



www.northshorelij.com/autism

Spring 2006

For more information about the services at the Fay J. Lindner Center for Autism and Developmental Disorders, 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.

Social Communication Development for Life-Long Success

Much has been documented about the social communication deficits experienced by individuals with autism, which can be particularly burdensome as they make the transition from childhood to adolescence and from adolescence to adulthood. With this in mind, the adolescent members of the language-based social skills group have been working on applying what they have learned in previous sessions to interactions and relationships with members of the other sex (the focus of the past eight weeks).

Because they are approaching maturity, their parents have been encouraging them to practice and master strategies for appropriate social interactions during this challenging period of transition.

Planning for Adulthood

Optimal planning for the transition into adulthood should include meaningful dialogue and active exploration of vital issues. This process should begin when the adolescents are 14 to 15 years old rather than at 18. Group members have been reflecting on past experiences (including instances of communication breakdown) and discussing ways to demonstrate respect to others, such as offering compliments, making pleasant remarks, introducing appropriate topics of conversation, and avoiding comments and topics that may cause discomfort in others.

Appropriate nonverbal communication has also been addressed. Ways to handle specific social situations have been discussed and practiced, such as:

- Making introductions
- Initiating conversations with girls/boys
- Describing and understanding the personality styles of others
- Deciding what personal information is appropriate to share with others
- Appreciating what comments and questions are potentially embarrassing
- Defining different types of relationships
- Identifying the type of relationship that would be appropriate to have with those of the other sex
- Understanding how one's appearance, comments and behavior influence the impressions that others form of you.

Practical Social Interaction Skills

Typically, these topics are introduced by staff members as a result of observations made during group sessions. The perspectives of the group members and their parents are also discussed. Parents report a clear need on the part of their adolescent children for information and practical suggestions for negotiating social interactions with their peers, especially with members of the other sex. They recalled past situations that were particularly challenging for their children, resulting in misunderstanding and an unfortunate choice of words and phrases that resulted in personal discomfort and embarrassment.

...continued on page 2



Touched by Someone with Autism? Want to Help?

Limited volunteer opportunities for high school, college or graduate students and adults are now available.

Contact us for more information:

- Telephone – 516-802-8600
- Fax – 516-802-8655
- E-mail – autismcenter@nshs.edu



Social Communication Training Groups Update

Previous newsletter articles describing the language-based social skills group at the Center (led by Gina-Marie Muscillo, CCC-SLP) emphasized the importance of developing both verbal and nonverbal social skills in a stepwise fashion.

This can be accomplished through task analysis, clear and detailed explanations, and the demonstration of each step within a chosen skill (e.g., initiating a conversation). For preadolescents and adolescents with high-functioning autism (HFA) and Asperger's syndrome (AS) (who demonstrate sophisticated verbal ability), the subtleties of social communication pose a particular challenge, since intuitive understanding of social meaning and intent is lacking. These subtleties include the full range of facial expressions, tone of voice, modulated eye gaze, interpersonal proximity, listening posture, and the appropriate use of informational and emphatic gestures to complement and/or highlight a specific verbal message. Conversational reciprocity is often overlooked by those with HFA/AS as they become engaged in formal presentations of factual information and data (unable to sustain mutually enjoyable social conversations).

Another factor that influences conversational flow and spontaneity is physiological



temperament, an individual's innate personality style. For example, adolescents and adults with HFA/AS who by nature are relatively easy-going, quiet, passive and even-tempered are unlikely to convey or demonstrate confusion and difficulty in following conversations. This can result in a false assumption by their conversational partners that they understood not only what was said but also the implied meanings underlying the message.

Peer Mentors Make a Difference

These aspects of social communication are specifically addressed in the social communication training groups. The approach includes the determination of expected verbal and nonverbal behaviors based on social contexts and contingencies, modeling,

role-playing, self-monitoring and feedback, as well as the analysis and interpretation of current media materials.

The addition of peer mentors to our groups has had a wonderful effect on group members, who have clearly benefited from the experience of interacting with and learning from their "neurotypical" peers (as one of the members often refers to them). Particularly enlightening for them has been recognition that other children experience many of the same struggles and challenges that they do. This understanding has increased their self-confidence, sense of kinship and interest in interacting with typically developing peers. When the peer mentors are present, students behave in a more socially appropriate manner and tend to refrain from exhibiting unwelcome or inappropriate behavior. For example, the group members become more aware of the effect that they have on others and resist the impulse to engage in lengthy discourse on topics of limited interest to their peers or to encroach on the personal space of others.

