



FOCUS ON Autism

SPRING 2008

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 Artist!

By Matthew Roth, B.A., and Shana Nichols, Ph.D.

The Spring 2008 issue's featured artist is Bill Ceffalia. Bill comes to the Fay J. Lindner Center for Autism once a week to work on food and sound desensitization, social skills and coping skills. Bill is wonderful to have around, and he loves to make everyone here at the Center laugh. His enthusiasm is infectious!

Bill is an extremely talented artist who enjoys drawing pictures of Sesame Street, SpongeBob SquarePants™ and Blue's Clues™. In fact, after he watches his favorite television shows, Bill draws his favorite scenes from the episodes to make elaborate storybooks. Bill draws pictures from memory, and he doesn't need to look at another picture for help! He enjoys coming to the Center to show everyone his works of art – he is very proud (and he should be) of his creativity. All of us at the Center look



Bill (second from left) brings holiday cheer to the Center with his special Sesame Street Fire Brigade picture.

forward to seeing Bill's latest creation, and we are very impressed with his talents.

As a holiday present for the staff, Bill drew (and framed!) a special picture of the Sesame Street

Fire Brigade! The picture can now be seen in the hallway next to the door leading to the lobby. We all hope you enjoy Bill's masterpiece.

Stay tuned for our next featured artist!

Peer Mentor Program at the Center for Autism

We are looking for peer mentors to assist with Center-based and community-based groups for children with autism and other related disorders. Peer mentors must be:

- Between the ages of 7 and 21;
- Enrolled in and regularly attending a local school on Long Island;
- Available to attend at least one after-school group weekly for an eight-week cycle;
- Energetic, friendly, willing to learn; and
- Dedicated to working with children with special needs.

Peers are highly encouraged to continue in groups throughout the year.

Peer mentors gain knowledge and experience working with children with special needs. These skills can lead to future career and networking opportunities by providing:

- Increased confidence and ability to relate to others;
- Enhanced communication skills by understanding the patterns related to developmental disorders;

- Training in group dynamics and autism;
- Continued contact, guidance and feedback from the center's Social Worker;
- Material for college entrance applications;
- Professional/educational recommendations; and
- Greater choice in educational and career paths based on broadened skills and experiences.

Please call Halley Ceglia, LMSW, staff social worker, for more information and to learn how to get involved at (516) 802-8600.

Tips for Communicating With Your Verbal (but Acting Like They're Not) Teen

By Shana Nichols, Ph.D., and Gina-Marie Muscillo, M.A., CCC-SLP

Adolescence can be a challenging time for all parents, especially for those of youth with autism spectrum disorders (ASDs). Recently, several mothers of teens with Asperger's Syndrome (AS) have come to the Center expressing similar concerns – their children's avoidance of communication about any topic, ranging from the simple question "How was your day?" to more difficult issues such as smoking, alcohol and puberty. They all say the same thing: "I often find myself asking, 'Which "A" is it? AS or adolescence? Or is it A2?'"

Be Aware of Changes in Behavior

Deciphering what might be contributing to your child's reluctance to communicate is not easy! You are likely experiencing a combination of obstacles, including your teen's:

- Difficulties with communication due to their AS;
- Adolescent ambivalence about how much they want to share or talk about with their parents;
- Struggling with not having a peer group with whom they can connect; and/or
- Possible difficulties with mood, anxiety and adjustment to the changes that accompany adolescence.

Pay attention to changes in your child's behavior, mood, attention, sleeping and eating habits, and try to note when they seem more anxious, sad, irritable, withdrawn or less interested in favorite activities. Difficulties with self-esteem, depression and anxiety can arise during adolescence as physiological changes and hormones play more of a role and teens begin to be more aware of any difficulties they may have trying to fit in. Be sure to seek professional help if you think your child may be struggling.

Communication Strategies

Connecting with your child is important at this time, but is not often easy to do, so we've compiled a list of popular communication strategies used by families of teens with high-functioning ASDs. We encourage you to take a look at the following tactics and their potential benefits. They may help you discover a way to interact more openly with your teen.

