

Steps to Success...

JAN-FEB 2004

Autism Project of R I Newsletter Debuts

Special points of interest:

- Executive Directors' Report
- Next "A Starting Point " series set for March 18th
- Matt Savage Concert
- Discussion Groups

A Note from the Executive Director

Welcome to the first issue of **STEPS TO SUCCESS**, the new Autism Project of Rhode Island's newsletter. We will be striving to make this an interesting, educational and valuable addition to The Project's other services. In the coming months we will be dealing with many issues confronting the community of autism families and educational professionals such as educational standards, best practices, practical applications, home-based services and many others. We also want your input. If you would like to see a particular topic dealt with, or have any suggestions about the content or presentation of this newsletter,

please let us hear from you. If you do have any suggestions just address your comments to us via e-mail at editor@theautismproject.org, or drop us a line at The Autism Project of RI, 51 Sockanosset Crossroad, Suite A, Cranston, RI 02920 or call (401) 785-2666. If you have any thoughts or suggestions on any of our services we'd love to hear those as well. We expect to make this a bi-monthly publication and will send it directly via e-mail as well as posting it on our website. Please update your e-mail address with us to be sure to receive your copy.

Joanne G. Quinn

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Imagine Walk is Coming April 25th

Last year we held our first **Imagine Walk and Family Fun Day**. This year we are going to do our best to make this even more fun for all the families that attend! This is our major fundraiser and helps us to do training, education, consultation, advocacy, support and summer camp. Registration forms for individuals and teams will be available March 12. New this year, you can register on line at our website. Please plan on coming out again this year.

If the weather didn't slow us down last year, nothing will!



Imagine Walk-2003

Next Starting Point Series Begins March 18th

The educational and highly successful series *A Starting Point* will begin its next nine week series on March 18th. The evening classes are scheduled for Thursdays from 6:30 to 8:30 pm and run through May 13th, allowing for a school vacation week. The location is at the Project's Training Center and Offices at 51 Sockanosset Crossroad in Cranston. This series will be taught by many different, highly

experienced professionals and has proven to be a valuable tool both for teachers in the classroom as well as parents in their homes. Some of the topics discussed are Overview of ASD, Communication, Visual Structures, Social Stories, Sensory Integration, Behavior and many others. If you have any questions please give us a call for the details at (401) 785-2666.

New Personnel Join The Project

As the Project continues to grow, so does our dedicated staff! In order to keep up with the demand for programs and information we are adding permanent staff at the Project. In April 2003 Melinda Lemos-Jackson joined us as the Operations Manager. Melinda works in a variety of areas, one of which is our two-week summer camp program for children with Autism Spectrum Disorder (ASD), **Move, Think, Create,**

Communicate. For more information about camp, feel free to call Melinda at the office or e-mail her at melinda@theautismproject.org. Thanks to a grant from Hasbro Charitable Trust we were able to hire Mary Farhoumand to oversee our fund raising and development. Mary has a wealth of experience in these areas and she has brought energy and commitment to this important work. Welcome Melinda and Mary!

Discussion Group Begins

The Autism Project of Rhode Island continues to grow and expand the programs we offer. In January 2004 we began to host a monthly *Discussion Group* for graduates of our training programs, *A Starting Point* and the *Intensive Summer Institute*. Our Discussion Groups are held at the Project's offices in Cranston on the last Saturday of the month, from 9:00 am to 11:00 am. Parents, educators and professionals who have graduated from *A Starting Point* or

the *Intensive Summer Institute* are welcome to join us for facilitated discussion. This is an informal and relaxed opportunity to talk with some of the Project's trained, experienced consultants, and other parents and educators, about what's working and what's not working for you and your child or student. Discussion Groups are free and refreshments are provided. Please call the office at 785-2666 to pre-register for this wonderful opportunity!

