Down syndrome were told 30 years ago: “He’ll need constant care. He may never go past the developmental age of three. He’ll need special schooling. Don’t set yourself up for disappointment — don’t expect too much. Maybe he’ll surprise you.” Nate and his parents proved them all wrong and their experience ought to inspire other parents of children with DS to hold high expectations and strive for an “ordinary life” in the community.

Despite 30 years of research and the personal experiences of thousands of children that support inclusive education, parents and professionals still face roadblocks based on outdated arguments against inclusion for students with DS. In the first part of this article, I addressed the arguments “some students are just too disabled,” “students need to learn functional skills outside the general education classroom,” and “there is no harm in not including children.” In this article, I’ll provide a rationale for why two other common arguments against inclusion are weak or unfounded.

ARGUMENT #1: Students need special instruction in a special place delivered by special staff.

Some argue students with DS and other developmental disabilities — those who are labeled as intellectually disabled, who have autism or experience multiple physical disabilities — can’t benefit from instruction in a general education classroom and need a special curriculum taught by special staff in a special education classroom. Wehmeyer and Agran (2006) propose the best place for students to access the general education curriculum may be the general education classroom. Research bears this out by showing a variety of important educational outcomes are positively correlated with the amount of time students with disabilities (regardless of the “severity” of their disability or label) spend in general education.

1 Pseudonyms are used for the students and teachers in this article.

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Inclusion Works!

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classrooms. These include: higher scores on standardized reading and math tests, fewer behavior referrals, better attendance and a greater likelihood of achieving post-high school independent living and employment (Blackorby, Chorost, Garza, & Guzman, 2003).

Certainly placement in general education classrooms is not enough. Effective curriculum, instruction, and supports for students with disabilities who are in general education classes are defined by the following characteristics (Jorgensen, McSheehan, & Sonnenmeier, 2009):

Curriculum is...

• Based on common content standards for all students.
• Presented in a variety of accessible formats including written information at appropriate reading levels, and in formats as indicated on a student support plan (e.g., video, picture/symbols, actual objects, demonstrations, orally, etc.).
• Individualized by developing personalized performance demonstrations for some students.

Instruction...

• Reflects the learning styles of all students in the class by using visual, tactile and kinesthetic materials and experiences.
• Prioritizes the use of research-based strategies for increasing student achievement, such as:
  − Identifying similarities and differences
  − Summarizing and note taking
  − Reinforcing effort and providing recognition
  − Homework and practice
  − Nonlinguistic representations
  − Cooperative learning
  − Setting objectives and providing feedback
  − Generating and testing hypotheses
  − Questions, cues and advance organizers
• Is provided in multiple formats such as individual, pairs, small groups and whole class.

Supports...

• Are provided within the general education class and other typical environments to enable the student to participate in and benefit from the general education curriculum and other inclusive learning opportunities and activities.
• Are defined by an individualized student support plan, and may include: physical, emotional, and sensory supports; adapted materials; assistive technology and AAC; personalized performance demonstrations; personalized instruction; and individualized grading and evaluation plans.
• Take into consideration the student’s sensory needs.

What does this look like in the classroom? Brianna was a ninth grader with DS enrolled in a general science class. Once a week Brianna’s special education teacher met with Mr. Barclay, the science teacher, to find out what he was teaching the following week. During this 15-minute meeting, they discussed: science standards; instructional materials he would use; assessments that would be given; and general instructional routines (e.g., whole class lecture, small group work, individual seatwork, using the Internet for reference) that would occur. The special education teacher took this information back to the other members of Brianna’s team, including her speech-language pathologist and occupational therapist. They planned the supports Brianna would need to fully participate in and learn from the general education teacher’s instruction.

During a Periodic Table of the Elements unit, Brianna’s team asked themselves two questions: “What supports does Brianna need to fully participate in and learn the general education curriculum?” “What are
naturally occurring opportunities for Brianna to work on functional and IEP skills within the classroom and other inclusive school and community environments?"

Brianna used balloons and a graphic organizer to depict the structure of the helium atom. She used a variety of supports during instruction and assessment including: enlarged text; animated clips from the Internet showing protons, neutrons, and electrons in the helium atom; fill-in-the-blank worksheets (created with Worksheet Magic®) along with a word bank of scientific terms taken directly from the textbook, and word prediction software (Write Out Loud®) that helped her compose her lab report. What did she learn? Brianna worked towards achieving the state science standard of “use models for illustration and understanding,” she had multiple opportunities to solidify her membership and relationships in the class and she improved her communication and organizational skills. Will Brianna eventually become a scientist? We don’t know the answer for her or for the other students in the class. But all students have learned valuable knowledge and skills that will serve them well in their adult lives.

