



99 Bald Hill Road  
Cranston, RI 02920

# DSSRI NEWS

Winter, 2006

SUPPORT  
•  
EDUCATION  
•  
ADVOCACY  
•  
PUBLIC AWARENESS

## President's Message

**W**ell, 2006 is nearing its end and DSSRI had a very productive year! In March, we had our conference attended by family and self-advocates; and in May, our Night of 1000 Laughs not only raised money but was a great time. The following took place also: New parent gathering at the East Providence Public Library; the successful Buddy Walk with 300 walkers; the very informative Medical Panel; and the exciting Holiday Party with Santa and Mrs. Claus.

The 2006 Holiday Party was also our election of Board Members. Please join me in welcoming to our Board: John Egan, Heidi Fanion, Allan Garcia and Jill Gauthier; Saadia Cicerone is graciously serving another term of office. The Officers for the coming year are: Marilyn Blanche, President; Saadia Cicerone, Vice President; Lori Coleman, Treasurer and Diane Cerep, Secretary. "Thank You" to our retiring Board Members.

We look forward to 2007 with some of our annual activities; New Parent Gathering TBA, Comedy Night, May 4, 2007; Buddy Walk, September 16, 2007 and Holiday Party, November 25, 2007. Also, on January 15, 2007 we are bringing in a speaker from Ohio State University-Nisonger Center to discuss and train attendees on, "The Next Chapter Book Club." This is a book club for young adults and adults. On March 14, 2007 our General Membership Meeting will address *Guardianships* and our scheduled speaker is Kate Sherlock from the RI Disability Law Center. Also, a Member's Luncheon is being planned for 2007.

In addition we are working on some activities for the younger crowd of children with Down syndrome. Please watch your mail for more information as it becomes available.

*Wishing you all a very Happy and Healthy  
Holiday Season,  
Marilyn*

## In Appreciation

Prescott H. Peirce Co., Inc.  
Brooks Pharmacy / Eckerd Pharmacy  
Guill Extrusion Tooling  
Sheraton Providence Airport Hotel  
IBEW Local Union #99  
Crystal Stamping Corp.  
Family and Friends of Jack Garcia  
Dot MacDonald  
Greenville Concrete  
John Egan and Friends  
Megan Fallon and Friends  
Joseph and Jane Degnan  
Daniel and Margaret Hurley  
Patricia Adams  
Regina and Franco Dellaposta  
Kevin and Robin Ford  
Marie Aguiar  
Cindy Tente  
Peter and Raquel David  
Scott Mason Design  
John and Marie Hennedy

Maryann Healy  
Kathleen McDonough  
Maureen and John Ricci  
Lenwood and Ellen Babbitt  
Staci Kolb  
Kathleen Mulligan & Gary Waldeck  
Susan Masse  
John and Colleen McCarthy  
Nancy and Donald Rowell  
Springfield Elementary Sunshine Club  
Siegfried M. Pueschel, MD Ph.D, J.D.  
Bill and Marie Therese Shaughnessy  
Friends of Senator Maryellen Goodwin  
Thomas and Patricia Goodwin  
LGP Distributors, Inc.  
Mignon Kolb  
Family and Friends of the late Robert Burbank  
Family and Friends of the late William Deignan  
Ocean State Parrot Head Club  
Joyce Moore  
Displays2Go

## 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.

## Yoga for the Special Child™ with Jane Mizrahi

**Y**oga for the Special Child™ is a comprehensive program of yoga techniques designed to enhance the natural development of children with special needs. This style of yoga is gentle and therapeutic. It is safe for babies and children with Down syndrome, cerebral palsy, autism and other developmental disabilities. These methods also provide a supportive treatment for children diagnosed with attention deficit disorder and learning disabilities.

Yoga for the Special Child™ is an integrated system of postures, breathing, chanting, eye exercises and deep relaxation for children and adults of all ages and abilities. Sonia Sumar is the founder and director of the Yoga for the Special Child™. She is internationally renowned for her pioneering work using Yoga therapy. Her program of 35 years has made a tremendous difference in the lives of children with special needs and their families throughout the world.

### Yoga and Down Syndrome

Yoga poses (asanas) help to stretch, tone and strengthen the entire body. Asanas also benefit the internal organs and help to balance and revitalize the endocrine glands. For this reason children with Down syndrome who practice yoga stay slim and flexible, while those who do not practice yoga tend to put on weight as they age. In conjunction with yogic breathing exercises, which have a beneficial effect on the central nervous system, asanas facilitate the development of body awareness, concentration and memory — vital skills for any child with a developmental disability.

### Jane Mizrahi, Licensed Practitioner

I have been practicing yoga since 1992. My training is with Marsha Wenig of Yoga Kids and Sonia Sumar of Yoga for the Special Child™. I am deeply committed to my practice of yoga and I feel blessed to offer my services as a licensed yoga practitioner of Yoga for the Special Child™. Through this program, I will support your child towards physical and spiritual growth in a private, one-on-one setting. In order to design a program that is specific for your child an initial consultation may be necessary. Please contact me, Jane Mizrahi at 401.245.0027 or email: janemiz@hotmail.com.

## Jack's Essay

*Sarah Crowell, September 19, 2006*

**I** had been waiting eagerly but patiently for nine months, nine long months. Around Valentine's Day of 2003, I found out that my neighbor Beth was pregnant with her second child. My family and I are extremely close with our neighbors and we have a great relationship. My sister and I baby-sit for their daughter and we are always invited to go on outings with them. When we found out that there would be a new addition to our families, everyone was thrilled. For my sister and I, it was like we would have a new sibling. Both families hoped for a boy to break the trend of the three girls and thought about what he would look like; blonde curls and bright, blue eyes was the unanimous image. The exhilaration of a new brother or sis-

ter made our three year-old neighbor, Olivia, so happy. She couldn't wait for someone to play with all the time and wanted to teach him or her everything she knew. As months passed, Olivia watched her mom's stomach grow bigger and we all felt the day drawing closer. The day that Beth and her husband Allan went to the hospital to get an ultrasound was full of anxious anticipation. We would finally know whether the baby was a boy or a girl. I was in school the day that those pictures came in. When I got home, I bolted next door across the backyard to find out if our wish for a boy had been granted and it was! There were now only a few more months until this new baby boy would be brought into our world. The next order of busi-

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## Jack's Essay

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ness was a name, a name that fit. Many names were considered, but only one stood above the rest. It was the perfect name for the little boy that we all had been imagining for months. Jack. Jack Allan Garcia. Visits to the hospital persisted for Beth and Allan and everything was going according to plan. By the time the cool winds of October blew in and the vibrant autumn leaves began to fall, something was going to change. Everyone was waiting impatiently to meet the little character we had all been talking to and feeling tumble around like an acrobat for eight months. Finally, after yet another appointment at the hospital, the date was set. On October 15th 2003, Jack Allan Garcia was to be brought into the world. The pregnancy had no complications and everything was running like clockwork. All day at school I was noticeably distracted, awaiting the 2:35 bell.

