



99 Bald Hill Road
Cranston, RI 02920

DSSRI QUARTERLY

Fall, 2003

SUPPORT
•
EDUCATION
•
ADVOCACY
•
PUBLIC AWARENESS

PRESIDENT'S MESSAGE

Happy New Year! Another year has gone by and many events have taken place since our last newsletter. The Buddy Walk was another success with special thanks to our Buddy Chair, Tina Egan for taking charge. Thanks again to the many volunteers who helped with cooking, serving, registration and organization of activities for the children.

The Holiday Party was a follow up to the Buddy Walk and Mr. & Mrs. Claus again graced us with their presence. We had a play area for the little guys and gals, dancing and Karaoke for the musically inclined, and arts and crafts for those aspiring artists. As always, everyone pitched in to bring refreshments and the extra calories were much appreciated and still being worn by many of us.

The NYC trip was not a complete bust, regardless of the weather. Those that were brave enough to battle the blizzard enjoyed their visit to the big apple.

Around the bend your energetic Board Members will be working fast and furiously to continue to offer some wonderful General Membership Meetings. The Fund Raising Chair, Phil Rizzuto will be rounding up his committee to organize our annual fundraiser. This is always a time consuming event and the most important financial resource we have. We are always looking for volunteers or donators of raffle items so if you are interested please contact the DSSRI office.

Dr. Penny Kadmon, our New Parent Committee Chair has been updating our contact lists in the medical community to get the most current information about Down syndrome into the hands of new parents and professionals so that everybody is well informed during a pre-natal or when a diagnosis after delivery is made.

There are many good things happening at DSSRI. It is my sincere pleasure to serve as President with such talented, energetic and dedicated Board Members who all share a unified vision of support, advocacy and inclusion for our family and friends with DS. ***Bring on the New Year!***

Sincerely,
Robin M. Pacheco
DSSRI President

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## VICE PRESIDENT'S MESSAGE

**Not available/non submitted**

## *In Appreciation:*

|                                |                                           |
|--------------------------------|-------------------------------------------|
| Debra M. Laperriere            | Blanche Deangelis, LTD                    |
| Patricia Peacock               | Displays2Go                               |
| Ms. Barbara J. Picard          | Holland Knight, LLP                       |
| Robert P. Proulx               | The Langan Group                          |
| Mrs. Paula Regan               | Plastics Plus, Inc.                       |
| Margaret Szlosek               | Nancy M. Rizzuto & Peter Avazis           |
| Michael Tocco                  | The Beacon Mutual Insurance Company       |
| Julie Valladares               | ETCO                                      |
| Phil Rizzuto, MD               | Crystal Stamping Corp.                    |
| Derek Cicerone                 | Fine Line Hair Design, Rachel Prendergast |
| The Nina Foundation            | Blackstone River Design/Build, LLC        |
| CVS/pharmacy                   | RI Arc                                    |
| CVS Charitable Trust, Inc.     | a. j. martin, inc.                        |
| Advertising Ventures, Inc.     | Fashion Accessories First                 |
| Santa and Mrs. Claus & Ms. Elf | Don's Restaurant, Cranston                |
| IBEW Local #99                 | Tony Petrarca, WPRI-TV 12                 |
| Horner Millwork                | Jodi and John Shemansky                   |
| Joanne Macdonald               | Jacki & Jim Marano                        |
| Marilyn & Steve Blanche        | Sig Pueschel, MD                          |
|                                | Mayor Scott Avedisian                     |

## Calendar of Events

January 26, 2004: Board Meeting  
February 23, 2004: Board Meeting  
March 10, 2004: General Membership Meeting, Safety Issues  
March 22, 2004: Board Meeting  
April 14, 2004: General Membership Meeting, Exhibit Night  
April 26, 2004: Board Meeting  
May 12, 2004: General Membership Meeting & Elections  
June 28, 2004: Board Meeting  
July 26, 2004: Board Meeting\*  
August 23, 2004: Board Meeting  
September 8, 2004: General Membership Meeting  
September 27, 2004: Board Meeting  
October 3, 2004: Buddy Walk\*  
October 25, 2004: Board Meeting  
November 10, 2004: General Membership Meeting  
November 22, 2004: Board Meeting  
November 28, 2004: Holiday Party\*

\*subject to change

## 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 Rd., Cranston, RI 02920

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

## **TALKING DURING DRESSING**

*By Anthony B. DeFeo, PhD.; Dicinn D. Gimm, MA, CCC, EdS., and Patricia A. Paige, MS, CCC*

### ***What's special about dressing time?***

The time you spend helping your child get dressed can easily become a language lesson. One-on-one attention is built into this situation. Dialogue is a natural part of it. You can talk about the here-and-now during dressing. ("Let's get your shirt over your head.") You can also talk about future events. ("We're going to the zoo today.")

Dressing is a series of actions that happen at least once a day, at about the same time and in a predictable order. The repetition involved in this experience is a great aid to language learning. Your child can expect certain language to be used over and over again within this familiar routine. This consistency of experience makes it easier for your child to learn new language.

Language forms such as plurals ("one foot, two feet") and prepositions ("socks on, shoes on") can be learned through daily discussion. Your child can also learn to communicate needs and wants. Then, the ability to express choices and opinions develops ("I want the blue shirt, not the red one").

Your child is also learning how to choose clothing based on weather (long pants versus shorts) and social events (play clothes versus dress-up clothes). Talking about how to make these decisions improves thinking skills.

### ***Dressing Time Concepts***

Language is based on ideas and experiences. Through interaction with the world, children learn meaning. Here are some concepts that are a natural part of the dressing routine. You can help your child learn these words and concepts by using them during dressing:

**NOUNS:** Shirt, socks, shoes, pants, dress, pajamas, etc. Undershirt, underpants, diaper, slip, belt, button, zipper, sleeve, collar, etc. Hat, raincoat, umbrella, boots, sunsuit, bathing suit, sunglasses, etc.

**MAJOR BODY PARTS:** Arm, leg, hand, foot, tummy, private parts, eye, ear, etc.

**LESS OBVIOUS BODY PARTS:** Fingers, cheeks, chin, elbow, wrist, heel, ankle, etc.

**ACTIONS:** Pull, push, put, raise, stand up, sit down, button, zip, snap, tie, hurry up, etc.

**PREPOSITIONS:** On, off, in, out, through, around, over, etc.

**TIME/SEQUENCE:** First, next, last, before, after, now, later, today, morning, afternoon, etc.

**ADJECTIVES:** Colors, dirty/clean, new/old, same/different, pretty/ugly, light/dark, hot/cold, warm/cool, long/short, right/left, striped, checked, plaid, print, etc.

**CATEGORIES:** Things to wear on your feet, hands, head.  
Things that keep you warm or cool.  
Things with buttons, zippers, snaps, Velcro.

**NUMBER:** One, two, three, etc., a pair, every, each, same size, etc.

continued on page 4

### **Sample statements to use during dressing**

Dressing concepts can be combined in unlimited ways. Here are some examples of statements that are tailored to children in: 1) the early stages, and 2) the later stages of language development. Use statements and questions like these to encourage language development during dressing.