ARGUMENT #2: Students will never make “real friends” in general education classrooms.

I recently did a Google search for friendship programs for students with disabilities. One site described a friendship between a student with a disability (Christine) and a young woman who volunteered to hang around with her to get community service credit towards fulfilling her high school graduate requirements (Lesley). Here is what the website reported:

‘November Buddy Pair of the Month: Christine and Lesley.’ Christine and Lesley have been friends for three years now. They share a beautiful relationship that truly illustrates the true meaning of friendship and serves as an example to all of us about the power of the ‘Friends for Life’ program. When we saw the two of them at this year’s Meet and Greet, it brought tears to our eyes as the two of them gave each other a real hug and asked how each other was after a summer apart. Every time I saw Lesley in the summer, all she could talk about was her ‘best buddy’ Christine and how excited she would be to see her in the fall. It is times like this that we are able to really realize the importance of true friendship and the impact it has on both the student buddy and the buddy.

After reading a few such anecdotes, I had to ask myself:

• Who are Lesley’s friends when the buddies program is not having a special, organized event?
• Do typical kids get awards for being one another’s friends?
• Do real friends see each other once a year at a “Meet and Greet?”
• Should we feel good when students with disabilities get “real hugs?”

I think, perhaps, that students with DS deserve more. Carol Tashie, Susan Shapiro-Barnard, and Zach Rossetti (2006) wrote a book called Seeing the Charade: What We Need to Do and Undo to Make Friendships Happen. These authors suggest that if we want our children to have authentic, reciprocal friendships, the first thing to do is address barriers we have, perhaps unwittingly, created to naturally developing social relationships, including:

• Students being “partially included”
• Not presuming competence
• Over-reliance on 1:1 assistants
• Mistaking peer support for friendship
• Creating “friendship programs”
• Seeing disability as “deficiency”
• Parents and educators not working together
• Thinking that friendship isn’t a school’s responsibility
• Inaccessible transportation and public spaces
• Implementing strategies before eliminating barriers

These barriers must be addressed before creating strategies for supporting students to fully participate in the social activities and environments in which friendships develop (Kennedy & Itkonen, 1994).

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In conclusion, in part one of this article, I suggested that parents and professionals who find they have to justify inclusive education might engage in the following activities to educate themselves and develop supportive allies:

- Know and be able to express your own deeply held values.
- Emphasize that children with DS are more like students without disabilities than they are different.
- Understand the law and be able to cite research.
- Visit inclusive schools and help connect professionals from your school with them.
- Engage outside experts for professional development and consultation.
- Start an inclusive education task force in your school that includes other like-minded parents and professionals as well as people who are not supportive of inclusion.
- Involve adults with disabilities in all your efforts so that they can share the wisdom of their experiences.

I would suggest the following additional strategies for parents or professionals who are facing these or other arguments against inclusive education.

- Join your school’s “School Improvement Team” or “Response to Intervention Task Force (RtI).” RtI is based on the idea that all students benefit from universally designed instruction that accommodates students with different learning styles. It’s important for parents and professionals who are concerned about students with disabilities to be part of all school improvement conversations.
- Identify a school in your area that successfully includes students with DS in general education classes and schedule a visit for a team from your school. Arrange for your principal to talk to their principal, for your speech pathologist to spend time with their speech pathologist and for your classroom teacher to shadow a general education colleague for a day. The ride to and from your visit can provide valuable time for discussion and shared reflection.
- Attend a national conference with others from your school to learn about best practices in inclusive education. Three wonderful events, to name just a few, are the annual PEAK Parent Center Conference on Inclusive Education (peakparent.org), the annual TASH Conference (tash.org), and the University of New Hampshire’s Autism Summer Institute (iod.unh.edu). Parent-teacher organizations or state Developmental Disabilities Councils might be willing to partially fund attendance for your school’s team if you commit to sharing information you learn with other parents and professionals upon your return.

In conclusion, if working to include students with DS seems an uphill battle against old prejudices and myths and you are tempted to give up the struggle, remember the wisdom of an old Japanese proverb: “Fall seven times, stand up eight.”