I had two friends visiting that afternoon and they too were ecstatic to hear the news. The call that we longed for arrived at about five that evening and Allan talked to my mom for what seemed like an eternity while my two friends and I waited tensely upstairs in my room. I heard my mom's light footsteps on the creaking wooden stairs and then a soft knock on my door. I was surprised not to see the smile that I expected across my mom's face, but in its place were tears streaming from her eyes and a broken down expression of defeat. "Jack...has Down syndrome." These four heart-wrenching words were the last thing that I had ever expected to hear on that cool, fall evening. I didn't believe it. I fell into my friends' arms and cried until my eyes ran dry. At the time, it seemed like all our dreams of how he would act, what we would teach him and even what he would look like were gone. All of those dreams were crushed by four words.

Feeling as though my world as I knew it would never be the same, I picked up the phone and began dialing the numbers of my other friends, to let them know the devastating news. No matter how hard I tried to keep it together, I kept falling apart every time I tried to tell my story. My friends' reactions were all very similar; they cried quietly, trying not to upset me anymore than I already was. I tried to be more positive each time, trying a new tactic to telling the

story, hoping that it would help me to hold my emotions in. After talking to all my friends each for the few minutes that I could, I began to replay in my head the conversations that had just taken place. I reflected upon each of them. They all were different, but still the same in one way. All of my friends had apologized to me. This made me think. Why were they sorry? There was nothing that anyone could have done. It was something that just happened, one tiny, extra chromosome had misplaced itself and we received Jack, a beautiful baby. That was it, this beautiful baby, who was still what he was all along. At first I thought of Jack as a Down syndrome baby, but he is a baby, a child, who needs and deserves the same amount of love that any other child should receive, if not more. At that moment, I knew I couldn't waste any more time crying about Jack. Things could have been much worse. I should have been celebrating his life. So what if Jack had Down syndrome. He was still the baby that we all loved and that we couldn't wait to hold and hug and kiss for nine months. When my mom told me that Allan said we could go to the hospital to visit Beth and Jack, my first reaction was that I didn't think that I could. I didn't want to make a fool of myself by breaking down in tears when I saw the family. It should be a happy occasion. I ended up going to visit two days later. Holding Jack was one of the most empowering experiences that I will ever have. Holding this tiny life that you know will depend on you and will look up to you is so incredible. It was especially inspirational to hold Jack. I remember thinking to myself how much that I will learn in my lifetime from this tiny baby and how wonderful it is to know someone like him. He will teach me so much and I will appreciate knowing him and growing up with him. Now, already at the young age of two, Jack has taught me that he is no different. Jack is an inspiration to me. Whenever I feel like I don't want to do something because it is too difficult, I think of Jack, who will have to face challenges all of his life and that they will be one hundred times harder than whatever it is that I don't want to do. Jack is still the same as every other child in the world, he just takes a little more time and we can't forget about all those hopes and dreams we had. They all will come true and along the way, Jack will teach us each something about himself and ourselves.

## Yoga Joins Treatment for Kids with Disabilities

By Rona Mona Marech  
Baltimore Sun

BALTIMORE —

**R**iley Jackson and Shane Perlow, both 7 and ordinarily full of energy, were lying on their backs and taking deep yoga breaths while little plastic frogs on their bellies steadily rose and fell. Soon, they were wobbling and grinning through “tree pose” and hissing enthusiastically for “cat pose.” Riley, who has missing front teeth, gaily sang “London Bridge is Falling Down” as he wiggled into bridge posture.

Yoga is a part of the occupational therapy the boys do at Hands On Therapy in Pikesville, Md., where Riley is being treated for a sensory disorder and Shane gets help for handwriting problems and some related spatial issues. As the half-hour yoga session wrapped up, Shane, a sweetly polite kid with wavy brown hair, declared that he felt good. “I feel more quieter,” he said. “More calmed down.”

Giggling and croaking like frogs may not be precisely what ancient Hindu practitioners had in mind, but as yoga continues to boom in popularity in the West, a new sort of follower is scurrying onto mats and into downward-facing dog position: a child with disabilities.

A growing number of kids with attention, anxiety and learning disorders, as well as autism, Down syndrome, cerebral palsy and multiple sclerosis, are embracing yoga. Their parents are reporting physical, mental and emotional benefits.

“People are calling about kids with almost every kind of diagnosis,” said Annie Mahon, who offers what she calls “therapeutic yoga” for children at her Chevy Chase studio, Circle Yoga. “It’s definitely blossoming.”

Yoga teachers are beginning to add a “special needs welcome” tag on their advertisements, and a variety of pediatric therapists are integrating yoga into their treatments. “There are so many parents with kids with

special needs. I don’t want to say they’re desperate, but they really want to find ways to help their kids,” Mahon said. “They may want to find complements to medication, to find natural ways to help them, and ways the kids can be empowered, too.”

Some of the “yoga” done with children can look a little more like plain old playing: running, wriggling, pretending to be animals. But many of the postures adults do are embedded in there - just with extra barking, snorting and chants with Sesame Street overtones.

And just like adults ensconced in an incense haze, children learn to meditate and to pay attention to their breathing. Teachers sneak in strands of yoga philosophy, reminding children to breath through the scary parts or to be present.

“We feel like all our kids are true yogis. We see in them a sense of their belonging in this world, and that they are valued in this world,” said Molly Kenny, a Seattle-based pioneer in the field, who has trained many of the people who work with children with disabilities.

Susan Whelan of Leonardtown found out about yoga for children with disabilities from another parent in her knitting group. She enrolled her 10-year-old daughter, who has a yet-unlabeled condition that may be cerebral palsy, and her 12-year-old son, who has autism, in classes.

“Because there’s no known cure for autism, I have always looked at all alternative and on-the-edge therapies,” Whelan said. She said yoga helps her son focus and he has learned to use the breathing techniques to calm himself.

Her daughter, who has trouble running, gained considerable flexibility through yoga. The class also boosted her self-confidence and even helped with a speech problem that often leaves her struggling to find words. “Something happens with the brain that frees up language,” Whelan said. “She’s a motor mouth during yoga.”

