



99 Bald Hill Road  
Cranston, RI 02920

# DSSRI NEWS

*Fall/Winter, 2004*

SUPPORT  
•  
EDUCATION  
•  
ADVOCACY  
•  
PUBLIC AWARENESS

## President's Message

**O**ur 10th Annual Buddy Walk was a huge success! We had nearly 400 walkers! Amazing! All had a great time thanks to our talented chefs led by DSSRI's own, Tony Pellegrino! Thanks so much, Tony to you and your crew! Those burgers and hot dogs were yummy!

We have several projects on the fire right now. One of which is a Library Project. DSSRI has purchased 17-20 books related to Down syndrome that will be donated to the Warwick Public Library. The Warwick Public Library is part of the CLAN system. Anyone throughout the state who should visit a CLAN library will be able to access these books. We hope to make the presentation in early December, 2004.

Our next project is an outreach to obstetricians in the RI area. We are hoping to do an "in service" type of presentation sometime in early 2005.

We have a Spanish section to our website now, with a link to the NDSS Spanish site so families have access to up to date info on Down syndrome in Spanish. We are collaborating with CEDARR – The Families First CEDARR Center at Hasbro Children's Hospital to outreach to Hispanic families of children with Down syndrome. Together with CEDARR's assistance, we have selected two books in Spanish to be available at the DSSRI Library, CEDARR – The Families First CEDARR Center at Hasbro Children's Hospital and the Warwick Public Library (CLAN).

Seven adults and young adults have been attending a Life Skills and Socialization Series, with Sally Fogel over the past several weeks.

On November 13, 2004 we welcomed three of our new families with a coffee and pastry hour. The families enjoyed the opportunity to share joys and concerns.

Over the last year we have presented the Down Syndrome Awareness Project (DSAP) to three elementary schools in RI with great success and appreciation. If you would like to bring the DSAP to your school of civic organization, please contact the office for further details.

Our September General Membership Meeting was held on September 8th. The topic was Positive Behavior Supports with Claire Rosenbaum from the Sherlock Center and RIPIN. It was a great meeting; unfortunately there were only 10 parents in attendance. The November General Membership Meeting, Meditation & Art Therapy with Lisa Landry, was held on November 10th. Eight folks attended this meeting; three of whom are members of DSSRI. Our next meeting is March 9, 2005 and our speaker is Connie Susa. Be sure to check inside the newsletter for a more complete listing of our meetings and events for the coming year. The Holiday Party is fast approaching! We look forward to seeing all of you there!

Wishing you all a Happy Holiday Season,  
**Marilyn Blanche,**  
*President*

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## Vice President Message

I learned a little something today. Not that I don't learn a little something everyday but this something was different. I had recently attended an IEP meeting that was somewhat adversarial to say the least. Yes, it was about inclusion, expectations, and communication but I felt there was more to it than that. I couldn't quite put my finger on it. The team managed to work through issues that surfaced in our meeting and I managed to find the time to double check that strategies and resources were being followed. There still remained a feeling of unfinished business that needed attention. I felt there was a person on my daughter's team that was not on board and it needed to be addressed.

I could approach this in a number of ways. I could preach to the choir about rights, expectations and least restrictive environment and as a mother and advocate my instincts are to protect. I could take measures to remove my child from her current placement with friends, break her routine, and place her in setting that is more "inclusion friendly" but what would that do to my daughter? I could also take time to talk to her teacher and share a little bit of who we are as parents and why we advocate so strongly for her.

All of these techniques have their place but for this situation, I chose to retract my claws, pick up the phone and talk. I talked about how important inclusion was for my daughter and that I didn't know what the future held but I knew what I could do today. I talked about how Down syndrome doesn't

shut off at 2:30 when school ends and how we are always working on better, more creative ways to reach our daughter at school and home. I talked about how we sometimes want to give up but only let it cross our minds because our hearts won't let us. I talked about how we parents rely on communication (both positive and negative) from all members of our daughter's IEP team because we can't always communicate with our own children. I talked about how there were no guarantees that our daughter will learn every concept that comes across her plate but that doesn't stop us from trying, and those she does get... the victory is that much sweeter. I talked about how our daughter was not born with instructions and while we have spent 7 years learning, we don't expect her teachers to know her overnight and that's where we come in.

So I learned something today. I learned that teachers can be students too. They don't always know how to reach our kids and they aren't sure if and when it's appropriate to ask us. I learned that her teacher had never had a child with Down syndrome in her class before, and questioned her own abilities as a teacher to help her. I learned that she had the same fears that I had when my daughter was born. I also learned that I needn't have those fears any more.

Robin Pacheco,  
*Vice President*

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## In Appreciation

Ocean State Parrot Head Club  
CVS/pharmacy  
Plastics Plus  
ETCO  
Beacon Mutual Insurance  
IBEW Local #99  
RI Arc  
Coca-Cola Bottling Companies  
McDonald's Reservoir Avenue  
Leo's Catering  
Coca-Cola  
Peter Ginaitt & the Warwick Fire Department  
Joanne MacDonald  
Fred Adler  
Edgewood Highlands School  
Nancy & Donald Rowell  
Anthony & Stacy Landi  
The Tarzwell Family  
John & Colleen McCarthy

Mark & Wendy Miller  
James & Jacki Marano  
Jane Ryan  
Friends of Paul Travares  
Gerard P. Guillemette  
Gloria Arruda  
Ellen & James Bruckshaw  
Michelle Mekhaeel  
Kathleen Cushing  
Dina Needham  
Karen & Brian Blanche  
Jerilyn Kronstadt  
John & Roberta Wilkinson  
Hannah Heifetz  
Douglas & Mary Holmes  
Steven & Laurie Myers  
David & Judith Centracchio  
Maureen Cobb  
Kathleen Egan  
Kathleen McDonough  
Frances O'Connell  
Michelle Buendia

David Dunn  
Dot MacDonald  
Mike Bagel Man  
Bruce & Patricia Parkes  
Maureen Goodwin  
Thomas & Patricia Goodwin  
Patricia Egan  
Judith Loens  
Paula Mazur  
Erin McGovern  
Lucinda Bechaz  
Elsie Holmes  
Christopher & Christine Waldeck  
Robert & Jo Anne Hallberg  
Karen Lee & Thomas Maltais  
Christopher Suchmann  
Mary R. Pendergast

### **Policy Disclaimer**

The Down Syndrome Society of Rhode Island, Inc. (DSSRI) was formed by people with a common interest – improving the lives of people with Down Syndrome and their families. It is for this reason that we welcome input from various parents and professionals.