Grocery Shop and Support the Autism Project of RI

The Autism Project of Rhode Island is a registered member of the Community Fund at Brigido's Fresh Market IGA, located in Scituate (25 Village Plaza Way), Pascoag (54 Sayles Avenue) and Slatersville (900 Victory Highway). Help support the Autism Project by saving your register receipts from Brigido's. Please mail them to Mary Farhoumand, Devel-

opment Director, at our offices, 51 Sockanosset Crossroad, Suite A, Cranston, RI 02920. We will submit the register receipts and receive one percent of the total of the Brigido's register receipts submitted (minimum submission from the Project at one time of \$2500.). The more shoppers we have, the quicker it will add up.

Kids Count Releases Autism Report on RI

The following are excerpts taken from the recently released report on the status of Autism in our state. The entire report can be read on the Kids Count website at www.rikidscount.org. This is the first report of its kind focusing on a specific disability. We are proud to have been a part of the report and are committed to using it as we continue to get the word out on the disability of autism spectrum disorders and what needs to be done to support individuals with ASD and their families across Rhode Island.

A special thank you to Elizabeth Burke Bryant, Veronika Kot, RI KIDS COUNT staff and Jennifer Hanley of the Autism Society of RI for all their hard work in putting this important brief together.

CHILDREN WITH AUTISM IN RI

Dec 2003

Autism is a neurological disorder that profoundly affects a person's ability to communicate, process and respond to sensory information, and form social relationships. Individuals diagnosed with Autism Spectrum Disorders (ASDs) have a range of symptoms and abilities, and experience challenges that range widely in severity.

Over the past decade, there has been growing concern and controversy over apparent increases in the childhood prevalence of Autism Spectrum Disorders, which until recently were considered rare (i.e. 4 per 10,000 children). Recent studies suggest that the prevalence rate may be nearly 1 in 250 children (3.4 per 1000). Between the 1992-93 and the 2002-03 school years, the number of students ages 3-21 with autism reported in the Rhode Island Department of Education Special Education Census increased from 30 to 605. National research indicates that early, intensive, sustained and appropriate intervention can result in significant improvements in the quality of life, level of inde-

pendent functioning and reduction of public costs associated with autism. However, due to a shortage of trained professionals, many children are not identified early. In addition, because of the high cost of intensive treatment and the lack of skilled professionals to deliver it, many children do not receive timely and appropriate services.

Prevalence rates and causes

The national prevalence of autism spectrum disorders, which were once considered rare (i.e. 4 per 10,000 children), is uncertain. Autism is 3 to 4 times more common in males than in females. A 2003 study of the metropolitan area of Atlanta, Georgia showed an ASD prevalence rate of 3.4 in 1,000 children, a higher rate than childhood cancer, diabetes or Down Syndrome. A 1998 study found a prevalence rate of 6.7 per 1,000 children with ASDs in Brick Township, New Jersey. U.S. Dept. of Education records indicate that autism rates in the special education census in every state increased between 1992-93 and 2001-02, in many instances by well over 1,000%. A recent California report documented a doubling in the caseload of individuals with "autistic disorder" or "classic autism" served through that state's developmental disabilities agency between 1998 and 2002. This was over and above a 273% increase between 1987 and 1998.

A review of epidemiological studies suggests that the rate for all Pervasive Developmental Disorders may be as high as 6 per 1,000 children.

Possible Causes

The cause of the increase in prevalence of ASDs is unknown. Genetic factors play a major role in autism; however, they would not account for increases. Improved diagnosis, a broadening of definition, changes in special education laws and increased awareness may account for the

Kids Count continued...

change. Some studies hypothesize that environmental toxins or immunizations or thimerosal (a mercury preservative found in immunizations and being phased out nationally due to safety concerns), are behind the increase in prevalence. Other studies have not confirmed a link to immunizations.

Still others believe that a combination of factors may be responsible. Several federally-funded studies are investigating a variety of causes including environmental toxins, immunizations and genetics.