# Yoga Joins Treatment for Kids with Disabilities

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Julie Peoples-Clark was suffering from postpartum depression when she saw an ad in the back of a yoga magazine for “yoga for the special child.” Her daughter, Ella, who is now 3, has cerebral palsy due to a birth injury.

She took a weeklong course and started practicing with her daughter every day. “It was a wonderful way for me to connect with Ella,” said Peoples-Clark, who recently moved to Vermont. “Finally, I felt like had a sense of power over her recovery.” Her depression lifted.

Other teachers and parents say yoga can help kids with concentration, balance, sleep, muscle development and brain function. Karen Soltes, a clinical social worker from Chevy Chase, does some conventional talk therapy during her yoga classes.

“This was a surprising byproduct,” she said. “Most adolescents don’t want to come and talk to you a lot about what’s bothering them. Through a lot of movement and sun salutations, all of the sudden they’d be talking about their lives.”

In addition to introducing yoga to children with severe disabilities, Soltes has worked with “regular stressed-out kids” doing yoga and yoganidra, which resembles a guided relaxation.

“There’s an enormous increase in anxiety in children,” Soltes said. “We can help kids find better ways to relax so it’s not taking a toll on their physiology.”

Research on the effect of yoga on children is scarce because the practice is fairly new, but the health benefits for adults are well documented, said William Stixrud, a clinical neuropsychologist in Silver Spring. He often recommends yoga to anxious children he sees in his private practice.

“For kids in general, stress is terrible for learning,” he said. “My emphasis on yoga and meditation is to minimize the extent to which stress molds their brains in such a way that they’re vulnerable to ongoing anxiety and recurrent depression.”

*Reprinted from The Cincinnati Post  
Tuesday, September 5, 2006*

## The Beatitudes for Friends of Exceptional Children

**B**lessed are you who take time to listen to difficult speech,

For you help us to know that if we persevere,  
We can be understood.

Blessed are you who walk with us in public places,

And ignore the stares of strangers,

For in your companionship,

We find a haven of peace.

Blessed are you who never bid us to “hurry up”,

And more blessed are you

Who do not snatch tasks from our hands to do them for us,

For often we need time rather than help.

Blessed are you who stand beside us

As we enter new and untried ventures,

For our failures will be outweighed

By the times we surprise ourselves and you.

Blessed are you who ask for our help,

For our greatest need is to be needed.

Blessed are you when you assure us,

That the one thing that makes us individuals

Is not our peculiar muscles,

Nor our wounded nervous systems,

Nor our difficulties in learning,

Nor any exterior difference,

But is in our inner, personal, individual self

Which no infirmity can diminish or erase.

*Author Unknown*

*Reprinted from NADS News, the newsletter of the National Association on Down Syndrome, September 2006*

## Phone Buddies

When Elizabeth started 3rd Grade at Half Day School in Lincolnshire, IL, she was like any other 3rd Grader. Elizabeth wanted to make friends and socialize after school. We had been trying since kindergarten to develop friendships for her but with limited success. It seemed that everyone had extra-curricular activities that interfered with friendships. This was a very frustrating year for Elizabeth, because even though her class was very accepting of her, she did not feel that inclusion outside of the classroom.

Toward the end of the 3rd grade, I had requested more intervention from the district to help Elizabeth with socialization. While researching "Circle of Friends", I came across the idea of a *Phone Buddy*. This really caught my attention, because Elizabeth was really desperate to talk on the phone with a friend. In fact, she would come home from school, grab the school directory, and start dialing. Well, one time she hit 9-1-1 by accident, and sure enough a police officer showed up a few minutes later. At that point, I realized how much Elizabeth was frustrated with wanting to talk on the phone. We were able to start a *Phone Buddy* system in early spring. I was disappointed in the low interest of the classmates, but, I was determined to make it work again at the start of the 4th Grade.

Now that Elizabeth is part way through 4th grade, I am just thrilled with *Phone Buddies*! This year has met my expectations and then some! *Phone Buddies* was planned and implemented about a month ago, and it has already made a big impact on Elizabeth and her friends at school. My goal for *Phone Buddies* reaches further than simply getting Elizabeth on the phone with a friend. I like to see inclusion as a whole picture, with the benefits reaching the parents of students and then community as a whole. As much as I was pushing disability awareness in my community, I felt I still had a long way to go. However, once *Phone Buddies* got going, I really felt that one of my long term goals was being realized.

Almost everyday, Elizabeth gets a phone call after school or in the evening. She is just thrilled to talk on the phone, asking her friends questions like, "How many brothers and sisters do you have? What's your favorite TV show?" Elizabeth's speech had greatly improved while she is on the phone, because she wants to speak clearly for her friends to understand her. Her *Phone Buddies* have great patience in waiting for a clear response – what a powerful impact such a call has made on these kids! I have gotten several phone calls in the last month from parents offering their support for *Phone Buddies*, and how they are

grateful such a program has been developed with an opportunity to have their children become involved and make a difference in Elizabeth's life. Not only does Elizabeth get to have a conversation with a friend, but these chats have turned into invitations to play. This feedback has been so heartwarming – to know that the benefits of *Phone Buddies* are reaching their potential.

I am so appreciative of the inclusion team adopting *Phone Buddies* and developing it further with *Phone Buddies Lunch Bunch* and *Phone Buddies Picture Dictionary* for Elizabeth. Inclusion works when we are able to take a risk. I encourage parents of kids with Down syndrome to establish *Phone Buddies* in their school district. As a side note, the principal had told us he was asked later if he would do this for a child without a disability if the parent requested it. His answer tells it all, "Why wouldn't I? It's about helping kids do their best and accept each other." The letter that went out to the entire 4th grade class is shown at the end of this article.

This is an account of *Phone Buddies* written by Elizabeth's one-on-one aide, Maggie Ahlberg:

At a weekly team meeting, Elizabeth's parents presented us with the idea of a telephone buddy system as a means of promoting socialization with her peers. To be honest, we were hesitant at first. We thought of several reasons why we shouldn't do this. First of all, we felt it really was not the job of the school to provide social opportunities for students. Where would we draw the line? What if everyone who felt that their child was not as "popular" or as "accepted" as they would like to be, wanted us to start setting up social situations for their children? Secondly, we were afraid that by putting our name to this, it would imply that we were promoting it, and that it was our opinion that people should participate. Our most important reason was the concern that not all third graders were proficient phone users. This might put unnecessary pressure on the children to perform a task that would make them uncomfortable.