We do not, however, as an organization, support or endorse any particular treatment or therapy. The purpose of this newsletter is to provide a forum for an exchange of ideas.

Please submit information or articles to:

**DSSRI**  
**99 Bald Hill Road**  
**Cranston, RI 02920**

*DSSRI reserves the right to edit any submissions for appropriate and "person-first" language.*

# Language is Powerful

—By Carol Mills, Ph.D., Tuscaloosa, AL

*Editor's note: Carol Mills is an assistant professor of Communication Studies at the University of Alabama at Birmingham and the mother of three. She presented at the Parent Group Leadership Seminar at the NDSC Convention on effectively crafting messages for different audiences. Mills' three-year-old daughter Maren Flanner's has Trisomy 21.*

*The NDSC joined Mills in advocating for ESPN to stop using the offensive song.*

This summer, ESPN promoted the NBA playoff with upbeat and funky promos featuring the song "Let's Get It Started" sung by the hip hop group, The Black Eyed Peas. The song was actually an adaptation of their earlier release, "Let's Get Retarded." When I discovered this, I contacted ESPN and encouraged others to do so, too.

Do you think ESPN would have used the BEPs song if it was originally "Let's Act Like \_\_\_\_ (insert racial, religious, cultural, or sexist) epithet or your choice? Absolutely not. Though hip hop may play by different cultural and language rules, the Disney subsidiary ESPN does not. Adapting a blatantly offensive song clearly violates appropriate cultural and business standards. During the same time period, teen actor Lindsay Lohan repeatedly replied "that's retarded," when questioned about various rumors. And, Jon Stewart, of *The Daily Show*, regularly used the phrase "like a bunch of retards." There was little attention or reprimand for any of them.

However, during the NBA finals weeks, there was intense media scrutiny and criticism for football coach Bill Parcells using the phrase "Jap play" during a press conference and basketball legend Larry Bird's comments about race affecting the NBA. And, comedian Jimmy Kimmel's show was taken off the air one night because he made an insensitive comment about people from Detroit.

These events reflect a larger social issue: Though dearly sensitive to slurs against other groups, the general population does not see the

derogatory use of "retarded" as offensive. Using the word as a pejorative term is common in entertainment venues, daily conversation and children's play. Though a child would be reprimanded for making a racist comment in most schools, it is not uncommon for students — even teachers — to use the word as an epithet for something they consider negative or inappropriate.

The implications for taking control of language are profound. If children grow up hearing that when they forget something they are "retarded" or that those who act poorly are "a bunch of retards," how do you think they will react when meeting someone with a diagnosis of mental retardation? Do you think neighborhood parents will fight inclusion if they hear about "retarded children" more than if they hear about "children with developmental delays?"

Our society's long-time use of "retarded" as an epithet is decidedly negative. We can work to end this. Speak up and educate people.

The best approach often is a direct one. You might say, "You know, 'retarded' actually means 'to do slowly.' The way you've just used it hurts me and many others. It's like hearing a racial slur." I've often done this, especially with college students, and they are surprised. Most have no idea they are being offensive. They think it's just another word until told otherwise.

If being direct is too scary a gentle question such as, "What did you mean by saying it is 'retarded'?" This can create an opportunity to share the term's negative use. Or, if it's comfortable, try humor. When someone says, "I'm so retarded..." you might say with a smile and a wink, "Oh, that's okay, so is my son and I love him anyway." After breaking the ice, explain why it's important.

This is not about confrontation —it is about education. After awhile, you'll find a comfortable approach. Yes, initially, it may feel awkward, especially when talking to a doctor,

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# Language is Powerful

—Continued

teacher or media representative. But remember, those people *need* to hear it most. The more you speak up, the more natural it becomes.

Similarly, you educate others about using “people first” language. If someone refers to your child as a “Down’s child,” simply say, “Actually, he is a child who has Down syndrome.” If the person says, “It’s the same thing,” or gives you “The Look,” you might ask if they’d like to be called by their last name first from now on. The words are the same, only the order is different, why should they care? Or, as many people do, ask if they’d want to be called the “ulcer woman,” or the “cancer dad.” Diagnoses should never define the person.

Finding our voice to educate others and correct language might be difficult, but it is imperative. This is not simply about semantics, political correctness or being overly sensitive. It is about respect. Once you start educating others, you will be surprised by reactions. A few may never get it, but most people will thank you. They will even tell you that they never realized the impact of their words. In that moment, you might say, “That’s why I said something. I knew you’d understand.” Then, breathe a sigh of relief and think of what and how you might respond the next time there’s a need to educate someone. And, we all know, there will be a next time.

*Down Syndrome News, Newsletter of NDSC Vol.27, No. 4*

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## Pain?

—Brian Chicoine, M.D., Medical Director of the Adult Down Syndrome Center, Park Ridge, IL

**Do people with Down syndrome have a greater pain tolerance than other people? Do people with Down syndrome have a normal pain tolerance but we misinterpret their complaints?**

The answer to both of these seemingly opposing questions is probably “yes”.

Many families and caregivers have commented to us that they think the person with Down syndrome they know has an increased pain tolerance. We have seen many examples that support those observations. Many patients have been seen with health problems that would seem to be quite uncomfortable but who had little or no complaint or discomfort.

Furthermore, a recent study provided supporting evidence in a “mouse model” for Down syndrome. Mice with a trisomy (extra chromosome) have been studied. They have been found to have similar health issues as people with Down syndrome. The mouse model was found to have a higher pain tolerance. The mouse had less response to painful stimuli.

While all that seems to support a higher pain tolerance, we also suspect that some of the

apparent pain tolerance may be due to our inability to interpret the complaints of some people with Down syndrome. It may be an impairment of verbal communication skills or the absence of someone who understands the person’s communication attempts.

Another possibility is the reduced ability of some people with Down syndrome to appropriately self-assess where the pain originates and thus a limited ability to make others understand that he is experiencing pain. The person may be experiencing pain but we are just not understanding.

### How can we avoid missing painful episodes?

- **Watch for subtle signs**

A grimace, pointing, a different spoken phrase, sweating for no apparent reason, and holding a limb differently can all be signs to note. There are probably many more that you have noticed as well.