Ages 3 to 21

Virtually the only statewide source of data regarding rates of children with autism in Rhode Island is found in the special education census of the Rhode Island Department of Elementary and Secondary Education. The special education census annually reports the number of students receiving special education services, by disability. These figures include children between the ages of 3 and 21. They are known to be an undercount because many children with autism are reported within other categories (mental retardation, speech/language or developmental delays). According to the special education census, the number of children with autism in Rhode Island increased from 30 to 605 between the 1992-93 and 2002-03 school years. This is a 1,900% increase. The percentage of students with autism (as a percentage of all spe-

cial education students) also increased. It is now fifteen times greater than it was ten years ago.

The reasons for increasing numbers and rates are unknown. They could reflect improved awareness and diagnosis, a broadened definition, increased prevalence, or a combination of factors. During the past ten years in Rhode Island, there has been no decline in other categories of disability in the special education census of a magnitude that might account for the full increase in autism rates.

The Autism Project of Rhode Island, a non-profit organization, sponsors trainings for parents and teachers, and has assisted 2 school districts with implementation of model demonstration classrooms. Demonstration classrooms must show a commitment to best practices. All staff must have significant training. The Project promotes replication of best practices throughout Rhode Island so students can be educated in home districts. School districts are encouraged to visit and learn from existing model classrooms. In 2003, 170 parents, teachers, clinicians, and home-based workers completed The Autism Project's nine-week training series and 30 professionals graduated from the five-day intensive summer ASD training.

Remember to see the entire report go to

www.rikidscount.org

Wine, Dine and Help A Child With Autism Go to Camp

Michael Andoscia of Waddell & Reed and Pat Orlando's Restaurant are hosting a wine tasting and dinner to benefit the Autism Project of Rhode Island on Thursday, April 8, 2004 at Pat Orlando's Restaurant, 175 Putnam Avenue, Johnston, RI. Please join us for a fun-filled evening including wine tasting, dinner, a silent auction and raffle. Festivities begin at 7:00 pm;

tickets are \$50.00 per person. For reservations please call Pat Orlando's Restaurant at (401) 231-6053. All proceeds from this event will benefit the Project's summer camp program for children with autism, **Move, Think, Create, Communicate.**

Autism Project Co-sponsors Matt Savage Trio Concert

Matt Savage is a Jazz pianist Extraordinaire as seen on the *TODAY Show* and at the New Orleans Jazz and Heritage Festival. We are co-sponsoring a concert with Barry Prizant and Community Autism Resources, Fall River, MA the Friday evening of the 2-day ASD symposium at the RI Convention Center. ([ASD Symposium](#))

Matt Savage is an eleven-year-old jazz piano genius who has been astounding audiences and setting the jazz world on fire. Matt has been studying jazz since 1999 and performing for amazed audiences since 2001 as the leader of The Matt Savage Trio. He has met and played for many of jazz's greatest musicians. He has been praised by Dave Brubeck and other famous jazz pianists for his natural

talents. Matt has become a [Bösendorfer](#) piano artist. He is the youngest artist and only child ever honored by [Bösendorfer](#) in their 175-year history. Read more about Matt at www.savagerecords.com. Partial proceeds from the Symposium support Weekend Retreats for parents of children with ASD and related disabilities at Alton Jones, RI.

Friday, March 12, 2004, 7:00 PM at the First Baptist Church of America, 75 North Main St., Providence, RI, Doors open at 6:30 pm, Tickets are \$20 for the general public, \$50 for a "meet the artist" reception that includes an autographed CD. For advance tickets, call Janet Balletto at 401-732-6335 or email at janetballetto@cox.net. Cash, check or credit card accepted.

Lessons In Learning

This section is the heart of the Autism Project of RI. Since we began, the sharing of information, best practices and what we've seen work remains the core of our mission. So, we've dedicated a section of the newsletter to do just that. Each issue will review a practical application of a particular intervention and follow up with a real life example of where and how it works.