After much discussion, we decided we would give it a try, with some modifications. We sent a letter to the parents of Elizabeth's 3rd grade classmates, former classmates, and students on her bus. We were pleasantly surprised by the response. We sent out a total of 88 letters and received about 15 back. With this information in hand, we printed up a calendar and began assigning times. We set it up so that Elizabeth would receive at least one phone call a day. We explained in the note that went home with the schedules that we

# Phone Buddies

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would like for the volunteers to make every effort to call on their assigned days, but they were not limited to those days. They were free to call as often as they liked. With the start of the next school year, it was decided that we would once again implement the phone buddy system. This time, we sent the letter home with all the 4th grades, approximately 200 students. We received approximately 25 volunteers. There was something new this year though! About half of the children who signed up were boys! The previous year only girls had signed up. We had to convince Elizabeth that this was fine, and that boys should be “included” too!

Some of the children who volunteered had never been in class with Elizabeth, and some were new to the school. Partially due to the concern that Elizabeth would not know the child to whom was speaking, and concern that children who did not know Elizabeth were not always clear, we decided we would have a *Lunch Bunch* to kick off the program. We invited all the children who had signed up to participate to a special in our classroom. While they ate, we introduced Elizabeth and all the children who were present. We asked them about the things that interested them, and

what types of things they might call a friend to discuss. We then asked Elizabeth if she would enjoy talking to her friends about those same things. Of course she would!

We decided that these *Lunch Bunches* might be a good thing to do on a monthly basis. This would help to reinforce the friendships, and give the children the forum to discuss any questions or concerns that they might have. One of our school social workers will conduct these monthly group meetings to give the children tips on successful phone communication, not only with Elizabeth, but with anyone. Elizabeth's parents report back to us that Elizabeth is thrilled to hear, “the phone is for you Elizabeth,” and that she grins from ear to ear. They can see a difference in her speech, and so can we! This small group of volunteers has given us the chance to make it a cozy, manageable clan. We are pleased with the success of the program, and it really doesn't take that much work once it is set in motion.

*Reprinted with permission from the NADS News, Newsletter of the National Association for Down Syndrome, January, 1999. Thank you Scott and Susan Gottlieb for the great idea!*

Dear Parents,

“Circle of Friends” is a concept that helps people with special needs participate more fully in the community, while giving others in their “circle” the means to help in a productive manner. It is an ongoing strategy for growth, change and development. As one aspect of developing, “Circle of Friends” we are putting together a phone buddy system for Elizabeth Gottlieb. We are looking for school friends who would like to volunteer to chat with Elizabeth on the phone for a few minutes at scheduled times after school or on weekends.

The benefits to Elizabeth are numerous. She would be able to practice speech, social skills, phone etiquette, as well as continue to develop friendships made at school. Your child's benefits include improved phone etiquette, a better understanding of a person with special needs and the knowledge that she/he is involved in helping Elizabeth in the inclusion process.

We would like for you to discuss this with your child. If she/he would like to volunteer to be involved in the phone buddy system, please complete the attached form. Your child has no obligation to do this and should only participate if she/he would truly enjoy helping out in this way. Please do not pressure your child, or the benefits of this program are negated.

*Thank you for your time and consideration,*

*Scott and Susan Gottlieb*

*Nathan A. Carter, Principal*

## **I WOULD LIKE TO CALL ELIZABETH ON THE PHONE AS PART OF HER “CIRCLE OF FRIENDS”**

NAME \_\_\_\_\_

### **WOULD YOU BE AVAILABLE TO CALL:**

AFTERNOONS \_\_\_\_\_ EVENINGS \_\_\_\_\_

WHAT DAYS ARE BEST FOR YOU? \_\_\_\_\_

# PARENT ADVOCACY: WHAT YOU SHOULD DO..... AND NOT DO

by Leslie Seid Margolis, Esq.

## ***WHAT PARENTS SHOULD DO***

### **Prepare for Meetings**

You should treat the IEP meeting as if it is the first step towards a due process hearing by preparing for the meeting and building a record. If you do this, you make it less likely that you will end up at a due process hearing. If you do end up at a hearing, you will be in a stronger position.

### **Prioritize Your Child's Needs**

Everything you want for your child is not equally important. Make a list of what your child really needs, what you want for your child (but may be willing to compromise on), and what would be nice to have but that you would definitely be willing to give up.

Think about the evidence you have to support each requested item (i.e., reports, assessments, experts, other documents). If you prioritize your issues and have facts and evidence that support what you want, it is more likely that you will be taken seriously.

### **Build Good Relationships**

Develop positive relationships with school personnel, to the greatest extent possible. Ask questions. Ask your child's team to explain things you do not understand.

Take the high road. As hard as this may be to do, being polite and courteous is always better than

being rude and nasty. If a meeting is deteriorating with nasty comments or behavior from any team member, ask for a break or ask that the meeting be continued to a later date and time.

Good relationships with school personnel and central office staff to the extent possible, will generally ensure that issues you bring up will be taken seriously.

### **Document Issues & Concerns**

Ask that items and issues you feel strongly about be documented in the meeting summary or notes. Review the summary before you leave the meeting. Know your rights about amending your child's records.

### **Use Advocacy Strategies**

Use advocacy strategies. Meetings do not have to be drawn out to the point of battle. For example, if the team cannot reach an agreement about the type or amount of service, suggest that the issue be tabled in order to obtain additional information from consultation or conversation(s) between your child's private therapist (if there is one) and the school therapist.

Rather than immediately asking for an independent assessment, disputes can sometimes be resolved by asking that an assessment be conducted by a school district evaluator who does not know your child.

## ***WHAT PARENTS SHOULD NOT DO***

### **Complain Loudly & Often**

Parents should not complain about every issue that comes up over the course of their child's school life. This is the equivalent of crying wolf, and ensures that when a serious issue does arise, you will not be taken seriously. This is because you are expending the same amount of complaint energy on the serious issue as you expended on trivial issues.

### **Assume the Worst**

Parents should not assume that the school district is out to get their child and deny services. While the reality is that the school district is a bureaucracy with its own interests to protect, most individuals in the district enter the field because they care about children.

While you need to enter the special education process with knowledge to protect your child's rights, you should treat the professionals with whom you deal as if those professionals have your child's best interests at heart.

### **Have a Closed Mind**

You need to have an open mind at IEP meetings. If your child's team proposes a placement with which you disagree, do not dismiss it, or refuse to observe it, or refuse to consider it. This is especially true if you may challenge the appropriateness of the proposed placement.