## STRATEGIES TO PROMOTE YOUR CHILD'S COMMUNICATION SKILLS

### **1. Comment on object-action-location**

During dressing, toileting, cooking, and play times, talk about what you are doing and about what your child is doing using short simple sentences. Comment on where things are, how they feel, what's going to happen next.

### **2. General statement**

- a) After dinner you place the dessert in view but out of reach and say, "I've got cookies etc. here."
- b) At bedtime, you might say "I've got a book here about X."

### **3. Indirect model**

- a) You observe that your child's shoes are untied so you say, "If you want your shoes tied, let me know."
- b) You see that your child is having trouble opening, reaching, or putting something on so you say, "If you want help, let me know."

### **4. Expectant waiting cue**

- a) You put dessert on the table in view, out of reach. Look at the child but don't say anything.
- b) You start to play with an interesting toy, then stop, look at your child and wait.  
Your goal is to encourage your child to initiate an interaction with you.

### **5. Obstacle presentation**

- a) You set the table but "forget" to give your child a cup for his juice, or a fork for his food.
- b) You give your child a familiar toy (puzzle) but "forget" to give him the piece that makes it work. Ex. bubbles but no wand; puzzle missing a piece.
- c) You put a preferred food/beverage/toy in view but out of reach so that he needs to "ask" for help or for the specific object/action he needs.
- d) You put favorite snack items in a difficult-to-open container and make the container available to him.

### **6. Adult coaching to initiate**

- a) Older sibling or other adult encourages child to go ask for something: "Tell Mom 'Want XV'"
- b) At dinner, you "forget" to give a cup. When child realizes he needs one, older sibling or adult says, "Tell Dad 'need cup'."
- c) At snack, child can't open container to get food, so sibling/adult says, "Tell Mom, 'Open'."

### **7. Peer modeling**

- a) Ask child a simple question. If he doesn't respond, ask brother/sister.
- b) At dinner, right before you pour the beverage, ask "What should I do?" If your child does not answer, ask his sibling the same question. Sibling gives the correct answer, so you redirect question to child so that he can respond correctly.

### **8. Adult coaching to respond**

- a) If you ask a question of child, and he isn't able to respond, have another adult or older sibling tell him what to say. Ex. playtime, you ask, "What are you doing." Child does not respond. Another adult says "pushing car." Child then repeats response.

b) At dinnertime, you ask, "What want?" If child does not respond, another adult or sibling says "juice" to child, who then repeats the word and gets the juice.

**9. Direct model**

a) Your child is standing with a shoe untied, so you say, "Tell me 'tie shoe'."

b) Your child holds out an empty juice cup, so you say, "Tell me 'want juice'."

Reprinted from the *cdsc Quarterly*, newsletter of the Connecticut Down Syndrome Congress, Summer 2003



## **Lessons from Noah's Ark**

*Reprinted TDSNews Spring/Summer 2003*

Don't miss the boat.

Don't forget that we are all in the same boat.

Plan ahead – it wasn't raining when Noah built the Ark.

Stay fit - when you are 600 years old someone might ask you to do something big.

Don't listen to critics, just get on with what has to be done.

For safety's sake, travel in pairs.

Two heads are better than one.

Speed isn't always an advantage, after all, the snails were on the same Ark as the cheetahs.

When you are stressed, float awhile.

Remember, the Ark was built by amateurs, the Titanic was built by professionals.

Remember that after the storm, there's a rainbow waiting.

# ESSENTIAL CONSIDERATIONS FOR FRIENDSHIPS:

Questions to ask about School Practices

By *Carol Tashie & Zach Rossetti*

UNIVERSITY OF NEW HAMPSHIRE INSTITUTE ON DISABILITY  
REPRINTED FROM INCLUSION NEWS 2002 (www.inclusion.com)

To connect best educational practices and the ways in which they affect friendship, a list of questions, entitled, "Essential Considerations for Friendships," has been developed. Use these questions to honestly assess the educational practices in your school. All "no" answers should be considered opportunities to improve both the educational and social outcomes for all students in your schools.

***Is the student fully included in all aspects of school, and family, and community life?*** Students must share time, space, and shared activities in order for friendships to develop. Most friendships are born from common experiences and interests. Remember full inclusion is defined as the student attending the general education classroom she would attend if she didn't have disabilities and being supported to be a successful, full time, and valued learner.

***Does the student have a way to communicate all day long?*** Although a system of communication is not a prerequisite for friendship, it is more difficult for two people to become friends without the ability to communicate with one another. All students must be supported to have effective means of communication. Additionally, all forms of the student's communication (body, gestural, behavioral) must be respected and listened to.

***Are the materials, expectations, conversations, and modifications used each day age-appropriate for the student's chronological age?*** Friendships among students tend to be with other students of similar ages. All ways of interacting with the student must be respectful of her age and grade.

***Does the student have opportunities to give as well as receive support in the classroom?*** Friendships are often born from a respect and admiration among students of one another's unique gifts and talents, and involve an equitable relationship.

***Are supports brought into the classroom instead of the student being "pulled-out" of the classroom?*** Friendships tend to occur between students who are viewed as more alike than different. When just one student leaves the room for a part of her day, the message of "this student is different than you..." is clearly sent to the other students.

***Is people-first language being used?*** Saying, "a child with Down syndrome" acknowledges the child as a person first. Saying, "an autistic child," put the greatest emphasis on the label. Children make friends with other children, not labels.

***Does everyone who supports the student presume her competence and make decisions based on the highest of expectations?*** When a student is not able to effectively communicate his complex thoughts or knowledge, teams should assume that the student is understanding all that is said and taught and should treat the student accordingly. The "least dangerous assumption" is always presumed competence.

***Do educators know how to modify the regular curriculum so that the student is both an active participant in all activities and learning meaningful skills and knowledge?*** If one student is always working on separate activities away from the group, it gives the message that she or he is not really "one of us" and all students are denied opportunities for friendships to occur.

***Does the classroom environment celebrate diversity?*** In classrooms where the strengths, abilities, and unique gifts of all students are acknowledged and celebrated, friendships between students with and without disabilities are more likely to develop.

***Does the class membership reflect natural proportions of students with and students without disabilities?*** If several students with disabilities are clustered into one class, it is likely that these students will be viewed as a group, rather than as individuals. This is an obvious barrier to friendship.

***Do students with disabilities use the same places, people, and things in the school building as students without disabilities?*** Special teachers, special places, and special expectations perpetuate separateness, not belonging and true membership. All students should be supported to go to the nurse when sick, the principal when in trouble, and the library for a quiet place to work.

***Does the student ride the regular school bus?*** Friendships often develop in other places other than

the classroom. The playground, the cafeteria, the bus, walking to and from school is all fertile ground for friendship to grow.

***Is friendship considered a priority goal?*** For some teams, IEPs reflect only paperwork obligations and friendship has no meaningful place. For others, the IEP is the record of the highest priorities for the year and clearly friendship belongs right there!

***Is the student supported to participate in typical extracurricular activities of his/her choosing?*** Friendships are born and grow during and after school hours. Students should be supported to participate in any and all extracurricular activities (school-sponsored or otherwise) based on their personal interests and desires.