This issue we review the basic concept of "FIRST/THEN". This concept is often a younger child's introduction to a schedule. Simply stated, the idea of "FIRST Socks, THEN Shoes" gives the child the basic information necessary to complete a simple task in small increments. The two-step schedule is then expanded gradually to a full day schedule or a schedule including all of the steps necessary to complete a task (i.e. getting dressed). As the child becomes more familiar with the idea and where receptive language allows, the FIRST/

THEN concept can be used verbally in many situations. The following is an example of the higher end use of FIRST/THEN in a verbal format.

One Family's Experience

My family typically takes an entire pew at our Sunday church services. We are members of a small church, and our parish friends and minister know our middle child has "some autism". I explain PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified) as "some autism", because it makes more sense than a bunch of letters that many people confuse with "ADD" or "ADHD".

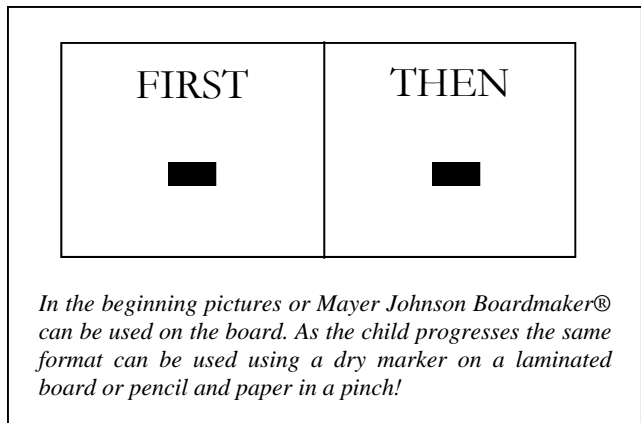
Last Sunday, my son was verbally quiet, but busily playing with his Silly Putty. His play sometimes looks like "stimming" (self-stimulatory behavior), but he was quiet and we were making it through the service. As the usher approached because it was time for us to go to the altar for communion, my husband said, "It's time for communion. Give me

Lessons In Learning continued...

the Silly Putty.” I anticipated the “NO!” before I heard it. I could see the resistance in our son’s body and facial expression. My husband requested it again, and now the usher had reached our pew. Bobby wasn’t budging, until I leaned over and said, “Bobby, look at me. *First* communion, *then* Silly Putty.” I held out my hand, with no further discussion Bobby gave me the Silly Putty and went up to the altar for communion. As soon as we returned to our pew, I gave Bobby his Silly Putty. All was well.

Of all the strategies I have learned over the last six years of autism education-conferences, seminars, classes, networking with families, discussions with professionals, **FIRST/THEN** has to be one of the best. It is a highly effec-

tive way to communicate a preferred or necessary sequence of events. It is easily communicated verbally or visually, can be applied in many settings, and it has been a successful strategy for our family on countless occasions. Bobby actually uses “First/Then” with us now!



Corporate Sponsors...

There is still time to sign on as one of the Corporate Sponsors for the Autism Project’s *Imagine Walk and Family Fun Day*. Companies interested in corporate sponsorships can contact Mary Farhoumand, Development Director, at (401) 785-2666 or mary@theautismproject.org for more information. Donations of products and services, in addition to monetary donations, are welcome! If your company is looking for a great cause to support, consider gathering a team to volunteer and help support the Autism Project of Rhode Island.

Upcoming Conferences

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| Mar 12-13, 2004 | 9th Annual ASD Symposium —
Academic and Social Success for
Persons with ASD
Hosted by Barry Prizant and Community
Autism Resources
www.barryprizant.com |
| Apr 29-30, 2004 | Autism: Sharing the Knowledge
Hosted by FEAT/RI
www.featri.org |
| May 1, 2004 | Autism Society of RI Conference
Bryant College
(401)726-9761 |

Go to hosting agencies’ websites for details!

Check out our website at
www.theautismproject.org

Other valuable sites include:

www.rikidscount.org
www.autism-society.org
www.ritap.org
www.barryprizant.com

