

IN BUT NOT WITH: A LOOK AT EDUCATIONAL PRACTICE BARRIERS TO FRIENDSHIP

By Carol Tashie & Zach Rossetti

UNIVERSITY OF NEW HAMPSHIRE INSTITUTE ON DISABILITY REPRINTED FROM INCLUSION NEWS 2002 (WWW.INCLUSION.COM)

It has been said that every good idea contains the seeds of its own perversion. Inclusion is no exception. Far too many students who are educated in general education classes are subjected to educational practices, whether they be pull-out services, curriculum modifications made disrespectful of a student's chronological age and abilities, or the over-reliance on paraprofessional supports, that serve as significant barriers to both educational success and social connectedness. These educational practices are not inclusion! Instead, they perpetuate the belief that students with disabilities are somehow deficient and must be provided with an educational experience different from all other students. These practices, which stem from the attitudinal barriers discussed in earlier articles, impede not only the development of true and reciprocal relationships, but are, in fact, antithetical to inclusive education. And, while the authors acknowledge that far too many students with disabilities are still educated in segregated classrooms and schools (which, of course, is an indefensible barrier to both social and educational accomplishment for any student), this article addresses the educational practice barriers that continue to exist even for students who are educated in general education classrooms.

PULL OUTS AND SEGREGATED CLASSES

The class was doing "daily oral language" when Donovan left to go to the special education classroom. When he returned the class was engaged in a lively discussion of Argentina, sparked by a student's comment about his visiting uncle. Donovan rejoined the class but never felt connected to the unexpected experience the rest of his classmates shared.

It should go without saying that students need to be together in order to develop respect, mutual interests, and real friendships. However, for too many students with disabilities, even those who are in general education classes, their school day still consists of separate places and lessons. Far too many students with disabilities continue to be "pulled out" of their classrooms to receive services from therapists and special educators. This practice, besides having questionable educational value, significantly impacts the student's ability to make friends. The student who leaves the classroom misses important opportunities to connect with classmates around content, knowledge, and activities. He often returns to the classroom unsure as to what he missed or to what the class has moved on. And as described in Roberta Schnorr's classic article, "Peter... He comes and goes" (1990), other students view the student who is often out of the classroom as someone significantly different from themselves. Clearly these are not optimal conditions for developing social relationships.

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Editor: Kathleen Reiss

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STATEMENT OF POLICY AND DISCLAIMER

The Connecticut Down Syndrome Congress is a non profit organization which acts as a resource for families and professionals involved with a person who has Down Syndrome. Its vision is to improve the lives of persons with Down Syndrome, and to encourage the community at large to receive and embrace them. This newsletter reports items of interest relating to Down Syndrome and will provide a forum for others. The Congress does not promote or recommend any therapy, treatment, etc. We will not espouse any particular political or religious view. Individuals or organizations referred to do not necessarily endorse this publication or its editor. The editor reserves the right to make corrections as appropriate, and in accord with established editorial practice in material submitted for publication.

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SAVE THE DATE !!!

18th Annual Convention "Down Syndrome: Celebrate the Differences"

Saturday, October 11th, 2003

Farmington-Marriott Conference Center

Co-sponsored by the UConn

A.J.Pappanikou Center

for Excellence in Developmental Disabilities (UCE)

This year's keynote speaker is Dr. Richard Villa, internationally recognized author and lecturer on inclusive practices, co-teaching, and curriculum adaptation. Dr. Villa will be also be hosting two workshops. His website is: ravillabayridge.com

There will be sixteen (16) other workshops that will focus on best practices in medicine, education, family support, advocacy and legal issues. We've many noted presenters such as Dr. Robert Greenstein, Kathy Whitbread PhD, Anne Eason Esq., and Sara Johnson Associates. CEU's are available for many of the workshops.

Musical entertainment will be provided by Mr. Sujeet Desai. Suj, a young man with Down syndrome, is accomplished on piano, violin, and clarinet, and is presently attending the Berkshire Hills Music Academy. His website is: Sujeet.com.

There will also be fun and educational vendors and other informational displays.

Please come join us for a great day of education, inspiration, and fun. Though we subsidize this event to keep it affordable, fee waivers due to financial need are available.

