

MENTAL HEALTH NEWS™

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SUMMER 2006 FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE VOL. 8 NO. 3

Understanding and Treating Autism Spectrum Disorders

National Institute
of Mental Health (NIMH)

Not until the middle of the twentieth century was there a name for a disorder that now appears to affect an estimated one of every five hundred children, a disorder that causes disruption in families and unfulfilled lives for many children. In 1943 Dr. Leo Kanner of the Johns Hopkins Hospital studied a group of 11 children and introduced the label early infantile autism into the English language. At the same time a German scientist, Dr. Hans Asperger, described a milder form of the disorder that became known as Asperger syndrome. Thus these two disorders were described and are today listed in the Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR (fourth edition, text revision) as two of the five pervasive developmental disorders (PDD), more often referred to today as autism spectrum disorders (ASD). All these disorders are characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotyped patterns of behavior.

The autism spectrum disorders can often



be reliably detected by the age of 3 years, and in some cases as early as 18 months. Studies suggest that many children eventually may be accurately identified by the age of 1 year or even younger. The appearance of any of the warning signs of ASD is reason to have a child evaluated by a professional specializing in these disorders.

Parents are usually the first to notice

unusual behaviors in their child. In some cases, the baby seemed "different" from birth, unresponsive to people or focusing intently on one item for long periods of time. The first signs of an ASD can also appear in children who seem to have been developing normally. When an engaging, babbling toddler suddenly becomes silent, withdrawn, self-abusive, or indifferent to

social overtures, something is wrong. Research has shown that parents are usually correct about noticing developmental problems, although they may not realize the specific nature or degree of the problem.

The pervasive developmental disorders, or autism spectrum disorders, range from a severe form, called autistic disorder, to a milder form, Asperger syndrome. If a child has symptoms of either of these disorders, but does not meet the specific criteria for either, the diagnosis is called pervasive developmental disorder not otherwise specified (PDD-NOS). Other rare, very severe disorders that are included in the autism spectrum disorders are Rett syndrome and childhood disintegrative disorder.

What Are
The Autism Spectrum Disorders?

What are the Autism Spectrum Disorders? The autism spectrum disorders are more common in the pediatric population than are some better known disorders such as diabetes, spinal bifida, or Down syndrome. Prevalence studies have been done in several states and also in the

see *NIMH Reviews ASD* on page 32

In Our House: This is Aspergers

By Debra Bloomgarden
Mother of an Asperger's Child

I asked, "What do you think this is?" The psychologist-evaluator from our school district's Committee for Pre-school Special Education (CPSE) had just finished telling me that my recently turned three year old daughter was an obviously bright little girl who also had her challenges.

"Some kind of learning disability?" I offered.

She shook her head. "I think this is Asperger's," she said slowly, and peered at me to see the effect of her words.

Asperger's. Well, I had heard of it, but my mind raced, trying to remember what I'd heard.

She watched me as I looked over at my daughter watching a video while we talked at the dining room table. "What are you feeling right now?" she asked.

"Mostly, relief that you didn't tell me there was nothing going on," I told her quietly.

For most of my daughter's life, my husband and I had been quietly asking people—our parents, other parents, our pediatrician—didn't they think there was something different about our child? And most of them looked at us with unbelieving eyes and just chuckled and said, "well, she's very bright."

And then the psychologist was handing me her card and telling me to call if there was anything she could do and a moment later, she was gone.

In one week, my husband and I were going to sit down with the CPSE and advocate for services for our daughter. What exactly was Asperger's and what should we be asking for? There followed a mostly sleepless week of taking care of my daughter through her seemingly endless meltdowns, reading the OASIS book* cover to cover, haunting the parenting

sections of the bookstores, pouring through websites, and making phone calls. There were some things that were somewhat familiar but other things that were harder to understand. We asked more questions.

Asperger's at three years old? The reaction was unanimous – wow, she's awfully young to be diagnosed with asperger's. Are you sure?

But after lots and lots of reading and talking, and lots of evenings in support groups and several trips down to the city to the Columbia University Developmental Neuropsychiatry Unit** for evaluation by a team of "experts," Asperger's Syndrome is now a part of our lives.

Routine. When things are routine and predictable, life can go fairly smoothly. School days can be routine. Weekends and vacation days are never routine.

Meltdowns are not tantrums, they are "overflow." Our child's life is too tough and her whole world is dissolving—

usually very noisily. And on "toast days," nothing helps—the meltdowns just wash over in waves—when something as simple as the butter melting in the "wrong pattern" on the toast becomes the domino that falls.

