

FOCUS ON Autism

WINTER 2009

For more information about the services at the Fay J. Lindner Center for Autism and Developmental Disorders, visit us online at www.northshorelij.com/autism, or to make an appointment, please call us at (516) 802-8600. The Fay J. Lindner Center for Autism is a member of the Greater New York Autism Research Center of Excellence.

Our Featured Artists!

By Stacey Kanin, M.S.

This edition's featured artists are brother and sister duo Richie and Ria Belesi-Kihm. Both Richie and Ria come to the center once a week. While Richie's sessions focus on developing social skills, Ria's sessions target reading and writing.

Richie and Ria are both artistically talented. They have graciously created numerous pieces of artwork for the center including greeting cards, masks and even 3-D animals. It's amazing to see what they can make from basic art supplies like pipe-cleaners and construction paper, and it is not surprising to find them in the waiting area making new creations! Our days are brightened to find artwork on our desks made just for us.

Richie and Ria are very proud of the work displayed in this picture. It was difficult for them to decide which of their artwork



Staff members with our featured artists, Richie (left) and Ria (right).

would be best to show to you. Ria chose to display a watercolor painting and her portrayal of a city skyline, and Richie chose to exhibit his abstract drawing of a cat. We all hope you enjoy Richie's and Ria's creations!

Stay tuned for our next featured artist!



Artwork done by (from top to bottom): Richie, Ria, Ria.

We're Growing! *Coming on Board at the Fay J. Lindner Center for Autism...*



Stacey Kanin, M.S.
Certified Speech
Language Pathologist



Georgianna Reilly, B.S.
Research Assistant



Samara Pulver Tetenbaum, M.A.
Behavioral Specialist



Susan Cuoccio, M.S.
Educational Consultation
Specialist



Laurie Better Perlis, Psy.D.
Psychology Post-Doctoral Fellow



I would like to take this time to introduce myself as the newest Research Staff Member at the Center. I graduated from Binghamton University in May 2007 with a Bachelor's degree in science in organismic psychobiology and evolutionary studies. In 2005, I started working as a research assistant at Binghamton University's Infant and Child Studies Lab doing research on perception and memory. In the winter of 2006, I was fortunate to get an internship with All About Kids on Long Island, where I worked with a wonderful little girl doing home-based ABA intervention.

I was able to form a strong bond with her over a few short weeks and confirmed for myself that I wanted to continue to work in this field and help children like her in the future. I went back to school that winter to become a research assistant and a teacher's aid at the Institute for Child Development for the rest of my undergrad career. Through these research and ABA experiences, I have developed a unique set of perspectives on autism spectrum disorders which enabled me to progress toward the position I now hold here at the Center.

I began working at the Center in December 2007 and I am currently a research assistant

for medication studies and the research coordinator for several behavioral and clinical studies. I am able to interact and help families in ways that I very much enjoy. I have also been able to broaden my knowledge of autism spectrum disorders while creating a career path for the future. With the experiences I have gained by working at the Center, I hope to pursue a PhD in neuropsychology. I hope that my ideas and assistance will contribute to the Center's expansion of its research program. I am sure that my current position will be one of the most important steps in my career path and am very thankful to be a part of the team!

What's New at the Center

Current Programs and Workshops

Employment Skill Building Group

The Center is pleased to be offering a six-week intervention series targeting interview and job skills for high school students and young adults. Through direct instruction, mock interviews and videotape reviews, participants will learn basic interview and job-related skills. Individualized goals will be created based on a screening and an initial mock interview conducted by the caregivers with each participant. Targeted areas may include: answering interview questions, nonverbal communication (including eye contact, body language and facial expressions), résumé creation and determining appropriate jobs/careers. Individual or group (two- to three-participant) sessions are available. Groups will be formulated following a screening and will be based on skill level, age and job/career interest.

For more information, please contact Stacey Kanin, CF-SLP, at **(516) 802-8600**.