For more info. contact Ken Cholewinski by e-mail at kencholewinski@aol.com or 860-663-2676.

We're looking forward to seeing you there.

PHOTOS NEEDED FOR THE CONVENTION

We are collecting photos of children with Down syndrome to be part of the convention brochure and convention program. If you would like to have your child's photo considered, please mail photos to Lynn Cholewinski, 47 Fawn Hill Rd., Killingworth, CT 06419.

Due to the large number of pictures received, we are unable to return them by mail. They will be available the day of the convention at the CDSC booth. Thanks!

President's Message

May 2003

What a coincidence! I am on the religious school committee at our synagogue, and it was my turn to prepare the D'var Torah, or Torah commentary, that is the first item of business at our monthly meeting. So, I dusted off my Old Testament and read about the qualifications of a koheyn, a priest. Among those who are excluded is anyone "who is blind, or lame, or has a limb too short or too long; who has a broken leg or a broken arm; or who is a hunchback, or a dwarf... for he has a defect. He shall not profane these places sacred..." (Leviticus 21:16-24). Perhaps this is the first recorded instance of job discrimination based on disability: if a priest suddenly acquired a physical disability, he was fired!

What this ancient law implies is that the external appearance of a person is a valid proxy for purity of heart or motive. In other words, the goodness of a person's character is easily known by the wholeness of his or her body. Well, we all know this is untrue. My daughter Eve, who happens to have Down syndrome, has certain physical characteristics that are noticeably different from other kids. I can see in other people's eyes, the recognition that Eve is different. Fortunately most people who meet Eve give her a chance. But old prejudices die hard: we did have one instance at the beginning of the school year where a parent asked Eve's teacher, "What is that kid doing in this class?"

But even though I deplore the ancient laws that imply, "you can judge a book by its cover," I want Eve to look like all the other kids as much as possible (and she hasn't yet taken away control of her daily wardrobe from me!). I know it's superficial, but society has a hard enough time accepting our kids' differences when they are neatly and appropriately dressed. If we want to improve conditions for them, help them achieve the basic civil and human rights to which they are entitled, encourage the public to get beyond the old stereotypes and prejudices and appreciate their positive qualities, we need to be willing to meet society halfway. All of our kids are ambassadors, whether we like it or not.

—Beth Lurie

THE CONNECTICUT DOWN SYNDROME CONGRESS NEEDS YOUR HELP!

For the last few years, CDSC has expanded programming to serve its members in new and exciting ways. We have upgraded our convention and upgraded our web site. We have made a long-term commitment to distributing scholarships and mini-grants. We have donated wonderful books featuring children with Down syndrome to any requesting preschool. We have increased the content quality of our newsletter. Our member picnic brings over 200 people to the beach for fun in the sun. At the local level, CDSC volunteers organize playgroups, Mom's Nights Out, trips to baseball games, Easter egg hunts, Halloween dances, and many other activities. CDSC volunteers also represent our families on numerous state committees.

But expanded programming requires expanded financial resources. CDSC needs to raise money in order to pay for the good work we do. As part of a fundraising initiative, we need your help in identifying companies and individuals that might want to support our cause. Also, we encourage member families to donate beyond the low \$35 membership fee.

In addition to improving our financial picture, CDSC is looking for people who can support the mission of improving the lives of persons with Down syndrome. The CDSC Board of Directors oversees numerous committees in areas such as outreach, local programming, convention, and so forth. If you have a few hours a month, and a desire to help other parents and communities embrace people with Down syndrome, please contact us. We can match you up with a CDSC task that best suits your interest and availability.

CDSC is first and foremost a parent support group: no one has to raise their child with Down syndrome alone. Our greatest resource is each other. But with every resource comes a responsibility to maintain it. Today's person asking for help is tomorrow's person providing answers. Get involved!

STATEWIDE CALENDAR OF EVENTS

for program details please visit www.spednet.org

JULY 1, AUGUST 5, SEPTEMBER 2: LYME DISEASE SUPPORT GROUP FOR TEENS. For more info, contact the Wilton Lyme Disease Support Groups at (203) 762-2437 or email kos@earthlink.net.