REFERENCES


MY SISTER, ALICIA MAY

By Nancy Tupper Ling
(Pleasant St. Press, P.O. Box 520, Raynham Center, MA 02768, www.pleasantstpress.com), 2009, (32 pp.), hard cover, $16.95

Rachel knows her sister, Alicia May, is special and she loves her. Rachel also knows that Alicia May can be very annoying and sometimes Rachel pretends she doesn’t know her sister. It’s a story that all children who have siblings (with Down syndrome or not) can relate to. It’s full of beautiful pictures by illustrator Shennen Bersani (who happens to have a little sister with DS.)

This would be a great book to give as a gift to a child, a teacher or a library. JA

PEER SUPPORT STRATEGIES FOR IMPROVING ALL STUDENTS’ SOCIAL LIVES AND LEARNING

By Erik W. Carter, Lisa S. Cushing & Craig H. Kennedy
(Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD, 21285, www.brookespublishing.com) 2009, (160 pp.), paperback, $29.95

Lately, several of the books that have crossed my desk have been about the evolving practice of using peer supports to foster learning and inclusion of students with moderate and severe disabilities in general education classrooms. Recent research demonstrates that this approach is effective in increasing access to the general curriculum and that the growing practice benefits all students, not just those with disabilities.

Teachers and schools that are committed to inclusion and looking for ideas on effectively implementing a peer support program will find this to be a helpful handbook to learn why and how peer supports work along with a step-by-step approach to setting up effective programs. As a parent, I got good information to share with my daughter’s teacher who needed some encouragement to find additional ideas for meeting Maren’s social and emotional goals. JA

GIFTS 2: HOW PEOPLE WITH DOWN SYNDROME ENRICH THE WORLD

Edited by Kathryn Lynard Soper

Down Syndrome News readers are likely familiar with the first Gifts, a collection of personal essays written by mothers of children with Down syndrome. This sequel includes essays from a variety of perspectives — family, friends, teachers, medical professionals and more. The book is organized into five

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sections — the gifts of acceptance, awareness, friendship, courage and joy.

I imagine the authors carefully crafted their stories, hoping to capture the essence of “their” person’s personality and spirit and wanting the world to know how lucky they feel that their lives have been touched by such an amazing soul. Pick it up and find your favorite!    JA

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
Julie Anderson
2929 Old Highway 8
Roseville, MN 55113
or anderjs@mninter.net

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

CALL FOR NDSC ANNUAL AWARD NOMINATIONS

WHO MAY NOMINATE?

Nominations may be submitted by any person or organization wishing to direct the attention of the NDSC’s board of directors to outstanding achievement.

In its selection, the board of directors will not necessarily be restricted to those programs or individuals, but may consider reports of outstanding achievement from other sources, and may, on its own initiative, select an award recipient.

AWARD GUIDELINES

• Does the program, publication or individual promote a positive image of people with Down syndrome?
• Does it accentuate abilities, not disability?
• Does it focus on people, not on the condition of DS?
• Does it celebrate diversity?
• Does it use people first language?
• Does it enhance the dignity of people with DS?
• Does it avoid stereotyping?
• Does it present accurate information?
• Does it recognize the value of persons with DS?

SUBMITTING A NOMINATION

A nomination form must accompany each nomination. The following form may be reproduced locally. All nomination forms and supporting materials must be submitted by mail, email, fax or overnight delivery to:

NDSC Center
1370 Center Dr., #102
Atlanta, GA 30338
1-770-604-9898 (fax)
or info@ndsccenter.org

AWARD CATEGORIES AND REQUIREMENTS

Exceptional Meritorious Service Award
This award recognizes an individual whose service and contributions to people with DS and their families have had local, state and national significance.

Employer of the Year Award
This award recognizes an employer for efforts in creating employment opportunities for people with DS.

Meritorious Service Award
This award recognizes an individual or organization for outstanding contributions to the NDSC.

Christian Pueschel Memorial Research Award
This award recognizes research, which has contributed to greater knowledge and understanding of DS.

ALL NOMINATIONS MUST BE RECEIVED NO LATER THAN MONDAY, MARCH 1, 2010
National Parent Group Award
This award recognizes an affiliate parent group of the NDSC, which has performed outstanding service on behalf of people with DS and their families. Parent groups will be judged on advocacy services, relationship to the NDSC, support to families, fundraising activities and local and regional programs and services.