Expansion of our Cognitive Behavioral Therapy Program

Our cognitive behavioral therapy (CBT) program has expanded! We provide individual therapy, for youth and adults ages 6 and older, and couples therapy. CBT is highly effective for working on coping, social and life skills, anxiety, depression, self-awareness, growing up issues and many other difficulties. Couples therapy can be effective for working on communication skills and relationship development when one or both partners have an autism spectrum disorder.

If you are interested in learning more about cognitive behavioral therapy for yourself or your child, please call Dr. Laurie Perlis at **(516) 802-8600**.

New Comprehensive Services for Adults with Autism Spectrum Disorders (ASDs)

We are now offering comprehensive services for adults with ASDs of all ability levels including assessments, therapy, skill-building, consultation and community referrals. Our multidisciplinary adult clinic can provide individualized services to meet your needs and/or the needs of your family member or client.

Services we offer include:

- Assessment Clinics: Diagnostic, Intellectual, Adaptive, Speech-Language, Eligibility
- Individual, Couples and Group Therapy
- Social and Relationship Skills
- Vocational and Educational Support and Skill Building
- Community Referrals
- Consultation
- Research Studies

If you are interested in learning more about the adult program, please call Dr. Laurie Perlis at **(516) 802-8600**.

New Speech Language Assessment: Identifying Semantic-Pragmatic Language Disorders

The Center is now offering a speech-language assessment protocol specifically

targeting areas of higher-level language (e.g., inference, ambiguity, pragmatics, humor, problem-solving and critical thinking). This assessment aids in the differential diagnosis of a secondary (to autism) language disorder known as semantic-pragmatic language disorder (SPLD). This disorder affects the language areas of content (particularly meaning and intent) and use (otherwise known as pragmatic language) despite the presence of average to superior form (grammar, speech) or expressiveness. This disorder is more common in children with Asperger syndrome and high-functioning autism but can also be present in children without an ASD.

Children with SPLD often speak with deficits in areas such as figurative language; understanding and using rules of social language; initiating, maintaining, and terminating conversational exchanges; conversation repairs; and perspective-taking. These deficits can also affect the child academically as they often struggle with assignments that require descriptions of social characteristics, overall themes, comprehension and explanations of abstract language.

If you are interested in pursuing a semantic-pragmatic language evaluation or would like further information please contact Stacey Kanin, CF-SLP, at **(516) 802-8600**.

Girls' Corner

In our Fall 2007 issue of the newsletter we announced the development of our "Girl Talk" Group Curriculum. Since then, our girls with ASDs program has flourished. We now offer a number of groups for girls and women across a wide range of ages and ability levels (see list at right). We also see clients for individual therapy, evaluations and consultation services, and our research program about girls with ASDs is under way.

Limited services and resources are available for families of girls and women with ASDs. We are very excited to be one of the first "girls clinics" in North America. In January 2008, *Nightline* on ABC news aired a program about girls with ASDs. We were privileged to have been interviewed for their story and are so proud of our girls who came to share with others what their experiences have been like as females on the autism spectrum.

Please contact **(516) 802-8600** for more information about any of these services or about our research program.

De-FEETing the Odds One Step at a Time: Local Autism Walks

Town of Oyster Bay Walk for Autism

On Sept. 7, The Town of Oyster Bay graciously hosted the first annual walk to benefit the Fay J. Lindner Center for Autism and Developmental Disorders. The walk, held at the John J. Burns Town Park in Massapequa, was a huge success, with more than 300 walkers! Family members, friends and teachers of children and adults with ASDs helped raise nearly \$6,000 for our Center. We would like to thank everyone who helped to make this event a success! The funds raised at this event will allow us to reach even more families in need of support. We can't wait to see what's in store for the walk next year and we hope you can join us!



May-Lynn Andresen, administrative director of the Fay J. Lindner Center for Autism, addresses walkers at the first annual Town of Oyster Bay Walk for Autism. Pictured with her are (from right to left): Donna Antetomaso, Town of Oyster Bay Recreation; Assemblyman Rob Walker; Richard Betz, Parks Commissioner; and Rose Marie Walker, Town Council Member.