- **Watch for behavioral changes**

Pain can often be expressed in a behavioral change. When I teach medical students or

## Pain?

—Continued

residents, I always emphasize that a change in behavior has to be viewed as a form of communication. This is true to some extent for all of us. People with Down syndrome are no different. However, the person with Down syndrome's ability to communicate verbally or non-verbally may be limited so he may end up telling us with a behavioral change. It could be less activity, more activity, seeking greater attention, seeking less attention, a sad affect, anger, emotional lability, reduced emotion, and many others.

- **Consider the possibility that a person with Down syndrome may have a reduced ability to perceive pain**

Remembering that the person with Down syndrome may also have a reduced ability to perceive pain is important as well. Keeping an eye on someone who has what appears to be a minor complaint can help prevent missing something more concerning.

If the pain persists longer than expected or

there are other symptoms that could suggest something more serious despite the person having little complaint, it could be time to have it further evaluated.

### Remembering a few ideas about communication can help us avoid missing painful episodes:

- A reduced ability to communicate symptoms may be the real cause of an apparent increased pain threshold in some people with Down syndrome.
- A reduced ability to communicate may cause a misinterpretation of the symptoms.

### What are the implications?

- Pain tolerance may or may not be less. It is important to consider physical problems and optimize physical health when evaluating behavioral changes.
- Communication: consider displays of behavioral changes as potential communication devices (of physical or mental pain).

*NADS News, newsletter of the National Association for Down Syndrome, September 2004*

## Better Late Than Never

### How David Finally Learned to Use the Bathroom

—By Linda Moran, Ridgewood, NJ

"Don't worry; He won't be in diapers when he enters high school." We've all heard this advice as it pertains to typical kids. It's intended to help us relax — and it's true. But what about our children with Down syndrome? Our son, David, took so long to train that he threw this advice into question. If you have or work with a child with DS, you know what it means to adjust expectations.

Although many children with DS are trained completely by age five, the range of what's typical is quite broad — some say anywhere between three and 11. Those numbers gave us some comfort, until David turned 11 and there was still no end in sight.

We had tried the standard method, suggested by a specialist, of putting him on a schedule. David likes schedules and memorizes his school schedule each year. But, starting in kindergarten, whenever we tried to put him on a

schedule for using the bathroom, he would rebel, and withhold his urine all day until he went to sleep. Since our doctor advised this was not good for David's health, we had to quickly give up.

Over the years, we read books, tried various approaches, and consulted psychology, special education and medical experts. We were perplexed, and spent long months doing nothing at all. Some experts felt we had started too late. Others felt that David was just "not ready." But what does that mean? Looking back, perhaps David was just not ready to give up control. That condition could reinforce itself forever.

Now he was 11, had outgrown night-time pull-ups, and was wearing adult diapers. The school psychologist and special education teacher were befuddled. And we, his parents, were exhausted and resigned. The school called in a behaviorist, but we didn't have much hope.

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## Better Late Than Never

—Continued

We were in for a surprise.

Jacqueline Dubil-Craig, with her master's degree in Applied Psychology, and a background working with children with autism, was, it turned out, just what the doctor ordered. Dubil-Craig concurred with us that this was not a pottying issue any more. From our point of view, David's power struggle with us was akin to that of a teenage girl with an eating disorder.

According to Dubil-Craig, it all came down to reinforcers. "I look at everything in terms of reinforcement," said Dubil-Craig. "The highest reinforcer is the control he is exerting over you. She explained that all the positive reinforcers we had tried (stickers, favorite foods and his interest in schedules); and all the negative reinforcers we had tried (no computer use in school), had less meaning to him than the power he was holding over everyone.

What she prescribed was so simple. It seemed, at the surface, to be something we had already tried, but we actually had not. She told us we were to show no interest in whether David used the bathroom. On the other hand, his toys would care deeply about it. All his favorite toys were to climb up on a high shelf which, would come to be known as the deprivation shelf. Each time he wanted a belonging, the toy would inform him (in my flat voice) that it would be happy to come down after he pees. For three weeks, those toys didn't budge, just as Dubil-Craig had predicted.

As we were instructed, never once did we, his parents or siblings, say a word about the toys or the bathroom. Then one day David got fed up. He wanted his favorite toy, a Madeline doll. We heard a flush, and then David emerged from the bathroom with a grin and reported, "I peed." Down came the Madeline doll, with no words of praise.

The power struggle had now shifted to David and the Madeline doll. We were out of the loop. But what was next? When would the doll return to the shelf each time?

Could we direct David to "go" before a long car trip? We made it up as we went along, but stayed strict about one thing — we ascribed all enthusiasm and control to his Madeline doll. She was in charge now. Sometimes we would

have to go behind closed doors to shout for joy.

After about six weeks, we sensed it was time for underwear. In David's mind, pull-ups get changed when wet. Since his pull-up was never wet, he would wear it until the elastic wore out. One day his gym teacher noticed a wad of bulk down around his knees inside his pants. It was an old, stretched out, dry pull-up.

Would he do any better changing underwear every day? We solved that problem with a laundry marker and the day of the week printed on each pair of underwear. Now, David was happy to match the correct underwear to the correct day of the week. It was four weeks short of his 12th birthday, and six weeks since the deprivation shelf was created. David was now in underwear, even at night. We extinguished the shelf.

In the final analysis, this method capitalized on David's social strength by creating a relationship between himself and a doll, and then later, between David and his underwear. We would say, "Your underwear wants to stay clean and dry;" It was never, "We want your underwear to stay clean and dry;" The wording is subtle, but it worked. The focus now was away from his relationship with us. "By acting as though you did not care whether he used the bathroom or not, his control reinforcer was removed," says Dubil-Craig. "Suddenly, depriving him of his favorite toy became meaningful again."

Today, upon reflection, what finally worked was both the easiest and the hardest. It was the easiest because we didn't have to go with him or be controlled by a schedule. It was the hardest because we had to stifle all enthusiasm. Had we shown excitement, we would have unwittingly recharged the power struggle. According to Kim Casey; M.S., Special Ed., all children, regardless of age or disability; need to have a say in their own lives. "If we constantly are battling with our children to gain control," says Casey, "then everyone loses and nobody really has any power. If you have the last say in every battle the child does not learn from the situation." David now was enjoying having control over his own toileting.

Now that David is trained, he still holds it for a long time. We hope to proceed cautiously with shifting him to a reasonable schedule.

## Better Late Than Never

—Continued

For the moment, trying to convince him to go before a long trip, means he holds it even longer. We have had to leave him alone and trust him to know what he needs — that is appropriate for an adolescent. Some things about David are quite on target.