Graduate Students Learn Valuable Skills

During the past fall/winter semester, the Center hosted graduate students in

...continued on page 6

Social Communication Development for Life-Long Success

continued from page 1

When the group members were asked how they benefited from the sessions and related community homework assignments, they reported the following improvements:

- Describing one's personality using words other than "nice" by focusing on interests and leisure activities, clothing choices and preferred topics of conversation.
- Refraining from "judging a book by its cover" by making an effort to engage others in conversation and getting to know them before forming opinions and making judgments.
- Widening the range of topics that they discuss and reducing their tendency to concentrate on their specific areas of interest.
- Experiencing and demonstrating greater self-confidence during conversations.
- Tolerating a range of communication styles, including those that tend to distract or annoy them.
- Introducing themselves and starting conversations with girls/boys.
- Deciding which topics are appropriate and "safe" to introduce and which should be avoided (e.g., weight, complexion).
- Knowing the "rules" when talking to girls/boys.
- Respecting personal space.
- Giving compliments.
- Not sharing overly personal information that might cause someone to feel uncomfortable.
- Knowing what to say and do to show that you respect another person's opinion.
- Accepting the ideas of others.
- Agreeing to disagree.

A special thanks to participants for being honest and allowing the Center to share their thoughts through this newsletter.

Current Research Studies

The Center is proud to be part of The Greater New York Autism Research Center of Excellence (GNY-ARCE), in collaboration with the Seaver Center at Mt. Sinai School of Medicine. The GNY-ARCE is one of several national centers funded by the National Institutes of Health through the Studies to Advance Autism Research and Treatment (STAART) mechanism. The goals of the STAART network include the advancement of scientific knowledge regarding the causes, diagnosis, early detection, prevention and treatment of autism.

The Center is also collaborating with investigators in the Psychology Department of SUNY Stony Brook and those in The Feinstein Institute for Medical Research at North Shore-LIJ.

Most recently, the Center has teamed with researchers at Zucker Hillside Hospital and the Division of Developmental and Behavioral Pediatrics at Schneider Children's Hospital in conducting an innovative neuroimaging study that utilizes a newly developed, potentially fruitful technique (see below). The following studies are currently recruiting volunteers.

Neuroimaging Study (Diffusion Tensor MRI)

Help us learn more about autism. In an ongoing effort to identify the neurobiological features of autism, with the ultimate goal of developing effective treatment interventions, a research study of brain development and functioning is being conducted.

Who is eligible to participate?

- Children diagnosed with high-functioning autism or Asperger's syndrome
- Typically developing children to serve as normal controls
- Ages 7-17
- Able to undergo MRI scanning (e.g., no metal implants or braces)

What does participation involve?

- An autism screening and evaluation
- An MRI scan, which takes approximately one to one and a half hours
- Approximately five hours of participation in total, which can be completed in three visits



Several opportunities for you or your child to participate in research studies are provided through the Fay J. Lindner Center for Autism.

Compensation for participation is provided, and an MRI report and feedback on diagnostic and neuropsychological testing is included at no cost. For more information, please contact Carolyn McIlree at **516/718-470-4587** or cmcilree@nshs.edu.

Medication Study for Children with Autism, PDD-NOS and Asperger's Syndrome

Does your child:

- 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 so, your child may be eligible to participate in research conducted at the Fay J. Lindner Center for Autism and Developmental Disorders. This multi-site study is sponsored by the National Institutes of Health, and its purpose is to determine if treatment with the study medication is effective in improving children's functioning and decreasing their repetitive behaviors.

Participation in this study involves:

- A comprehensive diagnostic evaluation and cognitive assessment.
- Frequent visits with study psychiatrists and research staff to closely monitor participants and assess change.

- Taking study medication for 12 weeks, with the option of 16 weeks total if significant improvement is noted.

All of the above is provided at no charge, including all aspects of the evaluation and a summary report, monitoring visits and medication. For more information about this project, contact the study coordinator, Linda Spritzer, at **516-802-8608** or e-mail at Lspritze@nshs.edu.

Contextual Assessment Inventory for Families and Schools

In collaboration with Edward Carr, Ph.D., and Stony Brook University, researchers at the Center are developing a survey designed to measure context events for problem behavior. Context events are situations that trigger problem behavior or that put people in a bad mood, causing problem behavior as a result. Participants in this study are parents or adult family members of children with an autism spectrum disorder or mental retardation who display problem behavior. The family member can participate by completing a survey about the child's problem behavior. Participation helps us develop an instrument for designing interventions that reduce problem behavior and help facilitate success. In addition, after completing the survey, participants are invited to a

...continued on page 4

Adolescent Community Group – Skills Training

The adolescent community skills training groups meet weekly to learn and then practice social skills. Age-appropriate trained peer-mentors help group members by role modeling appropriate conversation, money management skills and coping skills. Community outings include traveling to restaurants, arcades, shopping malls, movie theaters and bowling lanes. Peer mentors have also invited group members to watch them on the football field and while practicing other sports including lacrosse and track.