Autism Speaks Walk Now For Autism 2008

On Oct. 5, at Jones Beach State Park in Wantagh, N.Y., many families joined our Fay J. Lindner Team as we walked to "De-FEET the Odds One Step at a Time" at the annual Autism Speaks Walk Now for Autism. Thank you everyone for your donations and involvement!

Groups for Girls and Women with ASDs

Girls Coping Group

A new eight-week group is being offered this fall for 10- to 12-year-old girls on the autism spectrum focusing on emotional understanding and coping skills development.

Teen Girls Group: Friendships, Fun and Growing Up!

We are thrilled to be offering a brand new eight-week Teen Girls Group for 11- to 14-year-old girls on the autism spectrum which will focus on topics such as self-esteem, social skills, friendships and other "growing up" issues.

Teen Girls Community Group

The Teen Girls Community Group meets for eight weeks – four weeks are spent learning skills at the center (e.g., money skills) while the other four are spent in the community practicing and generalizing these new skills. High school peer mentors participate to model appropriate skills and serve as same-age role models.

Women's Support Group

The Women's Support Group meets for a total of eight weeks at the Center and focuses on feelings related to being an adult with an ASD, coping skills, social skills, future planning and overall support as a group.

A New Book Written by Our Staff!

"Girls Growing Up on the Autism Spectrum"

By Shana Nichols, PhD, with Gina Muscillo-Moravcik, SLP, and Samara Pulver Tetenbaum, MA

After much anticipation, the girls growing up book is finally ready! With collaboration from one of our mother-daughter families, Shana, Gina and Samara have written a practical guide to helping girls with ASDs enter and navigate adolescence.

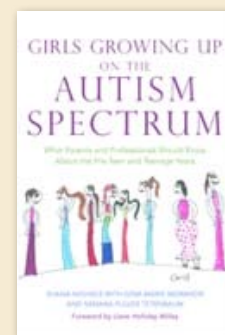
Available Now! Jessica Kingsley Publishers

Order your copy online at www.jkp.com today!

Growing up isn't easy, and the trials and tribulations of being a teenager can be particularly confusing for girls with autism spectrum disorders (ASDs). This book covers concerns commonly faced by girls with ASDs and their parents, from periods and puberty to worries over friendships and "fitting in."

Taking a good look at these adolescent issues, and many more, the authors provide families with the knowledge and advice they need to help their daughters – and the whole family – through the teenage years. This book addresses core issues such as cognition, communication, behavior, sensory sensitivities and social difficulties. It gives candid and realistic advice on a wide range of important teenage topics.

Providing professional perspectives alongside personal experiences from mothers, daughters and educators, this is a unique and indispensable guide for families and their daughters with ASDs, as well as the professionals who work with them.



Research Study Status Updates

Our research staff, Linda Spritzer and Georgianna Reilly, are working hard on our latest research projects. Here's what's been going on and what's to come!

Medication Studies

- **Medication Trial for Aggressive, Tantruming and Similar Behaviors** – This study is closed to enrollment and will be wrapping up at our site shortly.
- **Medication Trial for Repetitive Behaviors** – Enrollment began in November 2007 and is now closed.
- **Medication Trial on Irritability and Related Behaviors** – Enrollment began in May for this study and is continuing. If you are interested in being involved please see information below, on the investigational drug study for children with autistic disorder, for more details.



North Shore-Long Island Jewish Health System

Investigational Drug Study for Children with Autistic Disorder

*Does your child seem overly irritable or aggressive (towards either self and/or others)?
Does your child throw tantrums or have quick changes in mood?
Is your child between 5 and 17 years of age?*

If so, your child may be eligible to participate in a research study being conducted at the Fay J. Lindner Center for Autism and Developmental Disorders, a member of the North Shore-LIJ Health System. The purpose of this study is to evaluate the effectiveness of the study drug on irritability and related behaviors associated with autistic disorder in children and adolescents.