We may never know whether David could have trained years earlier than he did. However, his lack of fine motor coordination plays a role in his ability to use the bathroom independently. According to Marlene Targ Brill, author of *Keys to Parenting a Child with Down Syndrome*, physical readiness for toileting includes fine motor skills. Even at age 12, he needs to wear elastic waist pants with no zipper. Had he trained earlier, he would have been dependent on our help. Given his strong dose of stubbornness, coupled with our preoccupation with three younger children, it's possible the timing could not have been different.

As is often true with our wondrous children, the question of whether the ending of this story is neat and tidy is a matter of perception. When it comes to David doing his "number two," he awakens at night, changes his own dirty underwear, finds a plastic bag, carefully wraps up the mess, and leaves it in the kitchen for us to find in the morning. He awakens no one. Honestly, I can't complain.

*Editor's note: Linda Moran Lives with her husband and four children in Ridgewood, NJ. She writes about advocacy, disabilities, parenting, and self-help and was delighted to report that just a few weeks after writing this article, David began using the toilet for his "number two." To contact Moran, visit her Web site at [www.lindamorán.net](http://www.lindamorán.net).*

*Down Syndrome News, Newsletter of NDSC Vol.27, No. 4*

## Shoes

—by Veronica Swart

I know that it sounds funny, but I am in a shoe dilemma. Madison desperately needs a new pair of sandals and sneakers. Sounds simple enough, yet to a child with Down syndrome and feet like Maddie's, buying ~shoes that actually FIT is no small feat. (Pardon the pun.)

Madison has very short but extreeeeemly wide little feet. They are not just "wide" — they are "extra wide". Like other parents of children with Down syndrome, we must buy Maddie's shoes at a specialty shoe store, which means she only has two pair of shoes at a time because HER shoes are so much more expensive than ours! Besides enduring the painful process of getting Maddie to try shoes on, we must also schedule the time that we are going to buy her shoes because her size is never available for long. Do you have a shoe date on your calendar?

Upon entering Kindergarten in her new shoes, Maddie will be required to know how to tie her shoes. If she does not, she may be paired

with a buddy who DOES know how to tie and shame may fall upon our family, as the community will know that Maddie does not know how to cross the bunny ears. That poor family down the road... still shunned to this day. We don't even buy Maddie shoes with LACES!!! It's either zip and go or pull and Velcro when it comes to her shoes (which she can now put on all by herself!).

It seems that Maddie's shoes will have a lot to do with her approaching year in Kindergarten. Maddie will be wearing new 11-1/2 double extra wide Velcro sneakers when she gets there this year. Isn't it just so interesting how neither her shoes nor her education is a "One size fits all" entity?

*FYI Sidebar - Diane Lang, Ginny MacPhee, and Patti Fagan recommend the Stride Rite, Birkenstock and Teva companies for wide shoes. Thanks!*

*News & Notes, newsletter of Aim High, September 2004*

## When Special Needs Spark Sibling Rivalry

*Reprinted with permission from the Winter 2003-04 issue of Young and Healthy, the newsletter of Cincinnatti Children's Hospital Medical Center, [www.cincinattichildrens.org](http://www.cincinattichildrens.org)*

It's natural for parents to focus their energies on children with special needs, health problems or exceptional abilities — and feel the personal effects of raising them.

But it's also important not to overlook how their siblings are faring. On the sidelines of all that extra attention, these siblings can come under some major pressures, says pediatrician Scott Steinberg, MD.

"Parents are often emotionally drained or stressed, especially about the uncertainty of a diagnosis. They may be angry and frustrated that it happened," says Dr. Steinberg, with Northeast Cincinnati Pediatric Associates in Mason. "But the healthy child also has to adjust — both to a sibling taking up more parental time and resources, as well as to a parent who's tired and stressed."

Siblings of children with special abilities or needs may act out to get parents' attention. But the impact on family dynamics can go much deeper, he says, particularly with siblings of children with special needs, who may:

- Feel alone or jealous about extra attention for their sibling and interpret it as rejection
- Wish they had medical problems to get more attention
- Worry they might "catch" what their sibling has
- Be overly helpful or noncompliant for attention
- Try to ease parents' burdens by not making demands or feeling guilty if they do
- Feel guilty for their own good health or have negative thoughts about their special-needs sibling
- Feel embarrassed or resent having to involve their sibling with neighborhood friends
- Resent having to care for a sibling or worry about their sibling's future

### Tactics for Reducing the Rivalry

Dealing with misperceptions and emotional responses starts with fostering communication, Dr. Steinberg says. "Try to be a good listener. Encourage siblings to express themselves, including negative feelings. Ask them what they like best and least about each other. Let your children know it's okay to get mad at their sibling with special-needs and not to feel guilty if they sometimes resent the extra attention."

One good way to combat misperceptions, he says, is to describe to children their sibling's special needs or abilities, starting with simple explanations around ages 5 or 6. "Share with them how a health condition is evaluated and treated and what to expect. Talk about their sibling's strengths and weaknesses and the best ways to interact with that child."

It's impossible to treat all children equally, he says. But parents should be as fair as possible and take steps to prevent sibling rivalry.

"Have children with special-needs do as much for themselves as they can and assign them tasks so everybody has responsibilities. Do chores together as a family."

Dr. Steinberg suggests setting siblings up to cooperate rather than compete, for instance by having them race against the clock as a team rather than individually to complete chores. He recommends devoting time to family activities that everyone enjoys.

"Let each child know he or she is special," he says. "Make sure they're able to develop their own interests and identity. Try to get a few minutes a day alone between each parent and child." Exclusive time with parents will be especially valuable to the sibling of the child with special-needs. He also cautions against overburdening older children with care duties for their siblings. However, all siblings of the children with special-needs can be enlisted as "partners" with parents in understanding and addressing their sibling's requirements.

## When Special Needs Spark Sibling Rivalry

—Continued

### When to Seek Help

If sibling rivalry gets out of hand or parents see signs of depression or anxiety, counseling may be in order for children or the family, he says. Signs to watch for include sleep or appetite disturbance, hopelessness, poor concentration, low self-esteem, talk of hurting oneself, loss of interest in activities, frequent crying or worrying, difficulty separating from parents, perfectionism, or what can be physical symptoms of emotional distress, such as headaches or stomachaches.

"If you see these behaviors for more than a few weeks, seek counseling," Dr. Steinberg says. Sibling support groups can connect children with others who have similar experiences.