***Is there a system of communication established between home and school?*** Friendships go beyond the school day! Schools can provide families with great information about potential friends, opportunities for students to get together, and typical ways in which students connect. Families can provide schools with information about their children's interests, neighborhood friends, and ways in which their children most easily connect with others their age.

***Is someone on the team designated to coordinate intentional facilitation of social relationships?*** Although some friendships develop without help from anyone, many students require the support of someone to "intentionally" facilitate their connections with others. Intentional facilitation is the art of coordinating information about the student's interests and desires with what's typical for others his/her age, and supporting relationships via naturally occurring opportunities for connections.

***Are friendships "allowed" to end?*** Some friendships last forever; others are more situational. It's important to acknowledge this and not see "former friendships" as failures, but rather as evidence of true inclusion. Teams must be willing to review and refine the process of facilitation of social relationships on a regular basis.

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## ***VISUAL SCHEDULE SYSTEMS AND INCLUSION SOLUTION***

Visual schedule systems are an easy way to provide students with consistent cues about their daily activities. They provide a structure that allows a student to anticipate what will happen next, reduce anxiety by providing the student with a vision of his/her day and promote calmness between transitions. They are especially important for students who have a profile that includes difficulties with the understanding of oral language and directions. The consistency provided by a visual schedule is crucial in establishing an atmosphere of trust and security. Visual supports can also provide motivation to work through a less favored activity knowing a favored activity is to follow.

For example, using the First This /Then That strategy in visual form can provide high motivation for the student to work through one activity to get to a preferred activity. When dealing with students with behavioral difficulties, this can be a powerful strategy maintaining appropriate classroom behavior. For non-verbal students a visual schedule can be a way introduce symbols that the student can eventually use as an alternate form of communication. Through the consistent use of the schedule, the student can begin to pair the symbols presented with the activities that are occurring. A sure sign that this association is developing seeing the student begin to rearrange their schedule to include all of their favorite activities. Establishing a visual schedule can also provide a structure for the student begin to do some choice making, as they are encouraged to provide some input as to the order of some of the day's events. The student may also be introduced to choosing a specific activity from a teacher-selected group of activities.

The ultimate goal for all of our students is the development of independence and the enhancement of self-esteem. This can be an automatic result of allowing students to participate in the design of their day. The ability to look at a schedule and find the materials for the next adult support is a big step toward a student's independence. Visual supports can be a way to work toward this goal.

Each system developed is unique to the student and is created after a careful examination of following factors:

- The student's strengths and abilities
- The classroom teacher's orientation toward the concept
- The teacher assistant's commitment to its consistent use
- The classroom environment (the logistics, size, location and application of the schedule)
- Parental attitudes and home support
- Classmates' involvement

It has been our experience that when these factors are ignored or when any one factor does not receive adequate consideration as a system is created, the system may not succeed. Each system must be uniquely tailored to the student and the environment in which it is being used.

*Reprinted with permission from D.S. Press Down Syndrome Association of Greater Cincinnati and the newsletter of DSA of San Diego, September 2003.*

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### **Suggestions on how to live a happy and rewarding life.**

- ☺ **Never deprive someone of hope. It might be all they have.**
- ☺ **Don't be afraid to say "I'm sorry."**
- ☺ **Don't interrupt.**
- ☺ **Don't tailgate.**
- ☺ **Wave at children on the school bus.**
- ☺ **Listen to your children.**
- ☺ **Improve your performance by improving your attitude.**
- ☺ **Leave everything a little better than you found it.**
- ☺ **Make it a habit to do nice things for people who will never find out.**
- ☺ **Vote**
- ☺ **Be forgiving of yourself and others.**
- ☺ **Stop blaming others. Take responsibility of every area of your life.**
- ☺ **Do more than is expected.**
- ☺ **Be there when people need you.**
- ☺ **Take care of your reputation. It's your most valuable asset.**
- ☺ **Say "thank you" a lot.**
- ☺ **Say "please" a lot.**
- ☺ **Keep your promise.**
- ☺ **Judge your success by the degree that you're enjoying peace, health and love.**
- ☺ **Live so that when your children think about fairness, caring and integrity they think of you.**

***Never give anyone fruitcake!***

**Reprinted from the TDSNews**

**REED MARTIN, J.D. on IEP Goals**  
***www.reedrnartin.com***

We have had many questions from parents on goals on an IEP. The goals should be what we expect of regular students. The IEP explains how your child gets from “here” to “there.”

1. The direction we want to go
2. The problem we are addressing
3. The present level
4. The amount of change by the end of this school year
5. The methodology needed

***For example:***

**JOHNNY WILL**

- 1. increase*
- 2. in-seat on-task behavior*
- 3. from 0% of the time currently to*
- 4. 50% of the time by the end of this year*
- 5. by training the teacher in positive behavior interventions that give reinforcement to in-seat, on task behavior and do not unintentionally reinforce Johnny by giving attention to out of seat behavior.*

**SUSIE WILL**

- 1. increase*
- 2. self-control*
- 3. from overreacting emotionally to stimuli that are normal in the classroom*
- 4. to the ability to function with limited supervision in classroom settings*
- 5. through individual counseling and reinforcement of positive behaviors in the classroom.*

The IEP would then specify the short-term objectives in terms of the task or performance expected, conditions under which the performance is expected, the standard by which it will be measured, how the performance will be documented, and how the results will be reported to the parents.

*Being a Parent. Being a parent is the only job that requires no training, no degree, and lasts a lifetime. It pays no salary, has no vacations or holidays, and allows no sick leave. And you can never say, "I quit!" But it's a job with the most benefits. It's a job that changes you forever and shows you how deeply you are able to love.*

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## Homemade Picture Books

Some children with Down syndrome have difficulty going to new places or with new experiences. Here is an idea that may help all concerned with the transition. A homemade picture book will make the unknown more familiar and comfortable for the child.

For a new school, take photos of the outside of the building and of all the areas your child may use-the classroom, library, art room, music room, cafeteria, gym, playground, bathroom, front office, nurses office, etc. You can label the rooms with words if appropriate.

Laminate each picture. (Sheets of laminating paper are sold in office supply stores.) Punch a hole in the upper left-hand corner. Put the pictures together with a ring. Then take a picture of your child, cut out the background so you have a silhouette, and laminate it too.

Now your child can "visit" each place in the school. You can talk about what s/he will be doing in each place and who will be there with him/her. The child can carry the book there.

This idea can be adapted for other circumstances-a school bus ride, relative's home, the mall, a hair cut, a doctor or dentist appointment, a plane trip. Additional pictures are available in magazines, brochures, on the internet (i.e. Do2learn.com). You can also ask siblings to draw pictures to contribute to the book.

You will be happy when your child is no longer dependent on the book and has adjusted to the new place or experience. This is a fun way to help our children grow.

*Reprinted from NADS News, the newsletter of the National Association for Down Syndrome, September, 2003*

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## A Look Beyond

By Penny M. Kadmon, MD

Please look at me and tell me what you see,  
on my appearance do not judge me.

Once you see all of these things then you truly  
see me.

Please look beyond the Down syndrome that you see,  
do not allow my disability to bias your opinion of me.

So, please treat me like any other child and I will  
flourish, you will see.

Please, please, I beg of you to look deep, deep inside of me,  
tell me, tell me what do you see?