Participation in this study involves:

- A diagnostic assessment
- Monitoring visits with the study psychiatrist and research staff
- Study drug or placebo (a substance containing no medication) for six weeks, with the possibility of a 26-week extension trial where all participants will receive study drug

If your child qualifies, all of the above is provided at no charge, including all aspects of evaluation, study visits and study drug.

For more information about the project, contact the study coordinator, Linda Spritzer, at **(516) 802-8608** or e-mail at: LSpritzer@nshs.edu.

This study is being conducted at 4300 Hempstead Turnpike, Bethpage, NY 11714.

Non-medication Studies

- **Parent Education Group on Sexuality and Puberty** – Our final group finished over the summer and data analysis is in its final stages. This study was presented at IMFAR in London and at the OAR conference at the end of October. We would like to thank all families who participated and hope that we will be able to provide a number of similar groups to parents in the future.
- **Genetics Study** – This study, conducted in conjunction with the Feinstein Institute for Medical Research, is currently still enrolling. If you are interested please see our ad below for more information.
- **Temperament Survey Study** – This study, conducted in conjunction with the Cody Center in Stony Brook, has just completed enrollment. We hope that we will find trends in temperament within the ASD population.

Thank you to all families who have participated – you have been a great help! We are glad to have you as part of our research family and look forward to working with you again.



One in every 150 children will develop autism...

WE WANT TO KNOW WHY

The Feinstein Institute for Medical Research is committed to unraveling this complex disease.

We need your help. The Feinstein Recruitment Registry is open to people interested in being involved in research. Join our registry of potential research volunteers.

AND BECOME PART OF THE ANSWER

Autism is one of dozens of conditions studied at the Feinstein Institute and North Shore-LIJ Health System. There is no obligation to join a study. Being part of the registry keeps you informed about the latest available studies. All registry information will remain active for three years. Participation is strictly voluntary and you may withdraw your information any time.

CALL 1-877-GO-NSLIJ (1-877-466-7545)

Student and Professional Trainee Program Expands

The Center is pleased to be expanding our trainee program. Our trainees come from a variety of disciplines that work with individuals with ASDs. While we have the pleasure of mentoring bright students, they have the opportunity to receive hands-on experience in the field as part of our team.

Psychology Trainees

The psychology training program, run by Shana Nichols, PhD, clinical director, started in 2006 with one trainee and is growing. We now have five psychology trainees at the pre-master's, pre-doctoral and post-doctoral level.

Matthew J. Brightman, MS I am happy to be a part of the Fay J. Lindner Center for Autism team, working as a clinical psychology extern. I received my master's degree in clinical psychology in September 2007 and am currently working toward my Doctor of Psychology degree, with a concentration in developmental disabilities, at Long Island University/ C. W. Post's Clinical Psychology Doctoral Program.

Julie Ivans, MS I am delighted to be joining the Fay J. Lindner Center for Autism as a psychology extern. I received my master's degree in school psychology in May 2008 and am currently working toward my doctoral degree at St. John's University.

Mallory Stauber, MS I am a graduate student at Brooklyn College, working on my degree in school psychology. I received my master's degree in the spring of 2008, and am now working on my advanced certificate of school psychology.

Social Work Trainees

The Social Work Internship Program started its first year on Sept. 8, 2008. The program is run by Halley Ceglia, LMSW, the Center's social worker.

Mark Charney is a social work student at Adelphi University's School of Social Work and he is currently in the five year accelerated program.

Bernadette Petro is a second year social work student at Stony Brook University's School of Social Welfare.

Samantha Silverberg is a third year part-time mental health counseling student in her first year of interning at Adelphi University. Samantha will be working with both the social work and psychology departments throughout the duration of her internship year.

Speech and Language Trainees

Jaimee Fallon, BS and **Alyssa Scelfo, BS** The center is pleased to introduce our new speech-language pathology practicum students. Jaimee Fallon, BS, and Alyssa Scelfo, BS, are completing their second year in the communication disorders program at Adelphi University.