*Reprinted from the D.S. Press, Newsletter of the Down Syndrome Association of Greater Cincinnati, July/August 2004*

## Communications Tips

—By Ann Nobis

So often, when my daughter and I are out in the community, people will look at her but infrequently include her in conversation or ask if she needs to be waited on while standing at a counter. I believe that, if we as parents, teachers, therapists and other members of the community provide a variety of communication opportunities, the articulation, language, and pragmatic skills of our children would be greatly enhanced. Following are a few suggestions for facilitating communication while developing language skills while out in the community:

### In a restaurant:

- Encourage the waitress to give your child a menu also, even if they are not readers.
- If your child is able to order in a restaurant, allow them to do so.
- If your child needs some help in ordering, give them a choice in front of the waitress and when the child responds, encourage them to look at the waitress. You may follow with, "Yes, a cheese burger is a delicious choice," rather than merely repeating what your child has said.
- If your child is not able to verbally order, you can encourage them to point to what they want, sign, or hand the waitress an icon of choice.

Despite the potential problems, being the sibling (a child with special-needs can have pluses, too, he says. Research indicates they're more likely to develop such positive traits as maturity, social competence, ability to get along with others, insight, empathy, tolerance of differences between people pride in family accomplishments and loyalty.

"They have more negative issues to deal with," he says, but they have opportunity for personal growth and character development."

- Model for the waiter or waitress that your child is part of the group, and should be included as are the other group members through eye contact and acknowledgment that he or she is there and deserves to be spoken to, even if they are not directly able to respond.

### At the movies:

- Help your child make a choice as to what movie he or she would like to see. Discuss what is in the paper or draw simple pictures of the movie theme so he or she may point to the choice then tell or hand his or her choice to the ticket clerk.
- Again, facilitate your child to interact with the ticket clerk by letting him/her pay for the tickets.
- If you are choosing to purchase candy or popcorn, your child can ask for or point to what he or she would like. Again you can avoid merely repeating his or her choice, by expanding on the choice by saying, "mmm, a small popcorn is just what I wanted too!"
- Encourage the candy clerk to attend to your child by saying, "Sally, the clerk is asking you a question."

## Communications Tips

—Continued

### At the store:

- Make a plan before going, thus allowing your child time to plan, process, and practice what his or her jobs will be.
- Use “I wonder” statements to encourage your child to think about how to find something. “I wonder where I would find your favorite cereal.” Wait for a response or for the child to show you.
- Encourage your child to participate in making a list (written or pictured), and using the list to purchase items.
- Encourage your child to ask the clerk for things you can’t find; to give the money to the clerk, and to pack the bags according to cold, squishy, produce, etc., items.

**Model, practice and provide opportunity.**

*News & Notes, newsletter of Aim High, September/October 2004*

### Behind These Eyes

People show or tell what they are By the look in their eyes.  
 A man may be inspired by his Intelligent mind.  
 Another man shows that he is Soft and tender.  
 Behind other eyes you see  
 A face that is drawn  
 And looks much older  
 than he is.  
 Some eyes are filled with tears  
 And the face is bronzed  
 From their sting.  
 You may see a glow  
 As bright as the light of the sun.  
 Behind these are emotions of  
 Love, faith, admiration and tenderness  
 Sometimes these eyes show that  
 They want to talk to others.  
 And, sometimes, after talking  
 This person feels better.

Reprinted with permission; Bus Girl. Poems by Gretchen Josephson. Edited by Lula O. Lubchenco, Assistance by Allen C. Crocker ©1997 Brookline Books Inc.

## A Way to Teach Good Behavior

Here is a suggestion from a Mom whose son had behavior problems. Her son never made the connection between his behavior and the consequences and punishments. So she and the school devised a way to teach him the appropriate actions. Before he was just punished at school for his actions. Now he is being taught what to do. This is the form that they use with him at school and at home when he does something inappropriate. This is a great alternative to punishment because he actually learns how to behave, instead of being punished for something he easily forgets. Also this makes him responsible for his own actions. When he fills out the form, he has to admit to himself that what he did was not the right thing to do. The form can be modified to fit your needs. It can be filled out by someone asking the questions and writing in the person’s own responses.

**Who was around you?** \_\_\_\_\_

**What did they do?** \_\_\_\_\_

**How did that make you feel?** \_\_\_\_\_

**Do you think that was the best thing to do?**

**Why or why not?** \_\_\_\_\_

**What could you have done instead?** \_\_\_\_\_

**If this happens again, what will you do?** \_\_\_\_\_

*NADS News, newsletter of the National Association for Down Syndrome, September 2004*

## Feeding Issues: A Parent's Perspective

In this article, I will share with you some of the struggles we have had with our daughter, Maddie, specifically as it relates to feeding issues, and some of the gains we have made with the help of specialists.

Maddie was born in April of 1999. From birth, Maddie had problems feeding. She spent the first week in the Level 3 nursery for several reasons, one of which was that she wouldn't take a bottle fast enough. I had intended to nurse her but when she had so many problems, I decided it would be best for her to use a bottle for feeding. She learned to take a bottle well by the end of the first week and we came home. At about 6 months, based on recommendations of therapists, I decided to try her on baby cereal. She ate very slowly and was very messy but did learn to take small amounts of cereal. We were on our way!

In late November of that year, Maddie contracted RSV and was hospitalized for 11 days. During that time, she was in such respiratory distress that we only gave her formula. That illness seemed to be a turning point. Once she was released from the hospital, we could not get her to eat any solid foods. At that point, we called in a speech therapist who specialized in feeding issues. Sally began using a great number of oral exercises to begin strengthening the muscles in Maddie's mouth. It took her a while, but eventually Maddie didn't fight when Sally worked with her mouth. We found out that Maddie really relaxes when she is sung to, so Sally began to use music as a reinforcer. We began trying to feed her solids again. It was a very slow process. Another turning point in her therapy came when we discovered that Maddie would do just about anything to be read to. She loves books! So, we would give her a bite of yogurt, then read her a page in a book. Once she took another bite, she could have more book. It didn't take long for her to catch on to this concept. Soon she was eating a whole container of yogurt.

Maddie continued with these exercises for some time but we still could not get her to consistently take foods other than yogurt. We then visited the Down Syndrome Clinic at Children's Hospital in Cincinnati for a feeding evaluation. After a thorough interview of Maddie's history, they wanted to make sure that there was not something structurally wrong with her digestive system. They recommended a series of 5 tests that would probe her system from the tip of her tongue to the bottom of her bottom. Although I didn't want to subject her to the tests, I felt like we needed to rule out physical problems before we could move on. By the end of February 2003, all the tests were completed and came back normal. We began to see now that we were dealing with a lot of unknowns.