JULY 9, AUGUST 13, SEPTEMBER 13: LYME DISEASE SUPPORT GROUP. For more info, contact the Wilton Lyme Disease Support Groups at (203) 762-2437 or email kos@earthlink.net.

AUGUST 2: CDSC ANNUAL SUMMER PICNIC
Hammonasset State Park. For more information call Kathy Lopes 203-373-9885

SEPTEMBER 13, 2003 NDSS CT BUDDY WALK

SATURDAY OCTOBER 11TH, 2003: SAVE THE DATE!
CDSC Convention 2003 Down Syndrome: Celebrate the Differences! Farmington Marriott Hotel and Conference Center

This newsletter reports items of interest relating to Down syndrome and will provide a forum for others. The Congress does not promote or recommend any therapy, treatment, etc.

Golf Tournament Success

On May 18th yet another successful golf tournament was held. Over 100 participants enjoyed a glorious day of golf. The weather was spectacular as was the meal generously donated by Outback Steakhouse of Manchester. It is always wonderful to welcome back CDSC members and friends who have played in the tournament for 13 years as well as welcome new members to a fun day of supporting the CDSC.

*Thanks to all those who helped make
the day a success.*

UNDERSTANDING SPECIAL EDUCATION or

USE is an instructional course for educational professionals and parents of children with disabilities in Connecticut. The course provides participants with the skills they need to negotiate the special education system and improve its effectiveness for students with disabilities. The structure of the training includes the USE curriculum, the Individualized Education Plan process, and a section on inclusive education.

For more information on the training or to enroll in a class near you, please contact Kathleen Whitbread at (860) 679-1565; toll-free: (866) 623-1315 or email: whitbread@nso1.uhc.edu

CHILDCARE FOR CHILDREN WITH COMPLEX MEDICAL NEEDS

Does your child have complex medical needs? Are you struggling to find good quality childcare? Maybe we can help. The A.J. Pappanikou Center at the University of Connecticut is conducting a project aimed at helping you find childcare for your child with complex medical needs. Our goal is to link you and your child with a childcare center that will act as a partner with your family and your child's medical providers and early interventionist in order to provide the best possible care for your child.

To enroll in this project, children must be:

- Between 0 and 28 months on age with complex medical needs
- Currently receiving Birth to Three services

If you are interested in participating in this project or would like more information, please contact Dana Abbott at (860) 679-1552; toll-free (866) 623-1315; or e-mail: dabbott@uchc.edu

SOCIAL COMPETENCE CURRICULUM FOR TODDLERS WITH BEHAVIORAL CHALLENGES

Has your toddler's behavior become a real challenge? The A.J. Pappanikou Center at the University of Connecticut is conducting a project aimed at helping young children to develop strong, positive social skills. Children learn these very important skills early in life through play and interaction with other peers. Enhancing a child's social skills can improve a child's ability to interact appropriately with other children and adults. It can also help to develop friendships and success in school.

To enroll in this project, your child must be:

- Between 18 and 24 months of age
 - Currently enrolled in childcare
- Participation in the project is completely confidential. Stipends are available.

For more information or to enroll in this project, please contact Dana Abbott at (860) 679-1552; toll-free: (866) 623-1315; or e-mail: dabbott@uchc.edu

Continued from front cover

LOW EXPECTATIONS

Trey's teacher was leading a spirited discussion on slavery and asking students to voice their opinions on its modern day implications. When Trey raised his hand, the teacher asked him to tell the class his favorite color. His classmates were silent during his answer and then quickly resumed their boisterous discussion.

The ways in which a student is regarded by her classmates is strongly influenced by how she is perceived and treated by her teachers. Therefore, the likelihood that friendships will develop increases when people consider and treat the student as a valued, capable, and interesting person with a unique personality. When students with disabilities are consistently characterized by their labels (e.g., "an autistic student"), it is less likely that classmates will take the time to look past the label and get to know the person. When teachers and others who support a student with disabilities talk about that student as if he doesn't understand, a strong sense of disrespect and unworthiness is communicated. These and many other "not-so-subtle" messages convey to classmates that the student is "not worth knowing" and builds barriers to friendship.