Christian Pueschel Memorial Citizen Award
This award recognizes an individual with DS whose achievements, service and contributions have enhanced the value and dignity of people with DS and their families.

Theodore D. Tjossem Research Award
This award recognizes an individual(s) whose research contributes to the understanding of DS or whose research improves the lives of people with DS or their families.

National Media Award
This award honors outstanding national media efforts, which create better understanding of DS and people with DS. The award recognizes programs on network television and radio, national publications, serials and syndicated columns. National Media Awards may be presented for the categories of television, radio and print.

The media efforts must have been broadcast or published between March 1, 2009, and February 28, 2010.

Education Award
This award recognizes outstanding performance on behalf of students with DS. Nominees will be judged by their demonstrated leadership and innovation in creating or advancing best educational practices for students with DS.

PRESENTATION
All awards will be presented at the NDSC Annual Convention in Orlando, FL, on Saturday evening, July 17, 2010.

NDSC ANNUAL AWARDS NOMINATION FORM

Person submitting nomination
(nominator’s contact information required to consider submission)

Name: ________________________________________________________
Title: _________________________________________________________
Address: _______________________________________________________
Telephone: ____________________________________________________
Email: _________________________________________________________

Please provide a “description of outstanding achievement” on a separate sheet of paper along with supporting material for the award.

Please note: nominee’s contact information required to consider submission.

Nominee name: ________________________________________________
Address: _______________________________________________________
Telephone: ____________________________________________________

Deadline is Monday, March 1, 2010 (No nomination material will be returned).

Check category
(refer to criteria above)

☐ Exceptional Meritorious Service Award
☐ Employer of the Year Award
☐ Meritorious Service Award
☐ Christian Pueschel Memorial Research Award
☐ National Parent Group Award
☐ Christian Pueschel Memorial Citizen Award
☐ Theodore D. Tjossem Research Award
☐ National Media Award (specify)
  ☐ Television
  ☐ Radio
  ☐ Print
☐ Education Award

VOLUME 33, #1 • DOWN SYNDROME NEWS • 11
Parents and Genetic Counselors Define Essential Information about Down syndrome

By Kathryn B. Sheets, M.S., University of South Carolina

In 2008, 993 parents from the National Down Syndrome Congress (NDSC) and National Down Syndrome Society (NDSS), and 388 genetic counselors from the National Society of Genetic Counselors (NSGC) completed an online survey to define essential information for a complete and balanced description of Down syndrome. The study also aimed to distinguish differences in the informational needs of parents and the professional roles of genetic counselors between prenatal and postnatal settings. The results are summarized here.

Each genetic counseling session should be tailored to the unique needs of each counselee. Naturally, the information and extent of detail in each counseling session depends on the counselee who is receiving the information. However, recent standards of practice call for a more balanced representation, including presenting positive aspects of having DS. Consideration is warranted for the routine provision of information about the condition, and whether the conversation should be the same for prenatal and postnatal diagnoses.

As part of the online survey, parents and genetic counselors rated 100 informational features about DS as Essential, Important, or Not Too Important for the initial discussion of a diagnosis of DS. Genetic counselors rated these items twice, creating prenatal and postnatal groups, depending on the setting in which they work. Parent responses were separated into prenatal and postnatal groups based on the timing of their child’s diagnosis.

Study results identified 34 essential informational items for the initial discussion of a diagnosis of DS (see table on page 13). Twenty-two of these items were among the highest ranked items for all groups. Medical professionals should incorporate these items in their initial discussion of a diagnosis of DS, in both prenatal and postnatal settings.

Although the majority of each group rated 34 items as essential, there were statistical differences between group ratings. Significant differences between genetic counselors likely represent variations in professional roles between prenatal and postnatal settings. Prenatal genetic counselors appear to strive to provide a range of possible outcomes in order to illustrate what life might be like for individuals with DS and their families. Postnatal genetic counselors are more likely to address parents’ immediate concerns about their child’s health.

Based on the results of this study, parents and genetic counselors appear to appreciate the importance of similar information when discussing a new diagnosis of DS. Yet, these groups appear to emphasize the importance of items differently. It is unclear how these differences affect the provision of information about DS in practice. However, it could be assumed that disparities result in parent needs not being met and are a possible cause of parental dissatisfaction with both the information provided and the experience of receiving their child’s diagnosis.