In practicing these skills with peers, we carefully plan for generalization, which is a key issue for successful social skills training. Adolescents with an autism spectrum disorder have difficulty generalizing or performing a skill beyond the training session and maintaining the skill over time. The social skills training sessions allow for group members to practice and rehearse skills until adequate performance in natural environments is achieved.

During adolescence, it is essential that independence and self-sufficiency develop, since the availability and appropriateness of close adult supervision lessen. Our trained peer mentors help

group members achieve greater independence and self-confidence through support, modeling and constructive feedback across environments. Modeling and role-play exercises have focused on the following social tasks and activities: learning to play a school sport; shopping for athletic equipment; and participating in after-school events, such as dances and club meetings. These training and experiential activities also provide intrinsic rewards, including the development of new friendships.

For further information on community skills training, contact Anne Marie Swerz, LMSW, MA, at **516-802-8680** or mswerz@nshs.edu.



Practicum Graduate Student Josette Williams Shares Experiences

Having previously taken a class about autism through the University of St. John's Graduate Speech Pathology Program, I learned that a child diagnosed as having an Autism Spectrum Disorder (ASD)/PDD has a primary impairment in his or her ability to socially interact with others. With this "book" knowledge, I still took for granted the practical aspects of communication and how difficult it would be for those students to apply a given skill in real-time interactions. More specifically, I was unsure of what the term "social skills" actually meant to those diagnosed with high-functioning autism and Asperger's syndrome.

The practical part of communication about which I speak is the understanding of subtle cues and hints that tell us if a person is following and enjoying the conversation/interaction (facial expressions, commenting behavior, requesting additional information, body posture, etc.). This involves taking the perspective of another. Most children with ASD lack these skills. They are unsure of the communication process and potential benefits – to themselves and others – of such skills as introducing themselves, starting and ending a conversation, and understanding the feelings of others.

While receiving training and attending social skills groups, I have learned how to instruct students on ways to apply these skills with other group members and a similarly aged peer mentor. It seems illogical that children with autism can have average verbal and cognitive abilities yet remain unable to interact and communicate in a natural, intuitive manner without explicit training and modeling. The program has also made me more aware of my own behaviors: I now closely examine how I communicate with others, refrain from excessive use of figurative language (without explanations) and plan for future situations by anticipating the reactions and preferences of the current group members.

Current Research Studies

continued from page 3

small-group presentation to discuss the results and what may help in reducing problem behaviors in the future.

For more information, contact Linda Spritzer, research assistant, at **516-802-8608** or e-mail at Lspritze@nshs.edu.

Pitch Recognition in Autistic Spectrum Disorders (ASD)

Researchers at North Shore-LIJ Health System are conducting a research study of musical pitch or sound perception in families with children who have ASD. Participation is conducted by mail, Internet and telephone. You do not need any prior musical training to participate in this study. For more information, please contact Elena Kowalsky, study

coordinator, at **1-888-897-3098** or e-mail at ElenaK@nshs.edu. You can also write to Peter K. Gregersen, MD, Director, Center for Genomics and Human Genetics, Feinstein Institute for Medical Research, 350 Community Drive, Manhasset, NY 11030

Genetic Study

- Dense mapping of candidate regions linked to autistic disorders survey
- Survey of complementary and alternative treatments used by those with autism spectrum disorders

For more information about these studies, contact Linda Spritzer, research assistant, at **516-802-8608** or e-mail at Lspritze@nshs.edu.

Psychologist Shana Nichols, Ph.D., Joins Fay J. Lindner Center for Autism Team

I am excited to take this opportunity to introduce myself as the newest psychologist joining the multidisciplinary team at the Fay J. Lindner Center for Autism. I am looking forward to meeting and working with many of you, and I hope to hear from you if you want to learn more about me and the professional services I provide for youth and families.

My Background

Let me share with you a little about my background as I have come to New York from a number of different places, including your neighboring country to the north! I grew up in Ontario, Canada, and completed my doctoral training in clinical child psychology at Dalhousie University in Halifax, Nova Scotia. As the final stage of my doctoral training, I crossed the border, moved out west and completed an internship and post-doctoral fellowship at the University of Colorado at Denver and Health Sciences Center/JFK Partners Center for Autism and other Developmental Disorders.

During my two-and-a-half years at JFK Partners, I worked on a multidisciplinary autism and developmental disabilities diagnostic evaluation team, conducted social skills groups (e.g., teen groups, girls-only groups), provided individual therapy, ran parent groups related to puberty/sexuality and adolescent issues, and conducted clinical research as part of our Autism and Developmental Disorders Research Group.