**Reprinted from:**  
American Journal of Medical Genetics

Please take my hand and I will help you to see:  
a child who loves to laugh and play,  
a child who enjoys books, puzzles and music,  
a child who plays with other children,  
a child who admires his older sister and enjoys  
making his baby sister laugh,  
a child who strives to be independent,  
a child.

# How Can I Help My Child Be Ready to Read and Ready to Learn?

1. Talk to your infant and toddler to help him learn to speak and understand the meaning of words. Point to objects that are near and describe them as you play and do daily activities together. Having a large vocabulary gives a child a great start when he enters school.
2. Read to your baby every day starting at six months of age. Reading and playing with books is a wonderful way to spend special time with her. Hearing words over and over helps her become familiar with them. Reading to your baby is one of the best ways to help her learn.
3. Use sounds, songs, gestures and words that rhyme to help your baby learn about language and its many uses. Babies need to hear language from a human being. Television is just noise to a baby.
4. Point out the printed words in your home and other places you take your child such as the grocery store. Spend as much time listening to your child as you do talking to him.
5. Take children's books and writing materials with you whenever you leave home. This gives your child fun activities to entertain and occupy him while traveling and going to the doctor's office or other appointments.
6. Create a quiet, special place in your home for your child to read, write and draw. Keep books and other reading materials where your child can easily reach them.
7. Help your child see that reading is important. Set a good example for your child by reading books, newspapers and magazines.
8. Limit the amount and type of television you and your child watch. Better yet, turn off the television and spend more time cuddling and reading books with your child. The time and attention you give your child has many benefits beyond helping him be ready for success in school.
9. Reach out to libraries and community and faith-based organizations. These organizations can:
  - Help you find age-appropriate books to use at home with your child;
  - Show you creative ways to use books with your child and other tips to help her learn; and
  - Provide year-round children's reading and educational activities.

For more information visit: <http://www.ed.gov/parents/academic/help/partnership.html>  
or call 1-800-USA-LEARN

# Adaptation: What's Really Fair?

by Carolyn Ito

How many times have you heard the old lament, "It's not fair," from students colleagues, parents, perhaps your own children? When my children used the phrase, it was often because they felt cheated or slighted. A sibling appeared advantaged in some way. Or perhaps a friend was allowed a privilege my child wasn't. I often said, "It is not the same, but it is fair. Fair does not mean equal. Fair means that you get what you need. What you want may not be what you need. A want and a need are not identical."

The philosophy a teacher, student, parent, or administrator has about fairness has significant impact on the adaptations chosen to meet the learning needs of students. Most of us act upon our own philosophies or fairness as we work with students of various abilities. Many educators make decisions that help students get what they need to succeed: however, teachers' philosophies vary. Some professionals feel it is unfair to treat any student differently Others believe that students' unique needs must be considered and that everyone doesn't have to be treated the same.

Some adaptations are commonplace and universally accepted as fair in our society for people with disabilities. Glasses, contact lenses and seeing-eye dogs are accepted adaptations for people with visual disabilities. Hearing aids, telephone volume control, captioned TV programs and signers at national political conventions are taken for granted. Elevators, motorized wheelchairs, walkers and canes are accepted assistive equipment for people with limited mobility. In general, these adaptations are accepted as needed to help people succeed in schools, work environments and community settings.

Classroom adaptations are sometimes more difficult for professionals to accept as fair and appropriate. These adaptations address problems related to modifications in the curriculum (eg, a skills sequence change), the delivery system (eg, text on tape), or evaluation procedures (eg, oral testing) to help students benefit from instruction and perform more successfully in the classroom. It is important to think of classroom adaptations along a continuum. At one end, few adaptations are needed or those that are used require little effort to implement (eg, preferential seating). Along the continuum, students could be in large group, partnered with peers, at computers, in small groups, or with a volunteer. They could be listening to the text on tape or reading silently. They could draw an answer, take a test orally, or do fewer problems. At the other end of the continuum, more extensive accommodations may be required (eg, alternative curriculum full-time paraprofessional support). Adaptations should be provided based on what the students need to succeed.

Because your philosophy of fairness impacts your willingness to orchestrate adaptations, it is important to evaluate your philosophy on adaptations and where you would fall on the continuum. Perhaps the following questions will assist you in clarifying your own philosophy on adaptations. You may find it helpful to share and discuss this with your teachers.

## Adaptation Philosophy Questions (respond with Yes, No or Unsure)

1. Should all students be treated equally?
2. Should adaptations be made so that all students can succeed?
3. Is it fair to change the rules for some students?
4. Are teachers asked to do too much already and don't have time to adapt lessons?
5. Should I adapt my teaching to a child's way of learning?
6. Should I do whatever it takes to help a student succeed?
7. Do adaptations compromise academic integrity?
8. Can all my students learn if I can find a way to help them?
9. Do adaptations send the wrong message to students?
10. Will parents be upset if their child has different assignments?
11. Is it all right to have outcomes very within a class?
12. Adaptations are fair, but do I need help in designing them?
13. Do all students want to and try to learn?
14. Is the problem made worse by adapting a part of the curriculum?
15. If I let one student do something differently, will I have to let all students do it?

**If you answered Yes to numbers 1,3,4,7,9,10,14 & 15, your current adaptation philosophy may allow for few adaptations.**

**If you answered Yes to numbers 2,5,6,8,11,12 & 13, then you are more inclined to make adaptations.**

**Uncertain responses may suggest that your philosophy is not yet solidified and you may wish to further explore the issues and methods for adaptive instruction.**

Reprinted from the FCDSN, November 2003

# Good Nutrition

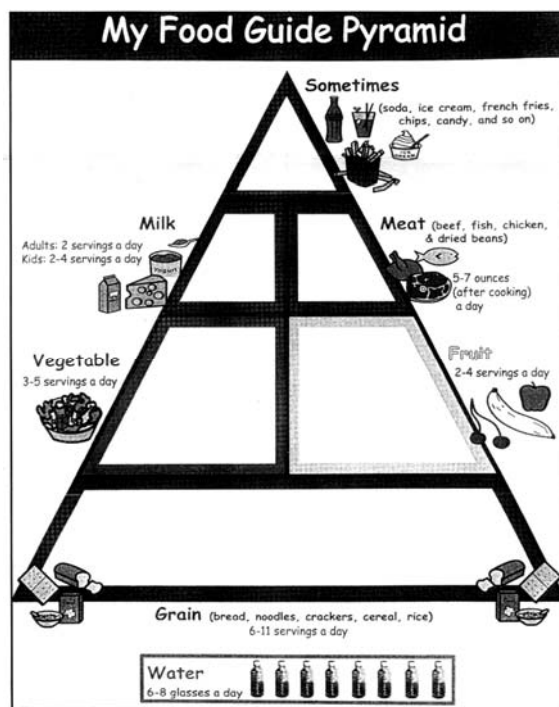
Eileen Walsh, Nutritionist, Adult Down Syndrome Center, Park Ridge, IL.

The popular media presentations (TV, magazines, newspapers) contain endless warnings about foods that are “bad”, cause disease and make us fat. Rather than fear foods, we should embrace a wide variety in our meals each day. Just as gasoline fuels an engine, food provides the fuel to create energy in the human body. The body needs in excess of 40 nutrients to achieve peak function. Here are some guidelines to meet those needs.