Interestingly, prenatal and postnatal parent ratings were statistically the same for 98/100 items. In other words, the informational needs of the parents surveyed were the same, regardless of whether they received a prenatal or postnatal diagnosis of DS for their child.

Finally, two informational resources, printed/written material and factsheets/brochures were highly rated by all groups with no statistical differences. Parents and genetic counselors alike appreciate the importance of these informational...
Essential Information about Down syndrome for Routine Provision

- Caused by extra genetic material from chromosome 21*
- Diagnosis confirmed by chromosome analysis*
- Recurrence risk for future pregnancies
- Hypotonia (80%)*
- One or more congenital abnormalities (50%)
- Heart defect possibly requiring open heart surgery (40-60%)*
- Gastrointestinal defect possibly requiring surgery (12%)
- Variable range of mental retardation from mild to moderate*
- Developmental delay in achieving milestones*
- Need for physical therapy*
- Need for occupational therapy*
- Need for speech and language therapy*
- Need for early intervention and case management*
- Participate in community sports, activities, and leagues*
- Inclusion in regular classes*
- Special education classes*
- Complete high school

- Employed competitively
- Employed in workshop setting
- Live independently
- Live in group home
- Have friends*
- Have intimate relationships
- Life Expectancy (age range of 50s-60s)
- More like other children than different*
- More time commitment
- Local support group(s)*
- Advocacy organizations and websites*
- Early Intervention centers*
- Printed or written material*
- Fact sheets or brochures*
- Books*
- Contact with families raising a child with Down syndrome*
- Specialist referral(s)

Note: These 34 items are rated essential by all group majorities. The 22 items with a * are among the highest rated items for all groups. The two items in bold type showed no statistical difference for any group.

In conclusion, medical professionals should be cognizant of information that parents value and evaluate the emphasis placed on clinical details that may be less helpful to parents. A better understanding of parents’ informational needs will enable medical professionals to better meet parents’ needs, improve parent satisfaction and facilitate adaptation to a new diagnosis of DS. These results are currently unpublished and were part of a more comprehensive study, which also identified examples of positive aspects of DS for routine provision, and provided more detail regarding the informational needs of parents receiving a new diagnosis of DS for their child.

Editor’s note: Robert G. Best, Ph.D., FACMG – University of South Carolina; Campbell K. Brasington, MS, CGC – Carolinas Medical Center; and Madeleine C. Will, MA – National Down Syndrome Society, were co-authors of Sheets’ research.
CONTINUE LEARNING THROUGH COMMUNITY SERVICE

By Sue Joe, NDSC Affiliate Relations Director

Sacramento convention attendees may have visited The Corporation for National and Community Service (CNCS) exhibit table, attended the volunteering and service workshop on Saturday or — best of all — had a chance to meet self-advocate Scott Carter of Elko, NV, serving as an AmeriCorps VISTA (Volunteers in Service to America) volunteer and working for People First of Nevada.

Did you know?

- Research recognizes service as an effective strategy to help young people learn through active participation.
- A recent CNCS study found that civic engagement has a positive impact on employment outcomes.
- CNCS provides opportunities for all Americans to serve their communities through Senior Corps, AmeriCorps and Learn and Serve America.
- Many people with Down syndrome develop independence and learn new skills as active community volunteers.
- The Kennedy Serve America Act, signed into law in April, 2009, intends to dramatically expand the number of service opportunities in the U.S.

CNCS has a strong commitment to including people with disabilities in national service and has a training and technical assistance provider, the National Service Inclusion Project, which is partnering with the NDSC to promote national service and volunteerism as a valued option for individuals with DS.

This is not about creating separate programs, but integrating people with disabilities as volunteers alongside those without disabilities. All CNCS programs have access to funding for reasonable accommodations that will support meaningful engagement of people with disabilities.

When considering life after high school, national and community service can be a terrific option for students with disabilities. A national service experience is a valuable place to develop skills, expand networks and explore career options while deciding whether to go on to employment or further education.

In Scott Carter’s case, a previous job experience just wasn’t a good fit and he was looking for a change. Instead of traditional employment, Vocational Rehabilitation was able to locate a VISTA position. For his one-year commitment, Scott receives a living stipend and an education award to use toward post-secondary education once his VISTA term is complete. Scott loves being a VISTA volunteer and feels great doing meaningful work in his community.