Again, the IEP meeting is important for record-building purposes. If the case goes to a due process hearing, it is important that you present as a cooperative person who thoughtfully considered

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# PARENT ADVOCACY: WHAT YOU SHOULD DO..... AND NOT DO

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## ***WHAT PARENTS SHOULD NOT DO***

the team's program, personally observed the program, and can explain why you believe the program does not meet your child's needs.

### **Stint on Experts**

Do not try to save money by stinting on experts. You need to find experts who can provide sound professional opinions and evidence. Experts are critical to successful cases, especially if parents are unrepresented.

If you truly cannot find experts, either through your children's medical service providers or other-

wise, you need to think about how to use supportive (or even hostile) school personnel to your advantage.

About the Author

Leslie Seid Margolis, Esq. is a managing attorney with the Maryland Disability Law Center (MDLC), a private, non-profit organization staffed by attorneys and paralegals. MDLC is the Protection and Advocacy organization for Maryland.

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## **The Second Diagnosis**

By Sharon Randall, North Andover, MA

***Editor's Note: Randall was moved to write this essay after reading "Finding Kindred Spirits When Down Syndrome Feels Like the Least of Your Problems" in the 2006 Convention issue of DSN. It's included here to keep the awareness and discussion alive.***

**W**e all remember where we were when we got the First Diagnosis - in the hospital right after delivery, in the doctor's office, on the phone with the geneticist. We heard the words, "Your child has Down syndrome." However we processed the information, those are words we will never forget. They instantly seem to divide us from all of the families who have only "typical" children, and they instantly lump us together with that group of families who have children with "special needs."

Hopefully we go on to find that being in that second group - of families with children with special needs and more specifically of families with children with DS - can be a good thing. We can form wonderful friendships, exchange information and share burdens. We are united as we stand together.

But then comes the Second Diagnosis, the one that we impose as it divides this wonderful community that has developed. Hints of it bubble up in conversation. She's already holding her neck up which the therapist says is a good sign, he's very alert which the doctor said is a good indicator, she's babbling quite a bit which is very promising, and then out it comes he surely is going to be "high functioning." And those around the table who also think that their child is "high functioning" nod in approval, and those with concerns about their children become silent. Tragically, the community has divided itself and increased the pain of some.

This discussion often begins as an outlet for a new parent's anxiety. Perhaps someone has an infant - not yet two months old - and is grasping for some indication

that the news isn't so bad. Perhaps this news of DS will be manageable if the child is high functioning.

If the hope of having the perfect baby has been dashed, there is a new hope that the child will be off the charts for children with DS. Perhaps this baby will be the one with just physical indicators, keeping all mental capacities functioning as normal. Perhaps amidst this feeling of failure that may come from already comparing our new baby to others there will be some feeling of accomplishment.

Certainly there is a clinical discussion to be had with medical professionals around one's ability to function. Therapies need to be decided upon. But since there are so many accounts of children who have exceeded the abilities predicted by medical professionals, I wonder if the discussion of high functioning vs. low functioning makes sense at all.

So, at the end of the day, what good is this discussion of high functioning vs. low functioning? Are these children loved? Yes. No more and no less for where they function on the spectrum. Do these children love back? Yes. No more, and no less for where they function on the spectrum. Is where one's child falls on the spectrum any indication of better parenting? Absolutely not.

As we know, we are in a society that loves to divide... by race, religion, gender or accomplishment, no matter how large or small. There are many wonderful things about the community we find ourselves in when we have children with DS. Let's hope that differentiating ourselves by refusing to buy into meaningless divisions is one of them.

## Paraprofessionals: *Destined to Help or Hinder*

by Michaela D'Aquani, PHD  
Smyrna, Georgia

**P**araprofessionals have been a part of our education system since the 1950s when a post-war teacher shortage triggered the need for classroom assistance with clerical and housekeeping chores. The role has changed dramatically, but paraprofessionals still are to be regarded as staff members who assist certified staff in carrying out educational programs with our students, both typical and those with disabilities. The key is that paraprofessionals assist and do not work in isolation without direction.

Over the last 20 years, I have worked with paraprofessionals in a variety of settings: directly in the classroom, individual and group training sessions, mentoring, and consulting with teams, which included paraprofessionals. I've learned that these individuals return year after year because they:

- Work within a schedule that meets their family needs;
- Work with children;
- Are listened to and appreciated as respected team members;
- Are acknowledged for their individual gifts and talents;
- Have a support system;
- Are professionally supervised;
- Have ongoing opportunities for growth and development;
- Are members of effective teams.

Not all paraprofessionals, however, find themselves in satisfying situations. Concerns often arise when paraprofessionals are assigned duties that go beyond their training and expertise. While many of them are very competent and work with students who need the most support, paraprofessionals do not receive the same training as teachers.

What do paraprofessionals need so they can be "Destined to Help" and "Not Hinder" our children's educational program? They need situations that support their abilities to do as such. Thus, whether you're a teacher or caregiver, administrator or paraprofessional, you can use the following guidelines to ensure this process occurs.

### **1. Learn the required qualifications for a paraprofessional.**

First, identify the titles within the state, district and local school.

Paraprofessionals may be identified by other titles, such as teaching assistant or teacher's aide. The

title may not make a difference, but the title may determine the tasks this person is allowed to carry out.

For example, in New York State, teaching assistants can assist with instruction, while teacher's aides may not. Therefore, it is important to verify if there are different job titles and what their possible designated roles are. Then be aware of the following federal requirements for paraprofessionals:

*No Child Left Behind (NCLB)*: Have completed at least two years of study in higher education, obtained an associate's degree (or higher) and met a rigorous standard of quality (taken a formal state or local academic assessment). (<http://www.ed.gov/nclb/landing.jhtml> (type in paraprofessionals in the search))

*Individuals with Disabilities Education Act (IDEA)*: Paraprofessionals must meet state-approved or state-recognized certification, licensing, registration or other comparable requirements that apply.

(<http://www.ed.gov/legislation/FedRegister/finrule/2006-3/081406a.pdf> (pg. 46554) )

### **2. Learn about required guidelines for a paraprofessional.**

*No Child Left Behind (NCLB)*: A paraprofessional may not provide any instructional service to a student unless working under a teacher's direct supervision.

*Individuals with Disabilities Education Act (IDEA)*: Paraprofessionals, teaching assistants and other similar personnel must be trained for their jobs and appropriately supervised.

### **3. Learn about the job descriptions for paraprofessionals in your state, district or school.**

Job descriptions may exist for paraprofessionals on a state level, within the district or even written and contained at the school. Research and see if these documents exist. If so, retain copies for reference and guidance.