- Communicate through e-mail (may be easier than talking).
- Use sticky notes for short notes and "daily check-ins" (staying connected).
- Use teachable moments as they arise: while watching television shows, news programs, movies, reading the newspaper or listening to music.
- Watch television programs or movies together (compromise – watch a program that is of interest to them in exchange for watching one that can provide opportunities to talk about important issues such as drugs, alcohol and safety).
- Initiate brief conversations on, at least, a weekly basis about a specific topic and reward any and all active participation (creating a basis from which to build up longer conversations and more open discussions).
- Comment on the positive behaviors you see in your child each day (fostering self-esteem).
- Be available to talk, and make sure your child knows you are available (encouraging trust).
- Listen carefully and non-judgmentally, and don't attribute everything to AS.
- Establish "talk time" while doing an activity your child enjoys (e.g., going for ice cream or going out to dinner).
- Talk with your child about his or her interests.
- Use time in the car as an opportunity for discussions.
- Encourage your child's siblings to talk with him or her. Big brother/sister talks can be private and special (unless dangerous situations are discussed, in which case the conversations need to be shared) and bring out feelings and thoughts your child may be unwilling to share with you.

Sometimes it helps to modify your own style of communication in order to encourage active expression from your teen. Some common strategies include:

- Supporting your communication with visual tools such as pictures, creating a social story together or even multiple choice questions or problem-solving maps/outlines when appropriate;



Do You Have High-Functioning Autism, Asperger's Disorder or PDD-NOS?

Are you between the ages of 21-65?

Are your cognitive abilities within the low-average to above-average range?

Would you be interested in learning more about yourself and how you feel about relationships and sexuality?

If you answered yes to the above questions, you are eligible to participate in a research study being conducted by researchers at North Shore - LIJ's Fay J. Lindner Center for Autism and the University of New Brunswick.

The purpose of this study is to better understand the topics of sexuality and relationships among adults with high-functioning autism spectrum disorders (ASDs). The information collected from the study aims to increase knowledge, and research the best methods, of helping teens and adults with ASDs to experience healthy sexual development.

Participation in this study involves completion of a set of online questionnaires at www.unbstudy.com that will take between 45 minutes and 1¼ hours to complete.

For more information about this project, please contact Shana Nichols, Ph.D., psychologist, at **(516) 802-8600** or Sandra Byers, Ph.D., psychologist, at **(506) 458-7697**.



- On account of your child's literalness, trying to ask specific questions rather than relying on overly broad or general ones (e.g., "Can you tell me one good thing that happened to you this afternoon?" as opposed to "How was your day?");
- Remembering that your child might not be able to understand what you are really asking or why you are asking such a general question, especially if you already know their schedules and activities for the day. They might not see the value in social chatting;
- Describing the perspectives of each person involved in a conversation. Do not assume that your child understands everyone's point of view;
- Avoiding questions about how they "feel." They might not be able to answer you because they physiologically may not be aware of their feelings, may not experience a range of feelings (our students often laugh about this) or may tend to only report extreme emotions, such as happy or angry;
- Mentioning emotions as part of a continuum in order to help them interpret the degree of an emotion, and how that one emotion may quickly lead to another (e.g., discomfort, frustration, anger or sadness) while tying actions, settings and events to each stage (e.g., "What was your reaction to being asked to write a lengthy story?"); and
- Immediately providing possible solutions (e.g., "What could you have done to improve your mood?").

Remember your teen years – how much fun did you have talking with your parents then? Take a step back and jump into your child's shoes to see his or her perspective when you can, and be patient.

Contact Us

For information on programs and services about "Adolescents With ASDs," such as social skills groups, community groups, individual therapy and consultations, call **(516) 802-8600**.

Volunteer Internship at the Fay J. Lindner Center for Autism and Developmental Disorders

The Fay J. Lindner Center for Autism and Developmental Disorders is seeking interns to assist with the compilation of a patient database that will become an integral part of the Center's daily functions. The database will be used to store, retrieve and organize patient information, and to run statistical analysis for research and performance improvement initiatives.

Working on the database will provide interns with valuable insight into the field of autism and the opportunity to learn the evaluation processes at the Center for Autism while gaining practical, real-life knowledge of the profession. Interns gain important experience in a friendly and educational office environment.

There is no financial compensation available.

Responsibilities will include:

- Data entry and tracking of:
 - Patient demographic information;
 - Testing results;

- Medical history; and,
- Diagnostic information into the database;
- Conducting chart reviews; and
- Ensuring smooth data-flow.

Qualifications:

Must be detail-oriented and conscientious. This is a great opportunity to gain experience in the field of psychology – though students majoring in all fields are welcome to apply.

If interested, please contact:

Linda Spritzer

Phone: **(516) 802- 8608**

E-mail: LSpritze@nshs.edu.

Clinical Trial to Test a Study Drug in Children and Adolescents with Autistic Disorder

**Does your child seem overly irritable or aggressive (toward self and/or others)?
Does your child throw tantrums or have quick changes in mood?**

If so, you may be interested in this study.