My daughter's photo from the first day of school this year shows a smiling, curly headed blonde beauty, dressed in sweatpants with a t-shirt that has a picture of a snarling, toothy, very scary reptile. She will only wear scary shirts to school—scary reptiles, amphibians, dinosaurs or insects. And she knows science facts about them, forward and backward.

We leave the house in predictable ways, mostly because mom uses a wheelchair and there is only one doorway out of our apartment building that is easily wheelchair accessible. Well, that and the fact that my daughter will usually be hiding under a coat or book to get out the

see *In Our House* on page 15

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**“Hope is a good thing.
Maybe the best of things.
And a good thing never dies.”**

**Spoken by Andy Dufresne
From the Movie
The Shawshank Redemption**

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From The Publisher

The Courageous Parents of Children with ASD: Rewriting the History of An Illness

By Ira H. Minot, LMSW, Founder and Publisher, Mental Health News

While preparing this issue of Mental Health News, devoted to Understanding and Treating Autism Spectrum Disorders, I am again reminded of the vital and courageous role parents play in the mental health community. Certainly, across the entire range of illnesses from depression to schizophrenia, to bipolar disorder, and other illnesses, parents and families have had a dramatic impact on the progress in how mental illnesses are perceived by society, increasing levels of private and government sponsored research, and on the efficacious and humane care and treatment of patients.

In the case of autism spectrum disorders (ASD's), the history of this illness has again seen dramatic changes due to the voices and advocacy efforts of involved parents and families. The National Alliance for Autism Research (NAAR), on their internet site www.naar.org, sheds light on early ideas about ASD—excerpts of which I would like to share with you.

“Throughout history, people have probably lived with what we know today as autism spectrum disorders. Some of the earliest published descriptions of behavior that resemble autism date back to the 18th century. In 1911, noted Swiss psychiatrist Eugen Bleuler, introduced the term autism to describe an individual's exclusion of the outside world and virtual withdrawal from social life. Autism was first described as a specific condition by Dr. Leo Kanner, of Baltimore, Md., who published his famous paper on the disorder in 1943. In 1944, Dr. Hans Asperger, of Vienna, Austria, published another famous paper that first described a similar condition that later became known as Asperger Syndrome. In the 1950s and 1960s, the medical community generally incorrectly believed autism was a psychological disturbance caused by detached, or uncaring mothers (refrigerator mothers). This belief, later completely disproven, was based on the observations and opinions of Dr. Bruno Bettelheim, one of the first child development specialists to focus on autism. For decades, generations of mothers of children with autism were unfairly accused of causing their child's disorder. In 1964, Dr. Rimland provided a definitive review of evidence that established autism as a biological condition, thus demonstrating Bettelheim's theory was wrong. Dr. Andreas Rett first described Rett Syndrome as a specific condition in 1966, and in 1977, Dr. Susan Folstein and Dr. Michael Rutter published the first autism twin study, which revealed evidence of a genetic basis for autism.”

Autism, like schizophrenia and other mental illnesses, were first interpreted incorrectly and harmfully as conditions that were caused by bad parenting, cold



Ira H. Minot, LMSW

mothers and absent fathers by psychoanalyst's and others of the day.

Over the years, and through grassroots efforts in communities across the nation, parents and families have united and have rewritten the history of ASD and other mental illnesses. A case in point is described in an article in this issue (page 8) entitled, *MHA in Orange County: A Caring Place for the Autism Community*. In her article, Anne Klingner describes how 15 years ago, at the insistence of one parent, a support group for ASD parents was formed. Today, MHA in Orange County has become a focal point for many families who help raise awareness and provide mutual support to one another.

In our NewsDesk section (page 6), we report on how the National Institute of Health (NIH) is partnering with volunteer organizations: Cure Autism Now (CAN), the National Alliance for Autism Research (NAAR), and the Southwest Autism Research & Resource Center (SARRC), to fund research into finding Autism Susceptibility Genes.

In my own hometown of Westchester County, New York (page 9), we learn that under the leadership of Dr. Jennifer Schaffer, Commissioner of the County's Department of Community Mental Health, a new “Speaking Out About Autism” website has been created to help families dealing with autism. In addition, County Executive Andy Spano is rallying fellow county executives from across the nation to support the “Combating Autism Act of 2005,” a bill which would authorize \$1 billion over the next five years to combat autism through research, screening, intervention and education efforts.