### **4. Individualize the paraprofessional's role in filling this position.**

Just as it is important to individualize IEPs to meet student needs, paraprofessional job descriptions must also be individualized to the situation. The paraprofessional's role may manifest itself in several ways ranging from extensive individual support to whole group general support: personal care, one-to-one instruction, implementing therapy, facilitating student involvement, peer facilitator, monitoring student performance, community based instruction, adapting materials, providing emotional support, providing general school sup-

## Paraprofessionals: *Destined to Help or Hinder*

—continued

port, acting as a family liaison (especially in the cases where English is not the mother tongue), providing support to a teacher and assisting a teacher with the entire class.

With the needs of the child or children in mind, outline and prioritize the assistance needed. Taking a few minutes to outline the specific needs of the child (or children) who needs instruction allows you to proactively and effectively meet the individual needs.

### **5. Dialogue with the Team (caregivers, paraprofessional, teachers, therapists, administrators, child(ren)):**

Once you have spent some individual time detailing the specific needs of the situation, it is time to dialogue with the team. The group is then responsible for determining and prioritizing the paraprofessional's responsibilities. If the team determines they need more information, they may choose to employ the MAPS Process (see reference below). By sharing the child's history and then collectively exploring the dreams, nightmares, gifts/talents and child's needs, the team can begin to create a complete picture.

### **6. Develop a Job Description:**

Having this complete framework then allows the team to prepare an informed description for the paraprofessional's role. While developing this description, it is critical for team members to honestly communicate their ideas about how the role should look. Assumptions and unstated expectations often lead to ambiguity, affecting a paraprofessional's ability to effectively carry out responsibilities. It also is imperative that a professional responsible for supervising the paraprofessional be identified now. Below is a form the team may choose to use as a guide to identify the child's individual needs and how a paraprofessional should provide support, ranging from least to most intrusive: observe, provide verbal guidance, provide hand over hand assistance, complete task/verbalize steps. The goal in every situation is for the paraprofessional to assist children in meeting their maximum level of independence. A critical factor when employing a paraprofessional to provide one-on-one assistance to a child is assuring that the person is assigned to assist in the classroom and not be viewed as a child's personal assistant. The paraprofessional should become "eyes from afar" providing assistance as needed, but at a distance and assisting other children, too.

***Just as it is important to individualize IEPs to meet student needs, paraprofessional job descriptions must also be individualized to the situation.***

### **7. Ongoing Professional Development:**

Every educator needs to be a lifelong learner to effectively meet our children's educational needs. The form included below can serve as a guide to this process for paraprofessionals by outlining strengths and interests, specific yearly goals, their classroom and team role, as well as books and materials and/or training and in-services that support further development. While some training may be done as a group, effective professional growth plans are individual to the person's need and interest.

### **8. Member of the Team:**

In my work with paraprofessionals, each stressed how they valued being a respected member of a team not just an ancillary support. Thus, creating a culture that supports effective teamwork is essential. So, discuss such issues as: control and flexibility, student expectations, strategies for working with students, instructional and organizational routines, developing and implementing accommodations and modifications, planning and problem solving, delegating tasks, mutual recognition and respect, noise level, classroom management, ways to provide and receive feedback, communication, pet peeves, confidentiality and more. Take advantage of the many resources available to assist educators in developing effective and joyful partnerships.

Don't forget: A paraprofessional's primary purpose is to assist a professional in responding to our children's educational goals. For paraprofessionals to be effective, they must be included, respected and have their individual learning needs addressed by:

1. *Gathering information;*
2. *Developing a plan;*
3. *Implementing the plan, and*
4. *Evaluating the plan.*

If any one of these fundamental elements is not systematically attended to then the effectiveness of the paraprofessional's role is compromised.

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*Reprinted from Down Syndrome News, the newsletter of the National Down Syndrome Congress, Vol. 29, #6*

## New Guidelines for Teacher Assistants

In an effort to increase the capacity of schools to help improve academic performance and positive outcomes for students with special needs in transition to adult life (14 to 21 years), the Rhode Island Department of Education (RIDOE) recently established new state pre-application requirements for all entry-level Teacher Assistants.

The new Guidelines for Teacher Assistants Assisting with Community-Based Instruction were developed by a cadre of education professionals and parents from across the state and represented by staff of the RIDOE, school personnel, and community agencies and programs like RIPIN and the RI Technical Assistance Project (RITAP). According to Peggy Hayden of RITAP, who served as facilitator of the Guidelines task force, "In implementing these new standards, Rhode Island has made an important step in ensuring that teacher assistants have the knowledge and experience to support students who are learning to be as independent as possible in various settings."

For more information about the new Guidelines for Teacher Assistants, visit [www.ritap.org/ta/legal-requirements/legal.php](http://www.ritap.org/ta/legal-requirements/legal.php).

Geri Elmer, one of RIPIN's Special Education Family Support Coordinators served on the task force and added that, "A two day training session will be held on November 15 and 16 through the Southern RI Regional Collaborative (SORICO) for teacher assistants assisting with community-based instruction." Topics for this training will include: the roles and responsibilities of a job coach; how to match a student to the appropriate job duties; job development; job coaching strategies; workplace accommodations; liability issues; and evaluation of student performance. Trainings will also be available through other collaboratives in the state.

For more information about the up-coming training, contact Alice Woods at SORICO by calling 295-2888 x109 or via email at [awoods@ride.ri.net](mailto:awoods@ride.ri.net).

*Reprinted with permission from the Networker, newsletter of The Rhode Island Parent Information Network, Vol. 5, Issue 3*

## New Research Initiatives

We invite you to participate in a research project studying computer usage by children and young adults with Down syndrome.

**To:** Parents of children and young adults with Down syndrome

**From:** Dr. Libby Kumin, Loyola College  
([lkumin@loyola.edu](mailto:lkumin@loyola.edu))

Dr. Heidi Feng, Towson University  
([jfeng@towson.edu](mailto:jfeng@towson.edu))

Dr. Jonathan Lazar, Towson University  
([jlazar@towson.edu](mailto:jlazar@towson.edu))

Dr. Ant Ozok, University of Maryland Baltimore County ([ozok@umbc.edu](mailto:ozok@umbc.edu))

We are beginning to study computer usage by children and young adults with Down syndrome using an on-line survey. This survey is appropriate for parents of children with Down Syndrome who are between the ages of 6 and 21. It can be filled out by parents or you and your child can fill it out together. You can participate from anywhere you live and the survey should not take more than 15 minutes to complete.