OVER-RELIANCE ON PARAPROFESSIONALS

When classmates were asked why no one ate lunch with Ani, her teachers expected to hear complaints of personal eating habits or difficulty with communication. Instead they got an earful: no one eats with Ani because no one wants to sit in the cafeteria with the adult that is always by Ani's side.

Students, especially as they get older, value their independence from adults. For too many students with disabilities, this independence is stifled by the presence of a paraprofessional or teacher. While these roles can be extremely useful in providing educational support, they can also act as barriers to students developing relationships with other classmates. Teachers and paraprofessionals must walk the delicate line of providing support when necessary and fading out of the picture as quickly as possible. Friendships are unlikely to develop when a third party is literally standing in the way.

ASSUMPTIONS AROUND COMMUNICATION

Maya came to Biology every day always holding a leather notebook. Despite the fact that she always had an adult supporting her, it was not until the end of the semester that her classmates realized the notebook held the letterboard she used to communicate. The students were confused as to why they were never given information on how Maya communicated. For many students with labels of disabilities, people continue to hold on to archaic assumptions that those labels actually mean these students are not able to communicate or have very little to say. Luckily, the advent of various forms of augmentative and alternative communication (AAC), including Facilitated Communication (FC), has exposed this myth and has taught us that each and every person can and does communicate. It is up to us to "learn to listen" to what students are communicating, through their body language, facial expressions, and behavior. Likewise, we must be undeterred in exploring and discovering the key to supporting each student to have a more effective means of communication to supplement the ones he already has. And although having a sophisticated system of communication is not a pre-requisite for friendship, it is more difficult for two students to become friends when one does not have a good understanding of how the other person communicates. Therefore, classmates must be asked about and given all of the information they need about all of the various ways a particular student communicates, including expressions, gestures, behavior, and the use of any communication devices. And we must ask classmates to help us develop communication supports that are respectful of a student's interests and age.

CULTURE OF TOLERANCE

The class was reading the book *The Acorn People* about a camp for children with disabilities. As an assignment, the teacher had the students write about their good fortune of having healthy bodies and how they would feel if they were one of the campers in the book.

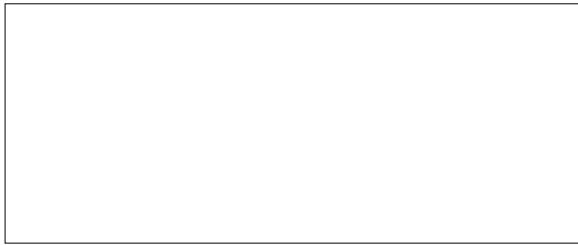
Many schools work hard to instill in their students the value of "tolerance." And while the intent is admirable, this practice places another barrier in the path of genuine and reciprocal relationships. It is not enough to simply "tolerate" the differences among us, for tolerance implies a hierarchy of value. One prizes good health, but tolerates a cold. So what, then, is implied when we strive for schools and classrooms that tolerate disability? Teachers and administrators can create schools and classrooms that express in word and deed that disability is an integral part of our human community -- it is neither better nor worse, it is different. These schools and classes respect the differences in all of us, and demonstrate it through curriculums rich in multiculturalism, lessons taught through multiple intelligences, cooperation valued over competition, and belonging as a priority educational goal. These schools reject the notion of traditional "disability awareness" activities, which tend to teach students to view disability as something either undesirable or as greater than all of the person's other characteristics. Instead, these teachers embed the contributions that people with disabilities have made in all walks of life into their standard lessons. These schools and classrooms celebrate the differences among us -- understanding that without these differences the world would be a very boring place indeed. And in these environments, the seeds for friendships between all students are sown.



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down syndrome
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1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____
4. _____	_____	_____
5. _____	_____	_____

Do you wish to serve on a committee? Yes No (If "Yes", we may be contacting you.)

Please enclose check payable to the Connecticut Down Syndrome Congress, Inc., PO. Box 340385, Hartford, CT 06134-0385. Membership may be either an individual, family or professional basis. A family membership entitles both parents to hold office and vote. We welcome membership from any and all interested individuals, families, businesses and organizations. Your contribution to CDSC, Inc., is tax deductible.

The above information will be kept confidential unless the following box is checked.

REMEMBER: A subscription to the CDSC Quarterly makes a great gift for teachers and therapists!