More grassroots voices can be heard in a piece by Bonnie Kaplan & Judy Omidvaran (page 10) who tell us about a support group they formed for parents of high functioning adults on the autism spectrum. I want to give a special thanks to Judy Omidvaran, who volunteered her

time to reach out to the autism community about our efforts to put this special autism issue together. Thanks to Judy and others, we are fortunate to feature many wonderful articles from parents, clinicians and autism organizations alike whose works are too many to mention individually.

An ardent supporter of Mental Health News, Connie Lieber, President of NARSAD, The National Alliance for Research on Schizophrenia and Depression, gives us an inspiring report on NARSAD Research in Autism (page 14). In 19 years NARSAD has awarded \$194.5 million to fund 2,901 grants to 2,264 scientists at 340 universities and medical research institutions worldwide—knowing that the cure for any one brain disorder may come from research in another.

Add this together with our wonderful family of public and private mental health agency supporters from our region—the heartbeat of Mental Health News, the dedicated authors of our regular columns and our growing list of advertising supporters, I hope you will find this issue to be a wonderful contribution to our mission of providing vital mental health education to the community.

Thanks to the courage and outspoken voices of parents and families, the cause to

improve the lives of people with mental illness continues. As reported in this issue's NAMI-NYS Corner column (page 18) by David Seay, Esq., Executive Director, “Family services are still too few and far between in New York State...Many gaps exist in the kinds of help that are offered, and there is no systematic means to provide that help according to individual family needs. Families have strengths that should be developed, weaknesses that should be mitigated, needs that should be met and limits that, once they have been reached, require someone else to take over. They are often “secondary consumers” as well as primary providers of care. They should be able to participate in an integrated system that takes these facts into account and provides services accordingly.”

With your continued support of our community education mission, we will not cease to bring vital issues that impact the lives of people with mental illness to the forefront. Please continue to send me your comments and suggestions to my E-mailbox at mhnmail@aol.com.

Good luck in your own recovery and NEVER give up trying.
Have a Wonderful Summer!!

Mental Health News **Upcoming Themes & Deadline Dates** *~ mark your calendar ~*

Fall 2006 Issue:

“The Psychological Dimensions Of Physical Illness”

Deadline: August 1, 2006

Winter 2007 Issue:

“Managing Life Transitions”

Deadline: November 1, 2006

Spring 2007 Issue: “Who Will Help?”

“The Challenge Of The Mental Health Workforce”

Deadline: February 1, 2007

Summer 2007 Issue:

Child and Adolescent Mental Health

Deadline: May 1, 2007

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In our Spring issue, we mistakenly listed Dr. Peter Campanelli as Executive Director of The Coalition of Voluntary Mental Health Agencies in the Coalition's Ad. Phillip Saperia is Executive Director of The Coalition, and we apologize for this error.

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MENTAL HEALTH NEWSDESK

NIH Joined by Advocacy Groups To Fund Research on Autism Susceptibility Genes

**National Institute
of Mental Health (NIMH)**

Five institutes at the National Institutes of Health (NIH) and three private autism organizations have formed a consortium to pursue their common goal of understanding a devastating disorder. This public-private partnership has funded five grants representing three projects to identify genes that may contribute to the development of autism and Autism Spectrum Disorders. The National Institute of Mental Health will administer the \$10.8 million awards over the next five years.

The participating NIH institutes are The National Institute of Child Health and Human Development (NICHD), The National Institute on Deafness and Other Communication Disorders (NIDCD), The National Institute of Environmental Health Sciences (NIEHS), The National Institute of Mental Health (NIMH), and The National Institute of Neurological Disorders and Stroke (NINDS). The voluntary organizations contributing funds are Cure Autism Now (CAN), National



Thomas R. Insel, MD

Alliance for Autism Research (NAAR), and the Southwest Autism Research & Resource Center (SARRC).

Autism is a neurodevelopmental disorder

that causes severe and pervasive impairment in thinking, feeling, language, and the ability to relate to others. In an average year, one to six new cases of autism arise per 1,000 children. Experts believe that as high as 90 percent of the variance in the disorder is due to hereditary factors, and research suggests a strong interaction between environmental factors and multiple unknown genes. As researchers gain a better understanding of the genes responsible for autism, they may be better able to distinguish between the different variants of the disorder and to develop targeted therapies and interventions to treat them.