Although the feeding team suggested an inpatient program, I felt it wouldn't work for our family. Her speech therapist and I came up with a rigorous program that would still work with our family. Maddie has had huge improvements since May. She eats a wider variety of foods. She still relies on Pediasure for her main nutrition, but she is able to eat foods that are not so smooth. Gagging and chewing are still issues so I rely on a food processor a lot! We also recently found a new cup with straw that holds the liquid in the straw so she doesn't have to suck so hard to get any liquid. Although I am very anxious to get beyond these problems, I am grateful that she is making progress and working towards normal eating habits.

*By Elizabeth Ray reprinted from Connections, newsletter of the Down Syndrome of Louisville, Inc., Fall 2003*

*For more information on feeding issues, contact The Jane & Richard Thomas Center for Down Syndrome at Cincinnati Childrens Hospital 513. 636. 0520*

*Reprinted from the D. S. Press, the newsletter of the Down Syndrome Association of Greater Cincinnati, November/December 2004*

# Inclusion at it's Best

## The Problem with "Problem"

***"Well, yes, she has a lot of problems with reading, math, behavior, social skills, and a few other things, but there's no reason she shouldn't be included in a regular ed class-room."***

***"Oh, I'd like my son to be in the community, but he has too many problems."***

***"I wish we could use a regular babysitter, but we have to use the respite care services because of all my daughter's problems."***

***"Well, we've been trying to place this guy in a job in the community, but he's got a lot of problems."***

***I tried to get my daughter in the Girl Scout Troop, but they said they couldn't handle all her problems."***

My unscientific study of language reveals that the #1 word used about people with disabilities is "problem." And the problem with "problem" is that it's also the #1 word that activates exclusion! Let's look at the bigger picture of the error of our ways and the "Duh!" factor will be revealed!

Peggy wants her daughter, Brittany, included in a regular ed classroom. She knows the law (IDEA), has done her homework prior to the IEP (Individualized Education Program) meeting, and feels confident she'll be successful. But her best-laid plans fall apart when the regular ed teacher hears the laundry list of Brittany's "problems." The classroom teacher just doesn't feel she can handle this "bundle of problems" named Brittany.

Similar situations are repeated every day, across all environments: inclusion in the community and in school, real employment, independent living, and everywhere else! In most cases, our efforts are noble: we attempt to ensure the needs of a person with a disability will be met by describing all their "problems." But when we use the word 'problem,' we set a person up for failure in our own minds, the minds of others, or both.

Worse, however, is how this makes children or adults with disabilities feel about themselves! What must it do to their hearts and minds to repeatedly hear others speak of them primarily—or only—in terms of their "problems"?

Forget for a moment that you know anything about people with disabilities. As a teacher, business owner, or leader of a community activity, what reaction would you have if someone wanted you to take responsibility for a person with a basketful of "problems?" You, too, would most likely reject the whole idea. So add a big "DUH!" when wondering why our efforts at inclusion often fail.

The solution to the dilemma we have created is relatively easy, however. It takes no more effort than speaking about people with disabilities in the same ways we speak about ourselves!

Think about the following two questions. Do you regularly tell friends, acquaintances, and even strangers, the most intimate and/or negative details of your life? Do you routinely detail what you need by describing your "problems?" Most likely, the answer to both questions is "no." If we don't do it to ourselves, we must not do it to people with disabilities!

Let's look at these two issues one at a time. We don't usually share intimate details of our own lives with casual acquaintances, but we routinely expose the lives of people with disabilities for public consumption. Parents, accustomed to reviewing a child's history to every professional they come in contact with, frequently get in the habit of blabbing very intimate details about their children to other parents, educators, and even strangers in the grocery store! Many adults with disabilities have inadvertently been "trained" to do the same about themselves. And professionals often divulge far more information about a child or adult than is actually necessary.

In general, we reveal intimate details about people with disabilities even though they have never given us their permission to do so. How dare we behave in such an arrogant and patronizing manner? How dare we violate a sacred trust? How would you feel if your spouse or best friend described personal details about you with three or four coworkers at lunch?

A very few circumstances (doctor visits, IEP meetings, and so forth) may require the sharing of personal information. But in general, way too many stories are told about people with disabilities—personal, intimate, private details—that are nobody's business!

## Inclusion at it's Best

—Continued

The second issue concerns how we talk during those few times we do need to discuss details about a person's life with others. Let's look at how we talk about ourselves, first.

In essence, we frame our "problems" as "needs." For example, I wear glasses or contact lenses. I do not announce, "I have a problem seeing." Instead, I say, "I need [or wear] glasses." If we change the way we talk—by changing "problems" to "needs"—not only will we speak more truthfully and with more respect for people with disabilities, but we'll also change the outcomes of our efforts!

If I described my son in the traditional way, I might say, "Benjamin has problems walking, writing, feeding himself, going to the bathroom by himself, and ... ." Shall I go on? And the odds are great that this description would scare the pants off a classroom teacher or a youth group leader. Instead, however, I speak about my son the way I speak about myself, by describing his needs:

"Benjamin uses a power chair, does his work on a computer, uses forks and spoons with big handles, and needs some assistance in the bathroom." This presents a far different—and more accurate and respectful—image than the "problem-filled" description!

But there's more. Most of us strive to create a good impression when we meet someone new, during our daily experiences, and anytime we're out in public. Common sense dictates that we share positive information about ourselves. In addition, if I want you to know about me, I would not describe my functional abilities: "I can walk, talk, feed myself, hold my temper (most of the time)..." and so forth. Instead, I would share positive characteristics about myself: I enjoy reading mysteries; I like to sew, travel, and camp out; I love being at home with my family; I dream of having an RV; and more.

We must do the same for people with disabilities! When we need to speak about children and adults with disabilities, let's make sure that in addition to describing a person's needs in a

positive way, we also detail who they are in terms of their wonderful and unique attributes: their interests, talents, abilities, and dreams!

Think about your most recent efforts to ensure a person with a disability was included. Did you inadvertently set failure in motion by the words you used? Is it time for the heel of your hand to make contact with your forehead in a "Duh!" moment?

If so, fear not! We've all done it, but each of us is capable of powerful change! Spend some time thinking about how you'll reframe "problems" as "needs." Consider which positive characteristics you'll add to the mix.