1. Eat three balanced meals each day.
2. Include whole grain carbohydrates at each meal-cereal, high fiber bread, etc.
3. Meat or meat alternatives (beans, fish, peanut butter) provide protein and should be included in 2 meals daily.
4. Eat a wide variety of fruits and vegetables-a minimum of 5 servings each day. Include as many colors of the rainbow as you can: purple, green, white, yellow and red. Substances contained in produce help keep the heart healthy, decrease the risk of some cancers, and help maintain a healthy weight.
5. Include small amounts of fat at each meal.
6. Use the Food Pyramid and nutrient labels to identify standard serving sizes. Eat a number of different foods at each meal in standard portions.
7. Eat slowly, chew food well, and enjoy the taste.

In our hurried world, the easy choice is fast food. It is available in moments, it hardly needs chewing and it tastes pretty good. But fast food is usually missing fruits, vegetables, and whole grain fiber. A mixed meal (protein, grain, vegetable, fruit) generally slows the rate of eating, increases enjoyment of food because the taste buds are exposed to food for a much longer time, and helps the satiety mechanism to activate. Good nutritional habits begun in childhood can improve health for a lifetime.

*Reprinted from NADS News, the newsletter of the National Association for Down Syndrome, September, 2003*



# Anti-Stuttering Device

Kim Xidas

Stuttering is an issue for many children and adults with Down syndrome. My son, Stefan, who is now 16 years old, has had a stuttering/disfluency problem from the time he started talking sentences around the age of three. We were told it is common for a child to stutter as he learns to talk in complete sentences, and that hopefully it would go away as he became more comfortable putting his thoughts together. Although there were times when he was more fluent than others, it never went away. We were told to speak slowly around him so that he would have good models to imitate. Although we all tried to be aware of modeling relaxed speech, this was not easy to do in our busy house with three children who have a lot to say! Over the years, he has had speech therapy in school with a goal to reduce disfluency. He has also had years of private speech therapy in an effort to teach him to control the stuttering. He did learn a very good technique for reducing stuttering by “stretching” the first word of his sentence-sometime called “easy speech”. Although he knew how to use this technique, it was difficult for him to use it all the time. It required him to constantly monitor everything he said, and he was not willing to do that.

The speech therapist at school last year told us about a fluency device called “SpeechEasy”, which claimed to reduce stuttering in 80-90% of the stuttering population. The device looks like a hearing aide, and the cost is about \$4000.00. The man who developed the device is a severe stutterer who noticed as a child that although he could not say a sentence on his own without stuttering, he was able to pray aloud in church with others and be completely fluent. The SpeechEasy device emulates choral speech through auditory feedback. In other words, the person wearing the device hears his own voice at a millisecond delay, and it sounds as though someone is speaking with him. The company which makes the device, Janus Development Group, will refund 90% of the purchase price of the device if it is returned undamaged within 30 days if you are not satisfied. After all the effort, time and money spent on traditional speech therapy, with limited success, we decided this was something we wanted to try.

Stefan has now had the device for about 3 months, and I can say without a doubt, that it has made a difference in his life. It was evident as soon as he put the device in his ear that his speech was much more relaxed and less disfluent. The device is not a cure for stuttering, but it is a tool that helps. With the device, he doesn't have to remember to “stretch” the first word or slow down his speech – it just happens! We have also noticed that he is much more fluent even when he is not wearing the device. We are told this often happens because the stress that revolved around trying to talk without stuttering is no longer there. He is much more confident, and we are happy to have finally found something that helps.

For more information on the SpeechEasy device, please visit these sites: [www.speecheasy.com](http://www.speecheasy.com) or [www.speecheasy.info](http://www.speecheasy.info).

**Reprinted from the November, 2003 issue of NADS News.**



The Warren/Swansea Redskins,  
Jr. Pee Wee

This is Katie Blair with her team mates from WSR Jr. Pee Wees. They won 1st Place in the NERI Competition held at RIC back in October, 2003. They went on to represent Rhode Island at the Regional Meet in Manchester, NH last November! RAH! RAH! You go girls!



Katie Blair

## When your child engages in difficult behaviors...

By David Pitonyak, Ph.D., Blacksburg, VA

*Editors note: David Pitonyak is a nationally recognized expert and popular speaker on the subject of Positive Behavior Support. He gave permission to reprint this article. Check out [www.dimage.com](http://www.dimage.com) to see more of his work.*

Several years ago I was asked to speak to a group of parents in Vermont. The title of the presentation was "Supporting Children with Special Needs." Five minutes into my talk, a parent stood up and interrupted me. She insisted that I stop referring to her daughter as someone with "special needs" (I had been using the term a lot).

"My daughter does not have special needs," she said. "My daughter has the *same* needs as anyone else. She has a need to live at home with her family. She has the need for a good education, friends, fun and a supportive family. Sometimes you professionals - in your efforts to provide special services to people - forget the ordinary, everyday things that people need."

She must have known that I was embarrassed. I'm sure I turned 80 shades of red as I muttered through the rest of my presentation. After it was over, she put her hand on my shoulder and said, "You'll be fine."

As awkward as I felt about the evening, I felt grateful too. I learned one of the most important lessons I have ever learned as a professional: sometimes, in our efforts to provide "special services to people, we often forget the ordinary things people need everyday: friends, family, interesting and fun things to do, safety and security, and a chance to make a contribution to the larger community (in short, a chance to belong).

What follows are 10 things to remember if your child, because he or she exhibits difficult behaviors, is at risk of *not belonging*. If you don't have the time or the energy to read one more word, remember these two ideas:

***Taking care of yourself is one of the most important things you can do.***

***If you don't it will be very difficult to take care of anyone else.***

***Remember that your child's problem behavior(s) has meaning. Finding out what your child needs is the first step in supporting your child, and the people who love your child, to change.***

### **1. Be Mom and Dad first.**

Chris Heimerl writes, "Of all the hats you must wear: advocate, care provider, therapist, teacher, the most important is Mom and Dad. Your love is the most powerful treatment any of us can imagine. If all the other stuff you have to do first interferes with being a parent, stop. Someone else can do some of the necessary stuff, but nobody else can be Mom and Dad.

### **2. Think of challenging behaviors as "messages."**

***Difficult behaviors result from unmet needs.*** In a sense, difficult behaviors are "messages" which can tell us important things about your child and the quality of his or her life. Here are some examples of the kinds of "messages" your child may be conveying with their behavior:

***"I'm lonely."*** Michael's brother was invited over to a friend's house to watch television. Michael is never invited to the homes of children because he goes to a "special" school 35 miles from his neighborhood.

Michael has no friends to play with.

**“I’m bored.”** Roberta’s sister is a doctor at the local hospital. She has her own house and is her parent’s pride and joy. Roberta works all day at a sheltered workshop where she packages plastic forks and knives. She lives at home and is tired of packaging. She wants to get a real job. Roberta’s case manager says she daydreams too much.

**“I have no power.”** John likes to sit down on the sidewalk when the bus arrives to take him to school. His mother becomes very angry and tells him that there will be no dessert when he gets home. John laughs when the bus driver threatens him with time out.