Contact Us

If you are interested in furthering your education with us, please call **(516) 802-8600** to be directed to the staff member who best matches your interests and educational experience. Come join our team!

2008 Appearances, Achievements and Accolades!

May-Lynn Andresen, RN: selected by New York State (NYS) to receive a one-year training and certification in the 2008 Partners in Policymaking program; served as panelist for *State of the State on Autism: New York State Board of Regents Vocational and Educational Services for Individuals with Disabilities (VESID) Committee Regional Meeting on Autism* hosted by the NYS Department of Education in April; co-directed a course for the American College of Physicians 2008 Annual Scientific Sessions and presented on *Your Next Patient Has Autism: Assessment and Examination of Adults with Autism*, in May; and presented at Autism Speaks annual WALK now for Autism in October.

Dr. Joel Bregman: served as chair and presenter of session titled *Adults with Autism* at the Annual Meeting of the American College of Physicians, in April (Washington, DC); served as chair and presenter at the 161st Annual Meeting of the American Psychiatric Association in May; and, presented *Autism Spectrum Disorders: New Developments* at Huntington Hospital, Pediatric Grand Rounds, in September.

Susan Cuoccio: conducted two Center-based workshops, *Understanding the Needs and Management of Students with Autism Spectrum Disorders*, in July, and *The Value of Visuals*, for parents and teachers of children with ASD, in August.

Stacey Kanin: conducted a Center-based workshop titled *Semantic-Pragmatic Language Disorder in Children with Autism Spectrum Disorders*, in July; and, offered her sold-out workshop titled *SPLD in Children with Autism Spectrum Disorders*, in November.

Gina-Marie Moravcik, CCCSLP: presented *Social Communication in Girls Growing up with Autism* at the 2008 NYS Speech Hearing and Language Association annual convention in April. (Saratoga, NY)

Shana Nichols: presented her funded research, titled *"I'm Not Sure We're Ready for This" Working with Parents and their Teens with ASDs Towards Healthy Sexuality Development*, at the Annual Organization

for Autism Research (OAR) Applied Autism Research and Intervention Conference in October. (Arlington, VA)

Georgianna Reilly: presented her research poster on *Complex Object Recognition in Preschool Aged Children* at the International Society of Infant Studies annual conference in March. (Vancouver, BC)

Samara P. Tetenbaum: awarded a graduate research grant from the Organization for Autism Research for her dissertation *Barriers to Effective Family-Based Intervention in Autism Spectrum Disorders*, in September.

As a Group

Shana Nichols: presented three research posters from the Center's Growing Up with ASDs Program at the Annual International Meeting for Autism Research, in May. (London, UK)

■ Trainee **Matt Roth's** poster titled *Puberty and Relationships 101: A Guide to Growing Up for High Functioning Adolescent Males with Autism Spectrum Disorders*.

■ **Samara Pulver Tetenbaum's** poster titled *Sexuality, Puberty, and Growing Up – Evaluating the Effectiveness of a Group Psycho-Education Curriculum for Parents of Youths with ASDs*. Co-authors included Audrey Blakeley-Smith, PhD, Susan Hepburn, PhD, and Judy Reaven, PhD, from JFK Partners in Denver.

■ **Shana Nichols'** own poster titled *Sexual Well-Being of High-Functioning Adults with Autism Spectrum Disorders*, based on work with collaborator Sandra Byers, PhD, from the University of New Brunswick.

Shana Nichols and Samara P. Tetenbaum: attended the Annual Meeting of the Autism Society of America and presented *Growing up with Autism: Developing a Healthy Sexuality Curriculum for Teens and Young Adults*, in July. (Orlando, FL)

■ **Shana Nichols** also presented *Girls Growing up on the Autism Spectrum: Addressing Your Daughter's Unique Learning Needs*, authored by Shana Nichols, Gina-Marie Moravcik and Halley Ceglia.