We are inspired by our young friends with Down syndrome who are using computers for entertainment and for schoolwork. Why shouldn't these skills be able to be developed into job skills? You can help us learn more about the computer usage of children with Down Syndrome, so that we can explore their current or potential computer use in detail. We hope, down the road, to develop effective computing tools or software, to help your children with Down Syndrome use computers for learning, leisure, and job skills. With computers playing such a large role in our daily lives, improving your children's computer use can improve daily life.

The first step is to study how people with Down syndrome are currently using computers. The survey will be on-line until January 31, but try to complete it as soon as possible. Thanks again for your participation. Together, we can make a difference!

You can complete the survey on-line at <http://www.surveymonkey.com/s.asp?u=750982588877>



## AWARENESS BRACELET

The Down Syndrome Society of Rhode Island (DSSRI) is dedicated to promoting the rights, dignity and potential of all individuals with Down syndrome through advocacy, education, public awareness, and support. We offer general membership meetings (open to the public), newsletters, a lending library, public awareness activities and conferences.

Profits from the sale of each bracelet will be used to implement programs benefiting individuals with Down syndrome.

♥ This bracelet was designed to further awareness about Down syndrome. Down syndrome is also called Trisomy 21 because there are 3 copies of chromosome #21 instead of the usual 2. In the bracelet, the 21st chromosome is represented by 21 cream colored Swarovski pearls and the three copies of this chromosome are signified by the pink, green and blue Swarovski crystals!

♥ The heart charm symbolizes the power of their love-a love that reminds us that all people deserve compassion, love, and an opportunity to show their abilities. To emphasize the uniqueness of individuals with Down syndrome, the heart charm on each bracelet is different. A parent cannot choose who their unborn child is going to be but they can choose to love them for who they are. Please accept the heart you have been given just as you would embrace and love the unique gifts each person with Down syndrome brings to the world.

For additional orders please call 401-463-5751. Price of bracelet: \$25.00.

♥ Thanks to Cindy and Michele for their beautiful explanation of the bracelet.



**Down Syndrome Society  
of Rhode Island**

99 Bald Hill Road, Cranston RI 02920 (401) 463-5751

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## A Parent's Thought on Life Skills

By Claudia Lowe

**J**une 17, 2006, was quite a day for our family! Our daughter Diana was married! The day was beautiful and filled with such happiness; words just don't express the feelings and emotions we shared. Diana had a large wedding party, with six bridesmaids including her two sisters and six groomsmen.

Of course I was an emotional mess! To see my baby come down the aisle on the arm of her dad, and my other babies all dressed up in their beautiful dresses, was overwhelming; in fact, I get all teary eyed just thinking about it now!



Ultima Photography & Video

Katie being the shorter of the girls was lucky enough to lead the procession into church. There was a bit of confusion (what would a wedding be without some confusion?) as to when Katie would begin. However, our friends and family at the back of the church helped to right the problem and cued Katie when it was her turn to process in. She did a great job!

Once the Mass was over, it was party time! Diana and Jeff planned such a terrific wedding! The dinner was scrumptious, and the bride and groom and all their friends danced the night away! Tom and I had a so much fun watching them have such a good time.

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## A Parent's Thought on Life Skills

—continued

I wanted to share with all of you, my extended family, this photo of my three beauties as they looked on June 17, 2006. Not too proud a mother, huh? I was not sure what to write that would relate to our lives in the Down syndrome world. For the past few days I've thought, and thought and thought. I realized that a wedding isn't, perhaps, such an enormous topic for me to write about. People get married every day, and their siblings take part in many aspects of the experience: planning showers and bachelorette and bachelor parties, giving feedback on dresses and flowers, and so much more. And Di, Jessica, and Katie all participated in making this day a joyous one.

You may be asking yourself: A wedding is nice, but what is the point? To me the connection is Life Skills! How many times have we all heard how important Life Skills are for our children with Down syndrome? And, we all know that they are. But how do children get these skills? Personally, I have always questioned the effectiveness of the Life Skills classes that take place in too many self-contained classrooms. How realistic can the "skills" being learned actually be? After all, for the most part, they happen in a room. One of our consistent goals for Katie has been for her to be able to mix, blend, join into regular life. Life Skills are learned by doing, participating, contributing...and sometimes being successful and sometimes making mistakes.

It seems that to be able to do laundry, it would be important to learn how to use your own washing machine; to be able to clean your room, you need to know where to put things away in your own room. You need to be able to make the foods that you enjoy at home with the tools that you have available. To learn how to get along with others at a job or school, you should be with all kinds of people in all kinds of

places. So, I guess to learn Life Skills, our children have to be out there living life!

Recently, there have been numerous articles featuring folks with Down syndrome who are attending colleges. Isn't that a wonderful thing! The variety of course study varies from person to person but, just like other students, they still are having the college experience. Then, there are others like our sociable Katie who would rather be in the workplace dealing with people...and being so proud of herself and of the job she does.

Since graduating from high school in 2001, Katie has had a variety of jobs, both paying jobs and volunteer jobs. One of her favorite positions was at a preschool in Warwick, which, unfortunately, had to close. While Katie was there, she was treated with respect from her colleagues, the students, and the parents. To this day, she still runs into former students, and it is such fun to be with Kate and hear someone call out, "Hi, Miss Katie!" Currently, Katie's job is as a volunteer at an adult day care close to our home. I drop Katie off in the morning; and if I am running late, she will tell me to, "Hurry up, mom; I have to help the young people with their exercises!" She arrives at work with a smile and leaves work the same way.

Also, Katie has become reacquainted with a male "friend" from high school. They have had fun going to the movies, to dances, and going out for a meal. They enjoy being with one another; and his mom and I do our best to get them together whenever they want.

Life: Katie has a great one and on the way she is acquiring so many Life Skills... and so am I.

## ***DSSRI Brings The Next Chapter Book Club to Rhode Island***

### **When:**

January 15, 2007

### **Where:**

Sheraton Providence Airport Hotel  
Post Road, Warwick, RI

### **Time:**

9-3

RSVP 1/10/07 coordinator@dssri.org

Call DSSRI (463-5751) for more information

### ***What is the Next Chapter Book Club?***

Adults with disabilities reading and learning to read, making friends, and enjoying a fun community gathering place.

### ***How Does it Work?***

A group of people with and without disabilities meet at local coffee shops and cafes to read and discuss a book of their choosing.

### ***Who Can Participate?***

Anyone can participate, no matter their reading level.

### ***Who Leads the Book Clubs?***

Groups are facilitated by volunteers, such as students, professionals and retirees.