**“I don’t feel safe.”** Conrad uses a wheel chair and is not able to defend himself from attacks. One of the people in his day program can be aggressive and Conrad worries that he will be hurt.

**“You don’t value me.”** Gloria has a “severe reputation.” People from *all* over the state have heard stories about her terrible tantrums. No one knows that she is a very caring person who worries about her father’s health. The only part of Gloria people pay attention to is her problem behaviors.

**“I don’t know how to tell you what I need.”** June did not know how to use words or sign to let other people know what she was thinking. She lives at home with her parents where she has learned that the best way to be “seen” is to bite your arms. It hurts, but it is the only thing that “works.”

**“My ears hurt.”** Walter hit his ears with his fists. His job coach wanted it to stop and wrote a behavior plan for “not hitting.” Weeks later, at a scheduled doctor’s appointment, it was learned that Walter had a low-grade ear infection. Antibiotics cleared up the infection and Walter stopped hitting his ears.

Obviously there are many needs that your child might be expressing through his or her behavior. A single behavior can “mean” many things. The important point is that difficult behaviors do not occur by accident, or because someone has a disability. Difficult behaviors are expressions of real and legitimate needs. All behavior, even if it is self-destructive, is “meaning-full.”

Ask yourself, *“Is my vision for my child similar to the vision I have for my other children (or the vision other parents have for their children)? When I think about what my child needs, do I focus on disability-related needs or do I think about things like friendships, fun, a sense of belonging?”*

### **3. Learn about person-centered planning.**

In the book, *A Little Book About Person-Centered Planning*, Connie Lyle O’Brien, John O’Brien and Beth Mount describe the powerful differences between traditional approaches and person-centered planning. Unlike traditional approaches to planning, which ask questions like, “What is wrong with you?” and “How can we fix you?”, person-centered planning focuses on questions like “What are your capacities and gifts and what supports do you need to express them?” and “What works well for you and what does not?” and “What are your visions and dreams of a brighter future and who will help you move toward that future?”

Describing the roots of person-centered planning Lyle O’Brien, O’Brien and Mount write (1998): “Person-centered planning did not ignore disability, it simply shifted the emphasis to a search for capacity in the person, among the person’s friends and family, in the community and among service workers. A person’s difficulties were not relevant to the process until how the person wanted to live was clear. Then it was necessary to imagine, and take steps to implement creative answers to this key question, “What particular assistance do you need because of your specific limitations (not labels) in order to pursue the life that we have envisioned together?”

#### **4. Don't assume anything.**

It is easy to make the mistake of underestimating your child's potential because of his or her labels or because he has failed to acquire certain skills. This is a tragic mistake. I have worked in the field for 15 years and I am less confident in my ability to predict how much a person understands or how much he will be able to accomplish with every passing day.

For example, the new AAMR definition of mental retardation states that an individual's success or failure in life is determined by the quality of his supports rather than a missing gene or "faulty" body chemistry. In short, professionals like me used to doom people because of an arbitrary diagnosis. What some of us have finally woken up to is the fact that nothing dooms people more than a lack of support.

You can speak volumes to your child about his self-worth by always including your child in conversations and explaining things as clearly as you can. Even if you doubt your child's ability to understand your words, know that at the very least your child will understand the tone of your voice; make sure it reflects dignity and respect as often as you can. Never speak about your child as if he were not in the room.

#### **5. Remember that relationships can make all the difference in the world.**

Loneliness may be the most significant disability your child will ever face. Many people with disabilities, young and old, live lives of extraordinary isolation. Some depend entirely upon their families for support. A brother or sister or mom or dad is the only source of company. Friends are often absent altogether.

All too often, the only relationships people have are with paid staff. Although staff can offer a great deal, they change jobs frequently or take on new responsibilities. The resulting instability can be devastating to someone who is fundamentally alone.

Involve your child with other children at a younger age (children with and without disabilities). It is easier to learn about the importance of relationships when their importance has been clear over a lifetime.

It's easier to be a friend when you have friends who know something about friendship. Insist that your child be included in regular classrooms. Inclusion is a powerful way of building relationships.

And don't let anyone fool you into thinking that inclusion of children with disabilities in regular classrooms is a bad idea. Doing it poorly is a bad idea. Doing it well is good for all children.

Make a commitment to learn more about personal futures planning and other person-centered approaches to planning for your child's future. Do it today!

#### **6. Help your child to have more fun.**

Fun is a powerful antidote to problem behaviors.

Count the number of things your child enjoys, the number of places she likes to go. Compare this to the number of things other children enjoy, the number of places other children go. Ask yourself, "Is my child having fun? Is she experiencing enough joy? Is this an interesting life?"

People with substantial disabilities often live in ghettos of reward. Indeed, it is often this poverty of reward, not a lack of skills, that keeps people separate from other community members.

Sadly, many people with disabilities are put on reward schedules for good behavior. The very few things that they enjoy are used contingently to reinforce compliance (talk about spoiling a good thing).

Help your child to add on to her list of interesting (and really fun) things to do.

Spend time in regular community places where people hang out. Make fun a goal.

## **7. Take care of yourself, take care of your partner, and join with other parents to support each other.**

Many parents suspend their own dreams and aspirations the day their child was born. They adopt an identity of “parent of a child with a disability,” putting their own needs on hold like a videotape that can resume at the touch of a button.

Many parents feel isolated because their child has a disability. They feel obligated to suspend their relationships with other people because the work of parenting their child seems all-consuming. Or they feel that other people will have difficulty understanding their child’s disability; there is a deep fear of rejection. As one parent put it, “It is better to be alone than to feel my child’s hurt when he is rejected.”

Chris Heimerl writes: “Take care of yourself, take care of your partner and join with other parents to take care of each other. Before you became a parent you were a partner in a relationship that had enough love, nurturing, and respect to want kids. Don’t lose sight of that relationship. Before you were a partner, you were a person that someone found attractive, vital and loving. Don’t lose sight of that person.”

Get connected and stay connected with parents of children with and without disabilities. Join organizations made up of parents who fight for the inclusion of their children in every aspect of community life.

Remember that the vast majority of innovations that have taken place in our service delivery system happen because parents and their children have become dissatisfied with “what is.” If you join forces with other parents you can make significant difference in your child’s life.

Learn about the laws and regulations that help and hurt your child’s inclusion in community life. Speak up whenever your child’s future is at stake. Above all, be respectful of people who disagree with you while remaining steadfast about your beliefs.

## **8. Help your child to make a contribution to others.**

Lou Brown has said that the least amount of difference between a child with disabilities and a child without disabilities may be the day that they were born, naked to the world. But then, because of the way our society separates the child with disabilities into “special services,” he or she becomes “different.”

Perhaps the most devastating effect of this separation is that the child with a disability does not learn what he or she can contribute to others. In a sad kind of way, the child becomes the “needy one.” Being needy all the time is dispiriting. Making a contribution to others (to your family, friends, and the larger community) is good for you. It’s good for the soul. It’s good for the heart, the brain...it’s probably a biological imperative to give. One day we may learn that the world actually revolves on its axis not because of the laws of physics, but because of the love we give to others. As John Bradshaw writes, “Our identity is the difference about us that makes a difference.”