"This initiative seeks to expand our knowledge of the genetic factors involved in this disorder that affects so many families," said NIMH Director Thomas R. Insel, MD. "New technologies in gene research can allow scientists to better understand the role genes play in the development of autism, and eventually lead to better treatments."

Five grants have been awarded to three teams of investigators:

- A three-site collaborative project, involving Rutgers University, the University of Medicine and Dentistry of New Jersey, the Robert Wood Johnson Medical School, and University of Iowa, for a project titled "Identification and Functional Assessment of Autism Susceptibility Genes" with investigators Linda Brzustowicz, M.D., James Millonig, Ph.D., and Veronica Vieland, Ph.D., respectively.

- Cold Spring Harbor Laboratory for a project entitled, "Determining the Genetic Basis of Autism by High-Resolution Analysis of Copy Number," directed by Jonathan Sebat, Ph.D.

- Emory University, for a project entitled, "Identifying Autism Susceptibility Genes by High-Throughput Chip Resequencing," directed by Michael Zwick, Ph.D.

The three-site collaborative project uses novel statistical methods, fine mapping of candidate regions across the genome, and animal models in the search for autism susceptibility genes.

Cold Spring Harbor Laboratory's proposal also is highly innovative, capitalizing

see Genes on page 37

Bronx Mental Health Court In National Learning Initiative

**Staff Writer
Mental Health News**

The Bronx Mental Health Court TASC (Treatment Alternatives to Safer Communities) has been selected as one of five national learning sites to participate in a new Mental Health Courts Learning Sites Initiative, a project of the U.D. Department of Justice, Office of Justice Programs' Bureau of Justice Assistance (BJA).

State and local officials considering whether to establish mental health courts in their jurisdictions, as well as those who have recently launched mental health courts, often seek out more experienced courts for guidance and advice. As one of the five learning sites, the Bronx mental health court will provide other jurisdictions with opportunities to observe operating and sustainable mental health courts; and showcase strategies for solving problems that mental health courts typically confront.

Sharon E. Carpinello, RN, PhD, Commissioner of the New York State Office of Mental Health said, "The Bronx Mental Health Court's designation as a national learning site recognizes the court's demonstrated excellence in responding to individuals with a mental illness who are involved in the criminal justice system.

This new role positions the Bronx Mental Health Court as a national leader in the field."

Assemblyman Peter M. Rivera, chair of the New York State Assembly Standing Committee on Mental Health, Mental Retardation and Developmental Disabilities, said, "The technical assistance that will be provided by the Bronx Mental Health Court is a tremendous resource that will allow for the effective and safe alternatives to incarceration for special populations coming before these types of courts. This is excellent news that places the Bronx efforts on this issue as a national model to be emulated. This is a tremendous accomplishment."

The Honorable John Collins, Administrative Judge of Bronx Supreme Court, Criminal Division, who presides over the Bronx Mental Health Court, said, "I am proud that Bronx Supreme Court, in partnership with the Bronx District Attorney's office, initiated one of the first mental health courts in New York State. I appreciate the services this innovative approach provides to the community, and share in individual success stories of these mentally ill defendants."

The Bronx Mental Health Court targets for diversion adult offenders with co-occurring alcohol drug and mental health

see Court on page 37

Pappas New EVP & COO At Institute for Community Living

**Staff Writer
Mental Health News**

The Institute for Community Living (ICL), one of New York City's premier mental health, multi-service agencies, has announced the appointment of Stella Pappas, LCSW, ACSW as its new Executive Vice President and Chief Operating Officer. The announcement was made by Dr. Peter Campanelli, President and CEO of ICL who stated, "Stella Pappas has been a key element of our administration for the past 6 years, and we are indeed fortunate to have her bring her many years of experience in the mental health field to her new position at ICL."

For the past three years, Pappas has been the Senior Vice President of ICL's Child, Family and Community Support Division, and was instrumental in leading ICL's response to the 9/11 tragedy and Project Liberty programs for the Brooklyn and Manhattan communities. Prior to coming to ICL, she was with the Staten Island Mental Health Society and Brookdale Hospital Medical Center in Brooklyn, New York.

According to Ms. Pappas, "I look forward to helping to provide growth, strategic planning and continued clinical excellence and ethical standards in my new



Stella Pappas, LCSW, ACSW

administrative role here at the Institute for Community Living."