### ***Why Join a NCBC?***

NCBC members have fun and

- *Improve literacy skills*
- *Make social connections*
- *Take part in the community*

### **Our Mission**

The Next Chapter Book Club is committed to providing adolescents and adults with intellectual disabilities literacy and social interaction experiences that encourage friendship and lifelong learning within a community-based setting.

### **History of The Next Chapter Book Club**

The NCBC is a program of The Ohio State University Nisonger Center, a research and training center on developmental disabilities. The program was founded in 2002 and has grown from two groups in Columbus, Ohio, to over 25 groups throughout Ohio and the United States.

A group of parents, professionals, students, and individuals with disabilities founded the NCBC after a discussion about the prevailing assumption that people with intellectual disabilities are not readers, nor are they interested in lifelong learning. The group also discussed the isolation and segregation experienced by so many adults with disabilities who are living in, but not a part of, their communities.

The NCBC is designed to promote **literacy, social connectedness, and community inclusion**. The premise is simple. A group of 5 to 9 people with intellectual disabilities, regardless of their reading skills, gather with two volunteer facilitators in a local bookstore or café to read and discuss a book for one hour a week. Much like members of any other book club, NCBC members choose the book they want to read, as well as how they would like to structure their book club. Members are learning and making friends and having a lot of fun doing it.

*Reprinted from [www.nextchapterbookclub.org](http://www.nextchapterbookclub.org)*

### **Are your membership dues up to date?**

Membership dues help DSSRI provide informational programs like *(The Next Chapter Book Club)* to our parents, members and interested professionals.

# Eight Effective Steps to Employment Success

by Cary Griffin and Dave Hammis

**A**licia\* received her Certificate of Attendance from public school and faced unemployment. Luckily, the local community rehabilitation program leveraged Vocational Rehabilitation and Developmental Disabilities funds to assist her in finding a job. Alicia made no secret of her love for children, but her school program only offered training in office skills and short unpaid work experiences bussing tables at a restaurant. With assistance from an employment specialist, Alicia visited several day care centers but found no jobs for individuals without experience. Digging deeper into her interests revealed that she enjoyed using computers with basic math and reading software. Even with minimal reading and math skills, the software served as her guide, and her ability to use the programs and her enthusiasm led the employment specialist to suggest that Alicia become a computer tutor for children.

Alicia worked with her team locating a pre-school program that needed computer equipment and an instructor. Using personal funds set aside for employment she brought a new computer and software into a day care facility, becoming their newest employee. The business charges families extra for

computer tutoring, and Alicia is paid for her work. Three years later, the initial investment in equipment and software, along with job coach support setting up the operation, has paid off, allowing Alicia the success she dreamed of and increasing the profitability of the business.

Alicia's story is not typical. Today, only 26 percent of adults with developmental disabilities are working (Hall, et al., 2006). However, with a bit of planning and an understanding of employment options, transition-aged youth can attain vocational success.

Alicia's story serves as an inventive, but simple, approach to creating employment. Traditional competitive employment fails people with disabilities. There are many entry level jobs available for people with disabilities, but career advancement and doing what one loves are less common for individuals with significant disabilities. Therefore, changing our understanding of employment and approach to getting jobs is necessary. The following eight steps are a starting point:

*\*Alicia's story is a composite of several people's experiences.*

## **1. RAISE EXPECTATIONS.**

Families are often discouraged from having dreams and setting high expectations for their children with disabilities. Expecting children to grow up and work is a crucial first step to success. Make certain that children have household chores, after-school jobs, and summer employment.

## **2. FOLLOW EXPECTATIONS WITH ACTION.**

One critical activity is saving for the future. Families should consider establishing an "employment fund" for their child just as they might for a sibling expected to attend college. This fund can be used for advanced training, buying tools, securing transportation or starting a business.

## **3. ADVOCATE FOR REAL WORK EXPERIENCE**

Work experiences should be paid either by the school, an arrangement through a youth employment program sponsored by the local Workforce Center or One-Stop, Vocational Rehabilitation or the employer. These time-limited tryouts can help clarify the interests of the individual, and reveal the supports necessary for success, the best teaching approaches, and future options for work and study. Wages build a work ethic, garner peer status, and reinforce the connection between labor and reward.

# Eight Effective Steps to Employment Success

—continued

## **4. AUGMENT EXPLOITABLE RESOURCES.**

The best jobs go to those who offer the greatest potential benefit to an employer. Having equipment or tools that enhance employability can help career advancement. Alicia's talents were augmented by computer equipment. Using these assets, a new job was created. Using valued resources to secure employment is analogous to using a college degree to get a job.

## **5. APPLY FOR SOCIAL SECURITY.**

As graduation approaches, parents should investigate eligibility for the Social Security system programs. Social Security provides a variety of work incentives available to individuals with disabilities.

## **6. ARRANGE FOR A SMOOTH TRANSITION.**

Many states have waiting lists for adult services, so graduating with work experience and a paid job are crucial. In addition, it is also critical to apply well before graduation to the state for case management services and for vocational supports at the local One-Stop center.

## **7. CONSIDER SELF-EMPLOYMENT.**

Business ownership is the fastest growing employment option in America and many people with disabilities have ideas and interests that easily translate into money-making opportunities. Consider starting early and remember how young most children are when they open their first lemonade stand.

## **8. USE THE FAMILY NETWORK.**

Most people get their jobs through personal contacts. Families consume local goods and services and have friends and colleagues. Use these contacts to help your child locate appropriate work experiences and jobs.

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Editor's note: Reprinted with permission from

*Impact: Feature Issue on Parenting Teens and Young Adults with Disabilities (Spring/Summer 2006) published by the Institute on Community Integration, University of Minnesota, Minneapolis. Cary Griffin and Dave Hammis are senior partners in Griffin-Hammis Associates. The entire issue is available at <http://ici.umn.edu/products/impact/192/default.html> or in print form 612-624-4512.*

# Buddy Walk



BUDDY WALK

# 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.

## MEMBER INFORMATION

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY \_\_\_\_\_ STATE \_\_\_\_\_ ZIP \_\_\_\_\_

PHONE (    ) \_\_\_\_\_

Please circle one or more of the following

Parent      Family      Member      Educator      Professional      Other

## MEMBERSHIP LEVEL

- Individual/Family Membership .....\$25
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- Contributor .....\$50+
- Sponsor .....\$100+
- Sustainer .....\$250+
- Benefactor .....\$500+
- President's Club .....\$1000+
- Friend .....\$\_\_\_\_\_

## YOUR MEMBERSHIP

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*Please make check payable to the Down Syndrome Society of Rhode Island*

- I'd like to help out as a volunteer. Please call me.



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