The purpose of this research study is to evaluate two dose levels of the study drug for irritability and related behaviors associated with autistic disorder in children and adolescents.

Study drug and procedures will be available to you at no cost.

To qualify, your child/adolescent must:

- Be at least 5 to 17 years old
- Be at least 44 lbs

Study participation involves:

- A study phase that can be, at most, eight weeks long
- At least seven visits with the study psychiatrist and research staff to closely monitor participants and assess change during this time
- The opportunity to take part in a 26-week open-label phase following the study phase

You will not qualify if your child/adolescent:

- Is pregnant or breastfeeding
- Has a history of prior or current DSM-IV psychotic disorder (e.g., schizophrenia, bipolar disorder, other psychosis)
- Has received an experimental drug or used an experimental medical device within three months before the planned start of treatment

If you're interested in this study and/or would like to learn more, please contact: Linda Spritzer at **(516) 802-8608** or via e-mail at: LSpritze@nshs.edu.



Research Opportunities at the Fay J. Lindner Center for Autism and Developmental Disorders



We are seeking motivated, organized and conscientious volunteers to help us run our various autism research studies.

Volunteers will gain valuable experience helping our staff with key aspects of conducting research, including:

- Data collection;
- Data entry and analysis;
- Organization of study files;
- Conducting chart reviews;
- Contacting eligible families; and
- Various administrative tasks necessary for running the research studies.

Volunteers may seek several opportunities in different areas of interest. Assisting in research is a great opportunity for students or individuals with an interest in autism, research and/or psychology and related fields to learn and gain valuable experience.

If interested, please call Linda Spritzer: **(516) 802-8608**.

DOES YOUR CHILD HAVE **AUTISTIC DISORDER?**

DOES YOUR CHILD HAVE **REPETITIVE BEHAVIORS?**

Get upset when interrupted from the usual routine

Repeat the same activities or movements again and again

Have intense preoccupations with certain topics or activities

If you answered “YES” to both questions, your child may be eligible to participate in research being conducted by researchers at the Fay J. Lindner Center for Autism and Developmental Disorders, North Shore-LIJ Health System.

This is a 14-week research study testing the safety and effectiveness of different doses of an investigational medication in children and adolescents who have been diagnosed with or have symptoms of autism. Participants will also be offered an open-label trial of the investigational medication at the end of the 14-week phase.

To be eligible for this study, participants must:

- **Be between the ages of 5 and 17**
- **Meet diagnostic criteria for autistic disorder**
- **Not have a significant medical condition (e.g., heart disease, high blood pressure, lung disease, liver or kidney failure, unstable seizure disorder, thyroid disease)**

All evaluations and medications for this study are provided without cost to participants. In addition, families who participate will be reimbursed for their time.

If you are interested in finding out more information about this study, please contact the study coordinator, **Linda Spritzer**, by phone **(516) 802-8608** or by e-mail at **Lspritze@nshs.edu**.

The Fay J. Lindner Center for Autism and Developmental Disorders, North Shore-LIJ Health System
4300 HEMPSTEAD TURNPIKE, BETHPAGE, NEW YORK 11714 • (516) 802-8600

**North
Shore LIJ** *Fay J. Lindner
Center for Autism*

North Shore-Long Island Jewish Health System

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Our Services:

- Educational Programming
- Psychiatric Evaluations
- Psychopharmacological Consultation (Medication) and Treatment Programs
- Parent Support, Trainings and Workshops
- Counseling (Individual, Couple and Family)
- Child-Specific and Programmatic Behavioral Consultation for School and/or Home
- Curriculum Development
- Social Skills and Peer Mentor Program Development
- Sexuality/Growing-Up Consultation Services
- Speech-Language Evaluation and Consultation Services
- Staff Trainings/Workshops
- Functional Analyses with Programmatic Recommendation Development
- Research Studies and Opportunities – If you are interested, contact Linda Spritzer at (516) 802-8608.
- Comprehensive Trans-Disciplinary Evaluation
- Family and Community Support/Counseling and Social Work Services
- Social Skills/Communication Therapy – social-language-based social skills groups and therapy for individuals between the ages of 5-30. Please call Halley Ceglia, LMSW, to discuss groups at (516) 802-8600.
- Adolescent Community Social Skills Program and Peer Mentor Program

Fay J. Lindner Center for Autism and Developmental Disorders

North Shore-LIJ Health System

Greater New York Autism Research

Center of Excellence (GNY-ARCE)

4300 Hempstead Turnpike Bethpage, NY 11714

Phone: (516) 802-8600 • Fax: (516) 802-8655

www.northshorelij.com/autism

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