The Institute for Community Living serves over 5,000 disabled adults, children and families each year through an array of services including housing, a unique family reunification program as an alternative to foster care; mental health and healthcare clinics.

Sometimes you can't go it alone...

When someone suffers from depression or a problem with drugs or alcohol, taking the first step toward feeling better can be the toughest part. For more than 125 years, St. Vincent's Westchester has provided compassionate care for many thousands of people dealing with mental health and chemical dependency problems. The hospital offers a complete range of behavioral health services, including:

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MHA in Orange County: A Caring Place for the Autism Community

By Anne Klingner, CAPIS Coordinator
MHA in Orange County

Researchers, physicians, scientists, biologists, mental health professionals and geneticists have been studying Autism Spectrum Disorders (ASD's) for many years, yet much about these illnesses remains a mystery. As program coordinator at the Mental Health Association in Orange County, New York (MHA), I have had the challenge and privilege to understand and provide support to families living with ASD's. I am the one parents are referred to when they suspect their child might have a spectrum disorder; who parents call when they are thinking of moving to Orange County and want to find out if there are appropriate services available for their child; and am the one with a file box full of listings of dentists, eye doctors and other specialists who are able to work with and treat children and adults with ASD's. I owe much of my knowledge and skills to the parents of children with Autism here in our county.

Back in the late 80's when Autism was still a considerably rare diagnosis among the families whose children were developmentally disabled, a few families contacted Crisis Assessment, Prevention and Intervention Services (CAPIS) at MHA in Orange County. A crisis intervention program funded through the New York State Office of Mental Retardation and Developmental Disabilities, CAPIS was facilitating a support group for parents of young children with developmental disabilities and some parents of children who had diagnoses or needs similar to children with Autism. It was a time when doctors were more reluctant to make the diagnosis of Autism for very young children and might say the diagnosis was "mental retardation with autistic tendencies".

At the urging of a parent from Orange



County, the CAPIS coordinator started a group for parents of children with Autism, and thru word of mouth and publicity, a successful support group was formed and has been in existence for over 15 years. Guest speakers to the support group and full day symposiums focusing on topics in Autism are today a reality. Parents form strong bonds within the group, supporting each other during difficult times. Personal and informal relationships are fostered and families gather outside the support group format as well. Families not involved in the group are even linked with others in similar situations making a rich fabric for the community. The CAPIS program now facilitates four groups for parents of children on the spectrum.

Support group attendees tend to be parents who already have resources and information but are looking to expand their horizons, gain more information, network with parents in similar situations and find social outlets for their children. Sharing information about treatment mo-

dalities, school issues, advocacy techniques, behavior tips and more is an integral part of the meetings. The facilitator listens, gathers information and keeps the discussion flowing. MHA has become a safe place for parents to vent, share, exalt, celebrate and cry.

To additionally support the parents, CAPIS keeps a very current lending library of books on therapies, special diets, the DAN (Defeat Autism Now) protocol, behavior issues, sibling issues and more. Periodicals are also available at CAPIS including: *Exceptional Parent Magazine*, *Autism/Asperger Digest*, *Spectrum*, *The Advocate* and the *Autism Research Review International*, from which articles are copied and shared at meetings. At each meeting, flyers and brochures of upcoming events of interest are disseminated to keep families up to date on conferences, training opportunities, information fairs and more.

Every year parents from Orange County travel to neighboring Dutchess

and Westchester County, New Jersey and beyond to participate in conferences, and fundraising events. Parents now help organize our own annual *Move-a-Thon* event here in Orange County which are a big success, three years running.

They meet once a month from January to August and once a week from late August until the October event. They do it by researching vendors from home, writing press releases and creating flyers on their own computers. They do it by canvassing community businesses for donations, recruiting family, friends and neighbors. They do it by e-mail and telephone when they can't get out because of child care issues and family responsibilities. They do it by themselves, in pairs and in groups. They do it with enthusiasm, creativity, passion and drive.

Funds raised from the Move-a-Thon's have gone to *Unlocking Autism*, *Autism Research International* and the *Access to Money (AMOC) Reimbursement Program* of MHA. Over 110 families have received stipends of \$100 dollars for the individual in their family who has autism and \$100 for parent education and training and raising awareness, understanding and acceptance of autism spectrum disorders in Orange County.