And when pondering how you'll speak differently in the future, keep in mind that respecting a person's privacy means there are times when it's best not to speak at all.

### **"PROBLEM"**

***He has behavior problems.***

***She has reading problems.***

***He's nonverbal.***

***She can't feed herself.***

***He can't walk.***

### **"NEED"**

***He needs behavior supports in the classroom. She needs large print [or books on tape].***

***He communicates with his eyes [or a speaking device]. She needs assistance with eating.***

***He uses a power chair.***

HOW CAN YOU REFRAME "PROBLEMS" INTO "NEEDS"? BE CREATIVE AND POSITIVE! ©2001-2004 Kathie Snow. For permission to reprint contact Kathy [ww.disabilityisnatural.com](http://www.disabilityisnatural.com)

*Reprinted from the D.S. Press, Newsletter of the Down Syndrome Association of Greater Cincinnati, July/August 2004*

## Self-Determination in Action: Learning to Make Choices

*All people need to have and make choices. That's what the self-determination movement is all about — making sure that people with disabilities are given the opportunity to make their own choices about how they will live their lives. Like so many things, making good choices is a learned skill. It does not happen without practice. It's never too late or early - to start practicing. Whether the people with Down syndrome that you care about are transitioning to adulthood or preschool, you can give them the right to decide for themselves what their lives will be like and what they need to do to make their dreams come true. Here's how.*

A self-determined person is one who sets goals, makes decisions, sees options, solves problems, speaks up for himself or herself, understands what supports are needed for success, and knows how to evaluate outcomes. The capabilities needed to become self-determined are most effectively learned through real-world experience, which inherently involves taking risks, making mistakes, and reflecting on outcomes. These experiences help a young person test his or her strengths and limitations and identify appropriate short- and long-term goals.

In addition to real-world experience, youth benefit from open, supportive acknowledgment and discussion of their disability. Too often, families, teachers and other well-intentioned people protect youth with disabilities from making mistakes and avoid discussing the details and potential ramifications of the youth's disability. Instead, they focus on the positive and steer the youth away from many experiences where there is a potential for failure.

However, in order to direct their own futures, youth need to know themselves and understand how their disability might affect academic learning, relationships, employment, participation in their communities and need for support. With this knowledge, they are better positioned to develop plans, make decisions and learn from experience. There can be a fine line, however, between experiencing the real world and losing one's sense of personal empowerment.

Supporting a young person in becoming self-determined is not about simply removing limits

and structure. It is, rather, about providing opportunities so a young person can make meaningful decisions about his or her own future. For families, teachers and other adults, supporting self-determination requires being open to new possibilities and taking seriously youths' dreams for the future.

### Promoting Self-Determination in Youth with Disabilities: Tips for Families and Professionals

#### Promote Choice Making

- Identify strengths, interests and learning styles;
- Provide choices about clothing, social activities, family events and methods of learning new information;
- Hold high expectations for youth;
- Teach youth about their disability;
- Involve children and youth in self-determination/self-advocacy; opportunities in school, home and community;
- Prepare children and youth for school meetings;
- Speak directly to children and youth
- Involve children and youth in educational, medical and family decisions;
- Allow for mistakes and natural consequences; Listen often to children.

#### Encourage Exploration of Possibilities

- Promote exploration of the world every day;
- Use personal, tactile, visual and auditory methods for exploration;
- Identify young adult mentors with similar disabilities;
- Develop personal collages/scrapbooks based on interests and goals;
- Involve children and youth in service learning (4H, Americorps, local volunteering).

#### Promote Reasonable Risk Taking

- Make choice maps listing risks, benefits and consequences of choice;
- Build safety nets through family members, friends, schools and others;

## Self-Determination in Action: *Learning to Make Choices*

—Continued

- Develop skills in problem solving;
- Develop skills in evaluating consequences.

### Encourage Problem Solving

- Teach problem solving skills
- Allow ownership of challenges and problems;
- Accept problems as part of healthy development;
- Hold family meetings to identify problems at home and in the community;
- Hold class meetings to identify problems in school;
- Allow children and youth to develop a list of self-identified consequences.

### Promote Self-Advocacy

- Encourage communication and self-representation;
- Praise all efforts of assertiveness and problem solving;
- Develop opportunities at home and in school for self-advocacy;
- Provide opportunities for leadership roles in home and in school;
- Encourage self-advocates to speak in class;
- Teach about appropriate accommodation needs
- Practice ways to disclose disability and accommodation needs;
- Create opportunities to speak about the disability in school, home, church, business and community.

### Facilitate Development of Self-Esteem

- Create a sense of belonging within schools and communities;
- Provide experiences for children and youth to use their talents
- Provide opportunities to youth for contributing to their families, schools and communities;
- Provide opportunities for individuality and independence;

- Identify caring adult mentors at home, school, church or in the community;
- Model a sense of self-esteem and self-confidence.

### Develop Goal Setting and Planning

- Teach children and youth family values, priorities and goals;
- Make posters that reflect values and are age-appropriate;
- Define what a goal is and demonstrate the steps to reach a goal;
- Make a road map to mark the short-term identifiers as they work toward a goal;
- Support children and youth in developing values and goals;
- Discuss family history and culture — make a family tree;
- Be flexible in supporting youth to reach their goals; some days they need much motivation and help; other days they'll want to try alone.

### Help Youth Understand Their Disabilities

- Develop a process that is directed by youth for self-identification: Who are you? What do you want? What are your challenges and barriers? What supports do you need?
- Direct children and youth to write an autobiography; Talk about the youth's disability;
- Talk about the youth's abilities;
- Involve children and youth in their IEPs;
- Use good learning style inventories and transition assessments;
- Identify and utilize support systems for all people.