The real danger, of course, is that if enough people begin to think of you as “needy,” you will begin to believe it too.

We all need to be needed.

It is my experience that people with difficult behaviors especially need to be needed.

Help your child to find a way to make a contribution to others. Start young because learning to give is a lifelong endeavor. Help your child to learn how to support friends (e.g., an invitation to a sleepover, birthday cards, learning to ask, “How are you doing?” or “What’s new?”). Things as simple as helping with household chores or helping out at church can teach your child that she can make a contribution.

## 9. **Instead of ultimatums, give choices.**

If it is 9 p.m. and you are sitting down to read these words, chances are good that you have made hundreds, if not thousands, of choices since 7 a.m. You may have decided to wear blue socks when getting dressed. You may have decided not to wear a heavy sweater, hoping the warmer weather would prevail. You may have decided to skip breakfast, buy unleaded gas, work on a report, clean the garage, take a hike, watch a football game, etc.

You may have made more monumental decisions: purchased a house, stopped drinking, decided to re-marry, purchased a major appliance, agreed to surgery, etc. The point is, we humans are decision-making machines.

Many people with disabilities have little or no control over their own lives. Many of the decisions that we take for granted—such as what to wear and whether or not to have a cup of coffee—are made by other people. How would you feel if you lived such a life?

The mistake we make with children and adults who have disabilities is that we assume that because they don't always make good decisions about *some* things they ought not to make decisions about *anything*.

Always remember that our tendency is to become directive and negative when our children are engaging in problem behaviors. We tend to take control when our children are out of control. Ironically, our children may need more control not less when their behavior is disturbing.

Choice is a powerful alternative to punishment. If your child's behavior challenges you, help him or her to find more desirable ways to express the needs underlying his or her behaviors. Instead of ultimatums, give choices (e.g., "Bill, I know you're upset. What would help? Would you like to go for a walk? Or take a ride? That will give you a chance to calm down and then we can talk about what you need?").

Allow your child to make decisions throughout the day. If he has trouble making choices, find a way to help. Make sure there are at least three desirable outcomes to choose from. As Norman Kunc has said, 1 option = tyranny; 2 options = a dilemma; 3 options = a real choice.

Make sure your child is invited to his or her IEP or IHP meetings. It is important that he/she have input whenever possible. This especially true when a problem behavior is being discussed (imagine how you would feel if people were trying to change your behavior and never stopped to ask you what you think). It is also important that your child be able to say "no."

If your child does not speak, ask anyway (suggest that he find a nonverbal way of letting you know what's needed).

Don't assume that helping your child to have more choices means letting him do what ever he wishes. Limit-setting is an important and fair part of any relationship. The real question is who is setting the limits and why. If limits are imposed upon children without their input, and if the limits are part and parcel of a life in which your child is powerless, even your best advice may be interpreted as one more statement of "do it my way or else."

Expect a general disregard for advice when the person receiving the advice is never heard. Rebellion may be healthy strategy for someone who is out of power. As Tom Harris put it, "It's better to have bad breath than no breath at all."

[Author's note: I heard the expression "Instead of ultimatums give choices" years ago, but I'll be darned if I remember where. My apologies to the author of this succinct phrase, wherever you are...]

## **10. Establish a working relationship with a good primary health care professional.**

Mark Durand has said, "People tend to get immature when they don't feel well."

How often have you experienced a general decline in your mood, your ability to empathize with the needs of others, when you don't feel well? When we are sick, we are not ourselves.

Many people who exhibit difficult behaviors do so because they don't feel well. The sudden appearance of behavior problems may be signal that your child does not feel well. Illnesses as common as a cold or earache can result in behaviors as inconsequential as grumpiness or as serious as head banging.

It is important to establish a working relationship with a good primary health care physician. Although this is easier said than done, your child, especially if he has difficulty communicating, will need a doctor who can help him to stay healthy and well.

Remember that physicians, like many other people who grew up in our "separate" society do not always understand (and may even fear) a person with substantial disabilities.

Don't be afraid of telling your child's doctor that you don't understand a recommendation or finding. It is important to get a clear and straightforward answer to all of your questions.

Remember too that it is important to go beyond a concept of health as the absence of a disease or illness. "Feeling well" and "being healthy" involves everything from a balanced diet to a good night's sleep. Help your child to learn about "wellness."

### **References**

Lyle O'Brien, C., O'Brien, J. & Mount, B. (1998) "Person—centered planning has arrived ... or has it?" In O'Brien, J. & Lyle O'Brien, C. (Eds). *A Little Book About Person—Centered Planning*, Toronto: Inclusion Press

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Treatment for Dysfunction in Sensory Integration

By Kim Kelley, M.A., O.T.R., Minneapolis, MN

What is sensory integration dysfunction (also called Dysfunction of Sensory Integration or DSI)?

Jean Ayres, O.T.R., Ph.D., defined sensory integration as "organization of sensory input for use" as she pioneered the research and development of sensory integration theory. Sensory information includes visual, auditory, olfactory, tactile (touch), vestibular (movement) and proprioception (body position). Ayres based much of her research on the last three—tactile, vestibular and proprioception—which are often called the "hidden senses."

These primitive senses are developed in utero prior to birth and are closely linked with other brain systems as development occurs. For most children, sensory integration is automatically part of childhood development. However, as Carol Stock Kranowitz describes in her easy to read book *The—Out—of—Sync Child*, it does not happen automatically.

Sensory integrative dysfunction occurs when the brain is unable to organize sensory information in a meaningful way. DSI impacts daily life for children and their families, as the children are not able to accurately register, modulate, discriminate and integrate sensory information. The result is that the child cannot adapt as well and may react negatively to everyday life sensations. The results are difficulties with the child's learning, development and behavior.

How does DSI overlap with Down syndrome?

Signs of sensory processing problems of a child with DS are often similar to that of a child traditionally labeled with sensory integration dysfunction:

- Delays in speech, language and motor skills
- Delays in learning
- Poor self-concept
- Poor self-control (impulsive)
- Low muscle tone
- Poor body awareness
- Over reaction to touch, sound, sight, movement (avoids)
- Under reaction to touch, sound, sight, movement (seeks)
- Resistance to change
- Poor transitions
- Poor social skills
- Poor balance
- Clumsy/awkward movement
- Usually high or low activity level
- Poor behavior organization

Children with DS often exhibit characteristics which impact motor skills such as hypotonia (low muscle tone), joint laxity, difficulty sensing position and movement, hypo or hyper responsivity to touch, discrimination, and integration of touch input. The motor performance and behaviors of a child with DS can also be impacted by sensory processing deficits including deficits in sensory registration, modulation, vestibular, proprioceptive, tactile, visual, and auditory processing.

Can DSI be treated effectively and what are the benefits?

Yes. An occupational or physical therapist performs an evaluation using standardized testing, clinical observations and parent surveys, and then makes recommendations regarding appropriate treatment. If treatment seems like a good option for your child, then an individualized treatment plan is designed for your child. Parental involvement is highly encouraged, as specific home program activities will be recommended for your child. These home activities (also known as a “sensory diet”) may be beneficial long after direct therapy ends.