To learn more, visit www.americorps.gov and search for available positions by entering your interests and location. Or, go to www.serviceandinclusion.org and contact your state’s disability coordinator for advice in finding a good match for your interests.

A national service experience is a valuable place to develop skills, expand networks and explore career options while deciding whether to go on to employment or further education.
Thank you for supporting the NDSC Annual Appeal Fund

The first phase of the NDSC’s 2010 annual appeal campaign wrapped up as the clock ran out on 2009. Many members took the opportunity to make a year-end contribution to help ensure the NDSC will kick off a new year of programs and services for people with Down syndrome without interruption.

NDSC leaders expressed appreciation for the strong response. “All of us are keenly aware that tough economic times make it harder to contribute,” said Executive Director David Tolleson, who added those same economic challenges also put added burdens on nonprofit organizations, like NDSC. “We appreciate so many members responding and giving to our appeal. It is very gratifying.”

Tolleson noted the appeal is designed as a grassroots campaign, where contributions of all sizes are important. “As important as big donations are, we are very proud of the large number of people who send in smaller amounts. Those add up fast and can make the difference in funding our programs.”

There is still time to make a contribution to the annual appeal fund drive and add your name to our Honor Roll of Donors. Mail a check or go to the “donate” page at ndsccenter.org. Either way, you’ll help kick off a strong new year for people with DS and their families.

Stay for a round of golf after the NDSC Convention

Many people in the NDSC know and admire Brad Hennefer because he is a great self-advocate. Many more people in the golf community know and admire him because he is a skilled golfer. Under the tutelage of his father, Bob, and brother, Bobby, a PGA professional, Brad began playing golf at an early age. This led his family to create “Golf for Life,” a nonprofit organization which sponsors golf instruction programs and tournaments around the country for individuals with DS.

For Bob Hennefer, the chance to hold a “Golf for Life” tournament in conjunction with the NDSC’s Orlando convention (July 16-18) was too good to pass up. It’s set for Monday, July 19, 2010, at Disney’s Palm Golf Course near the convention hotel in Walt Disney World. All proceeds from this tournament will benefit the NDSC.

Space is limited and the tournament is expected to sell out quickly. For more information or to register, call Bob or Nancy Hennefer at 1-856-354-0584 or via email at golforlife@comcast.net.

NDSC wants to hear from you

But, it doesn’t end there. We want to share what you are doing and what you are proud of — your accomplishments, achievements and more. We are especially interested in news about self-advocates.

Member news will be just one part of a new e-newsletter planned for NDSC members and friends with information about upcoming events, book reviews, advice columns, links to articles, and Q & A interviews with interesting people.

Submit your news, ideas or suggestions any time via email to tom@ndsccenter.org. We may not make you famous, but it’s still nice to see your name in print.
**Down Syndrome News** is a benefit of your annual membership in the National Down Syndrome Congress. To renew or join today, visit ndscccenter.org or call 1-800-232-NDSC (6372).

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### Annual Convention 2010

**July 16-18, 2010**

**Disney’s Coronado Springs Resort in Walt Disney World, FL**

The NDSC annual convention provides the opportunity to learn from U.S. and international experts covering the lifespan of people with Down syndrome. It also brings self-advocates, families and professionals together to learn, grow, celebrate, connect and exchange personal experiences.

This is the largest annual gathering of parents and professionals as well as the largest reunion of adolescents and adults with Down syndrome.

Event registration will open in March, but you can make your hotel reservations by calling 1-407-939-1020, or online at ndsccenter.org/news/events.php

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### Convención anual 2010

**Julio 16-18, 2010**

**Disney’s Coronado Springs Resort en Walt Disney World, Florida**

La convención anual del NDSC brinda la oportunidad de aprender de expertos nacionales e internacionales lo más actualizado en lo que se refiere al síndrome de Down. También reúne a jóvenes y adultos con síndrome de Down, hermanos, padres y profesionales que juntos viven la incomparable experiencia de intercambiar ideas.

Esta es la reunión familiar más grande de padres, profesionales, jóvenes y adultos con síndrome de Down.

Las inscripciones abrirán en marzo, mientras tanto le sugerimos hacer su reservación de hotel al 1-407-939-1020, o vía internet en http://www.disneynow.com/profile/web/index.cfm?PKwebID=0x780e864