*From Self-Determination; Supporting Successful Transition by Christine D. Bremer, Mera Kachgal and Kris Schoeller, a National Center on Secondary Education and Transition Research to Practice Brief (Vol. 2, Issue 1) [www.ncset.org/publications](http://www.ncset.org/publications).*

## Indicators For An OT Referral

- DO your students rest their heads on their desks even when they are not in trouble?**  
*Try providing more postural support with a properly sized desk that supports the student's back firmly and comfortably and allows for the feet to rest on the floor.*
  - DOES it take "forever" for a student to print or write on line?**  
*Try bringing the work area closer to your student's eye level with a tilted desktop. Multi-sensory tools such as vibrating pens, pencil grips and raised line paper (available through PREP) also give students the extra feedback needed to get the job done quicker.*
  - DOES it seem like your student is always "on the go?"**  
*Try balancing your student's energy level with the introduction of a "sensory diet" to help regulate their energy for seatwork.*
  - DOES your student frequently "bump" into people or things?**  
*Try improving your student's awareness of personal space by practicing keeping an "arm's length" distance from your neighbor when sitting on the floor or walking to his desk.*
  - DOES your student "hate" getting their hands dirty?**  
*Try providing weight-bearing activities (i.e. push ups) or hand massages before the messy work begins.*
  - DOES your student always "touch" things?**  
*Try redirecting your student's need for touching to more socially appropriate worry beads, Koosh ball or an elastic band to rub. For some students it is a good idea to chew sugarless gum in class!*
- If you answered "YES" to any of these questions, a consultation with an occupational therapist may prove to be very beneficial.

## Buddy Walk 2004



## Is it Alzheimer's Disease?

—By Brian Chicolne, M.D., Park Ridge, IL

*Editor's note: Thanks to Dr. Chicoine, medical director at the Adult Down Syndrome Clinic at Lutheran General Hospital for writing this article for Down Syndrome News.*

"My 24-year-old son was diagnosed last week with Alzheimer's disease, what do you think?" This is an example of a phone call, an e-mail, or a concern voiced at an office visit that we have been hearing more frequently. Is it Alzheimer's disease? Do people with Down syndrome develop Alzheimer's disease at that age?

Before answering those questions, it is helpful to go back and look at the information we know about Alzheimer's disease in people with DS.

Alzheimer's disease is a progressive neurological condition. Brain cells are destroyed and the person experiences decline in function in multiple areas including memory cognition, control of bodily functions and others. Microscopically, the brain tissue demonstrates changes called plaques and tangles.

Several years ago researchers did autopsy studies on a number of people with DS that had died for a variety of reasons. They concluded that essentially all people with DS develop plaques and tangles by the age of 35 or 40. Many people have concluded from this information that all people with DS over the age of 35 or 40 years develop clinical Alzheimer's disease.

We have looked at the information we have gathered after serving over 2,500 adults with DS and have not found that all people with DS over the age of 35 or 40 develop Alzheimer's disease. Some other researchers have published similar findings. In fact, the percentage of our patients who have developed Alzheimer's disease is actually pretty similar to the general population. The difference in our data is that our patients, on average, develop Alzheimer's disease 20 years earlier than people in the general population. Therefore, the rate of Alzheimer's disease in our patients in their forties is similar to those without DS in their sixties, our patients in

their fifties compare to others in their seventies, and sixties to eighties. This is not to say that these are small numbers. In the general population, the incidence of Alzheimer's disease in people in their eighties is thought to be 40 percent.

While this information regarding populations of people is helpful, it doesn't answer the question of whether an individual has Alzheimer's disease. A thorough evaluation is needed. There is no one test that makes the diagnosis.

The diagnosis is made by looking for a pattern of decline, looking for supporting information (such as findings on a CT scan), and "ruling-out" other causes of decline.

There are many reasons someone may have a decline in skills. Some of the causes are not reversible. Unfortunately, as of 2004, Alzheimer's disease is one of the non-reversible causes. However, many of the other causes are reversible and the evaluation must include an assessment for these. The evaluation includes assessment for the following:

- **Sleep apnea**
- **Hypothyroidism**
- **Vitamin B12 deficiency**
- **Depression**

There are many other possibilities as well.

Particularly in younger people who have declined, one of the things we have seen is a person becoming overwhelmed. This is often a case of expectations exceeding ability.

We have seen several people who had fine skills in self-care, tasks in the home, and tasks in the workplace. Unfortunately, some of these folks have a difficult time organizing their time or dealing with fluctuations in their schedules.

Others have a difficult time knowing how to use their "downtime" or recreation time. This occurs even when the person has the skill to do all the activities but may lack the ability

# Is it Alzheimer's Disease?

—Continued

to “pull it together.” This is where the expectations exceed the actual ability. Before the decline, the person appeared to function so well because of the ability to do so many tasks but not as independently as was expected. When the expectations are too great, in a sense, the person “shuts down.”

In Alzheimer's disease, the symptoms we typically see include the following:

- **Memory impairment**
- **Decline in cognitive skills**
- **Incontinence of urine and/or stool**
- **Gait disturbance**
- **Personality or psychological changes**
  - ***depressed mood***
  - ***aggressiveness***
  - ***paranoia***
  - ***compulsiveness***
  - ***loss of interest in activities***

- **Seizures and/or myoclonic jerks**
- **Swallowing dysfunction**
- **Sleep changes (day-night reversal, daytime fatigue)**
- **Altered appetite and thirst**

These symptoms develop over time and not all of them are present in the early stages.

Does the 24-year-old young man mentioned at the beginning of the article have Alzheimer's disease? It certainly would not be the first thing I would consider. In fact, the youngest person we diagnosed with DS was about 35 years old when his symptoms began. Alzheimer's disease is lower on our list of diagnostic possibilities for any of our younger patients who present with a decline in skills. While there may be some people who fall outside the typical age range, it is more likely there is an alternative explanation. Careful assessment, support, observation over time, and treatment of any potentially reversible conditions will often help make the diagnosis more clear and lead to improvement in those individuals who don't have Alzheimer's disease.

## Calendar of Events

Jan. 31, 2005:	Board Meeting	May 23, 2005:	Board Meeting
Feb. 28, 2005:	Board Meeting	June 27, 2005:	Board Meeting
March 9, 2005:	Community Based Education, Connie Susa	July 25, 2005:	Board Meeting (only if needed)
March 28, 2005:	Board Meeting	Aug. 27, 2005:	Board Meeting
April 13, 2005:	General Membership Meeting (speaker to be announced)	Sept. 14, 2005:	General Membership Meeting (speaker to be announced)
April 25, 2005:	Board Meeting	Sept. 26, 2005:	Board Meeting
May 11, 2005:	Medical Panel (speakers to be announced)	Oct. 2, 2005:	Buddy Walk
May 13, 2005:	Comedy Night	Oct. 24, 2005:	Board Meeting
		Nov. 27, 2005:	Holiday Party
		Nov. 28, 2005:	Board Meeting

# Down Syndrome Society of Rhode Island

## DEDICATED

To promoting the rights, dignity and potential of all individuals with Down syndrome through advocacy, education, public awareness and support.

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