Sensory Integrative Treatment includes direct therapy (one to three times per week for at least a year) in a clinical, home or school setting with collaboration among parents, doctors, school staff and therapists. A sensory-rich environment is important for effective treatment. A spacious treatment area that includes a variety of suspended equipment (swings, climbing walls, ladders) for movement as well as a number of tactile, visual, auditory and taste opportunities is ideal. Most of all, treatment should be fun and motivating for your child!

When a sensory integrative approach is effective, then your child will be able to process environmental sensory information more appropriately. Observed benefits may include improved daily function, increased self-esteem, emotional security, self-regulation, sensory motor skills, language and social skills. Parents often report the child is easier to live with and appears happier.

What do you look for in a therapist?

A qualified occupational therapist has graduated with either a bachelor's or master's degree from an accredited college that includes coursework in biological, physical, medical and behavioral sciences. The most qualified therapist should also have post-graduate training in pediatrics, specifically sensory integrative theory and treatment. Additional continuing education courses in auditory training, oral motor and brushing protocol can be helpful. Children with developmental disabilities have complex needs that require a combination of sensory integrative principles with other

approaches such as neuro-developmental, behavioral, skills training and biomechanical. A skilled therapist will use a “holistic” approach to treatment and be flexible to your child’s specific needs.

Elizabeth

In September 2001, Elizabeth, a 5-1/2 year old girl with DS, began treatment for sensory integration dysfunction. Therapy consisted of twice-weekly clinical sessions focusing on neuro-muscular developmental treatment, brushing, sensory integration, reflex maturation and oral-motor skills. A brushing program and therapeutic listening program were implemented at home and a sensory diet was in place at school and home.

Home and school reports indicate Elizabeth is happier, less frustrated and thriving socially and academically. Parents and school staff believe Elizabeth’s SI treatment lay the groundwork for developing other skills, such as toilet training. Elizabeth once avoided all peer contact and had extremely limited expressive language. She talks more and is beginning to answer simple questions and follow more complex instructions. She actively seeks out her classmates and peers—who respond in kind. Elizabeth now has excellent eye contact and her attention span has grown considerably. Before SI treatment, she forcefully protested when pushed to try fine motor activities. Today, one of Elizabeth’s favorite activities is to write alphabet letters. Haircuts and nail trimming are no longer torture and teeth grinding has nearly stopped. Paper flapping and other self-stimulating behaviors have decreased dramatically and are often self-monitored. Auditory and oral defensiveness is greatly reduced, making meal times and family outings much more pleasant.

Resources

A Parents Guide to Understanding Sensory Integration, (1991). Published by Sensory Integration International, 1402

Rhode Island:

www.riota.org

Rebecca Simon, MS, OTR/L
401-397-4494

Physiotherapy Associates—Rehab New England
Lise Faulise 941-9111
1160 Post Road, Suite 8
Warwick, RI 02888

National Resources

American Occupational Therapy Association, Inc.
(AOTA) www.aota.org

4720 Montgomery Lane
Bethesda, MD
Mail: PO Box 31220
Bethesda, MD 20824-1220
1-301-652-AOTA

Sensory Integration International
(SII)/The Ayres Clinic
PO Box 5239
Torrance, CA 90501-5339
Phone: 1-301-320-2335
E-mail: sensoryint@earthlink.com
Web site: www.sensoryint.com

Star Center (The Sensory Integration Dysfunction Treatment
and Research Center)
The Children’s Hospital
Location: Denver, Colorado 80218
Mail: 1901 West Littleton Blvd.,
Littleton, CO 80120
Phone: 1-303-794-1182
Web site: www.Sinetwork.org

Cravens Avenue, Torrance, CA 90501-2701

Combining Neuro-developmental and Sensory Integrative Principles: An Approach to Pediatric Therapy (1995) by Blanche, Erna I., M.A., OTR, Botticelli, M.S., PT, Hallway, Mary K., OTR. Tucson: Therapy Skill Builders.

Reprinted from Down Syndrome News, Volume 26, Number 4



Best Buddies is a non-profit organization dedicated to enhancing the lives of people with intellectual disabilities by providing 1:1 friendships and integrated employment. Since its inception in 1989, Best Buddies has had an impact on the lives of more than 250,000 volunteers and people with intellectual disabilities in hundreds of communities around the world.

The Big Picture - Making a Difference

Founded in 1989 by Anthony K. Shriver, Best Buddies has grown from one chapter at one college campus to a vibrant, international organization involving 50,000 participants on 900 middle school, high school and college campuses in the U.S., Canada, Cuba, Egypt, Greece, Ireland, the Philippines, Saudi Arabia and Sweden, with programs developing in Brazil, Guatemala, Mexico and Turkey.

The Big Picture - Vision

Best Buddies ambitiously envisions a world where people with intellectual disabilities are so successfully integrated into our schools, our workplaces and our general communities that our current efforts and services will be unnecessary. Until this becomes a reality, our mission is to provide education about the emotional, functional and natural needs and abilities of people with intellectual disabilities.

The Big Picture - Future Goals

Our goal is to bring Best Buddies to every corner of the U.S. and the world, making Best Buddies program active in every community and on every middle school, high school and college campus. Specifically, by 2010, Best Buddies will operate in all 50 states, establish programs in 50 countries and have 500,000 participants worldwide.

History of Service

Best Buddies was born when Founder Anthony K. Shriver recognized the unjustified lack of opportunity for people with intellectual disabilities to socialize with non-disabled peers, as well as the power and impact of friendship in development their self-esteem and improving their outlook on society. A college student himself, Shriver knew that his fellow colleagues had the energy and commitment to positively transform their communities.

Best Buddies Programs

Today, Best Buddies offers six programs:

- Middle Schools
- High Schools
- Colleges
- Citizens
- e-Buddies
- Best Buddies Jobs



College Programs in Rhode Island

Providence College was launched in 1991. The host site is Fogarty Center. Since that time Best Buddies has created 196 buddy matches at the college. The University of Rhode Island also launched a college program in conjunction with Alternatives, Inc., now known as Perspectives, Inc. In 1993, Best Buddies International asked Fogarty Center to start another college chapter at Brown University due, in part to the success of the Providence College chapter. The Brown chapter has created over 153 buddy matches since its inception.

2003-2004 Goals

Best Buddies Rhode Island funding comes from a portion of a \$5,000,000 federal grant. Congressman Kennedy (RI) and Congressman Obey (WI) were instrumental in securing these monies which will open five state offices as well as provide support to regional offices throughout the country.

This year, Best Buddies Rhode Island will introduce our organization to the public through presentations to education providers, adult service providers, other non profit organizations as well as the general public. We will offer opportunities for 20 high schools and colleges to participate in our high school and college programs. In addition, we will develop an advisory board to support our state office in fundraising and community development.

Future Goals for Best Buddies RI

With community support and fundraising Best Buddies RI hopes to launch a middle school program in 2005. We intend to increase the high school and college programs by doubling these opportunities each year for the next five years to ultimately offer our Best Buddies programs to 100 schools in Rhode Island. We will achieve these ambitious goals by hosting two fundraisers in 2004. In addition, we will seek funding from corporate sponsorships, through local and state government support, individual donations, private foundations and state and federal grants.

To Learn More about Best Buddies Rhode Island

Visit us at our website:

www.bestbuddiesrhodeisland.org

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