It was an exciting time in my career development and has played an important role in shaping my current interests in the field.

Current Professional Focus

In February 2006, I moved with my family to Long Island and was thrilled to accept a position as psychologist at the Fay J. Lindner Center for Autism. I will be working as part of the interdisciplinary diagnostic assessment team in addition to expanding and developing clinical programs and writing grants for clinical research projects and service delivery programs at our center, in the schools and community.

When I first started working 10 years ago in the field of autism spectrum disorders, I was an undergraduate student doing home-based preschool intensive behavioral programming. More recently since my time in Colorado, I have seen a need for professionals and parents to work together toward future planning, including addressing adolescent issues, further development of social/relationship skills, coping with puberty and developing safe and healthy sexuality, transition planning (e.g., to middle school, high school and adulthood), and focusing on mental health and self-concept/esteem development.

Together with my colleagues in Colorado, and in independent work, I have developed interests which I hope to continue to expand while working with our team and

families at the Fay J. Lindner Center for Autism and with other professionals statewide, nationally and internationally. Some of these interests include:

- Helping families and youth with the transition to adolescence, including coping with puberty and developing health/sexuality, particularly social skill development which is a key foundation of healthy sexuality.
- Working with our team at the Fay J. Lindner Center for Autism to continue to develop evidence-based social skills programming that emphasizes the critical role played by typically developing peers (e.g., peer mentoring) and generalization of skills into community and school settings.
- Treating anxiety disorders in individuals with autism spectrum disorders using an adapted cognitive-behavioral approach to therapy.
- Working with families of girls diagnosed with an autism spectrum disorder to understand better the potentially unique clinical profile for females on the autism spectrum and to help families address issues specifically relevant for their daughters.
- Developing strategies and programs for effective transition planning from middle school to high school and toward adult life.

Adolescence and the transition to adulthood can be a difficult period for individuals with autism spectrum disorders and their parents, and yet issues related to negotiating developmental transitions and the biological processes associated with growing up have generally been neglected in the field. Together with my colleagues at the Fay J. Lindner Center for Autism, I hope to be able to develop and evaluate programs and conduct research to help parents and professionals work together to promote healthy development and successfully navigate life during adolescence and beyond.

The team at the Fay J. Lindner Center for Autism is caring, innovative, inspiring and energetic, and I am delighted to have come aboard.

Learn More about Growing Up on the Autism Spectrum

In continuing work that began in Colorado, Shana Nichols, Ph.D., licensed clinical psychologist, will be hosting some parent focus groups to find out more about parents' concerns and hopes regarding their children's adolescent development (particularly puberty, sexuality and social skills).

She is also applying for grant funding to continue to develop her Colorado-funded parent education and skill-building group curriculum. This is the first study to evaluate the effectiveness of a group-based parent curriculum designed to:

- Increase parents' sense of competence and comfort level in teaching their children about sexuality and relationships.
- Reduce stress reported by parents regarding issues related to puberty and growing up.
- Facilitate implementation of teaching goals and behavior management approaches related to sexuality.

Please call the Center for Autism at **516-802-8600** to learn more about these parent groups.

Focus on Autism

www.northshorelij.com/autism

INSIDE:

Social Communication Development
for Life-Long Success.....Pg 1



Social Communication
Training Update.....Pg 2

Research StudiesPg 3

Adolescent Community Group –
Skills Training.....Pg 4



Psychologist Joins
Fay J. Linder Center for
Autism Team.....Pg 5

...Training Groups Update *continued from page 2*

speech/language pathology from several local universities, including St. John's, Adelphi, Hofstra and Long Island (CW Post Campus) Universities. The students participated in the language-based social skills groups for the purpose of learning about the practical implications of semantic-pragmatic communication impairments and receiving training in teaching strategies that are beneficial in promoting social communication among children with autism spectrum disorders. This experience will enhance the graduate students' ability to incorporate social skills training interventions into their speech/language therapy for children with ASD following graduation from their master's level programs.

It truly has been a pleasure to welcome both graduate students and peer mentors to our training groups. The Center's professional staff and social skills group participants extend a special thanks to the students for their hard work and dedication while participating in our groups. The best reward is to see our group members enter the room with a smile and an exclamation of "I'm here!" The greatest compliment we can receive is when parents tell us that their children speak excitedly about the group and look forward to having fun and "hanging out" with group friends, especially when they have not experienced social success in the past.

This publication does not constitute professional medical advice. Although it is intended to be accurate, neither the publisher nor any other party assumes liability for loss or damage due to reliance on this material. If you have a medical question, consult your medical professional. ©2006 North Shore-Long Island Jewish Health System.

Fay J. Lindner Center for Autism and Developmental Disorders • 4300 Hempstead Turnpike • Bethpage, NY 11714