MHA in Orange County provides families with information, support, resources and a safe place to learn all that they can, and parents have taught the MHA staff about their needs and in helping them find the best services and support for themselves and their children. MHA provides additional services to families including Medicaid Service Coordination, Residential Habilitation, respite and a monthly Super Sibling meeting. □

For information about services for families of individuals on the Autism spectrum or with other developmental disabilities living in Orange County, New York, call CAPIS at (845) 294-7411 ext. 253/254 or go to www.mhaorangenyny.com.

Finding A Voice for My Son

By Lisa Currao
Orange County, NY

In the children's book *Trumpet of the Swan* by E.B. White, the father swan exclaims when he finds out his son is mute, "I must find my son a voice." This is what parents of children with autism struggle to do every day of their lives.

Currently, the Center for Disease Control places the autism rate at 1 in 166 children. Autism is defined as a complex developmental disability that usually appears during the first 3 years of life. It impacts the normal development of the brain, especially in the areas of social interaction, verbal and non-verbal communication, and play activities. It is a life-long disability with no known cure. In the United States over one half million individuals live with autism making it more prevalent than Down's syndrome,

juvenile diabetes, and childhood cancer combined.

I am a parent of one of those 1 in 166 children. His name is Brendan and he is 4 1/2 years of age. Brendan has 2 brothers, Bryan age 7 and Kieran age 18 months. Brendan receives close to 30 hours of therapy a week. This includes speech, occupational therapy, physical therapy and special education services.

Autism is called a pervasive developmental disorder for good reason. Not only does it affect many aspects of a child's life but it seeps into all aspects of a family's life. It changes the way you look at the world. I no longer take for granted the smiles, eye contact and waves my 18 month old can do or the conversations I have with my older son because I am still waiting for Brendan to master those skills.

One of the most frustrating things about autism is how difficult it is to get the simplest of tasks done. Much thought needs to go into helping the child with autism navi-

gate through his environment. Venturing out of the house to go to the store, attend a birthday party, or participate in a family gathering can be very daunting tasks for the parent as well as the child.

As a family, you spend a tremendous amount of time working on skills your child with autism needs to learn. This includes setting up situations to encourage language, taking him places to develop social skills and working on many self-help skills to make him as independent as possible. The family also needs to educate friends and extended family about the disability and help facilitate relationships with these people.

Children that are affected with autism exhibit a wide range of challenges as well as abilities. This diversity within this disability makes it necessary to offer a wide range of educational programming. However, in this county, we, as parents, have very limited choices in picking the most appropriate educational program-

ming for our child. As a result, many children have to travel outside the county for an appropriate education. There bus ride can be over a hour each way. These are Orange County's children and we need to begin offering a wider array of programming here in the county.

Currently, the Mental Health Association of Orange County provides invaluable support to many families who have a child with autism. In addition, they collaborated with a parent group called, Parents Run AMOC to sponsor the Autism Move-a-thon of Orange County and a Bowl-a-thon. These 2 fundraisers help us to raise awareness about the disability and provide support to many families.

In closing, I would like you to remember that what we consider routine with our typically developing children requires great effort and is considered a tremendous feat for the child with autism. It is imperative that we join together as a community and help them find their voice. □

Westchester County Speaks Out About Autism

Staff Writer
Mental Health News

In recognition of April being declared national Autism Awareness Month Westchester County launched a special campaign to educate the community about this growing developmental disability. The Foundation for Educating Children with Autism (FECA) and local families gathered on Monday, April 3, with County Executive Andy Spano and school officials to unveil a new website and call for more funding for the fastest-growing serious developmental disability in the U.S.

The event was held at the Devereux Millwood Learning Center (DMLC) for autistic children in Millwood.

To help kick off Autism Awareness Month, Spano sent a letter asking county executives across the nation to push for the passage of landmark legislation that would expand the federal response to autism, a developmental disorder that affects a person's ability to communicate and relate to others. He also announced a new website by the Westchester County Office of Community Mental Health dedicated to autism-related programs.

Parents are increasingly concerned because autism is on the rise -- with 1 in 166 children diagnosed today compared to 1 in



John O'Keefe, Devereux NY; Constance Dena Saxe, DMLC; Phil Orlando, FECA (back); Matthew Harris, Autism Speaks Club; Andrew Spano, Westchester County Executive; Ann DiChiara, FECA.

10,000 just 13 years ago. The disorder is more common than pediatric cancer, diabetes, and AIDS combined and ranks the second most common developmental disability next to mental retardation.

The bill Spano is supporting -- the Combating Autism Act of 2005 -- would authorize \$1 billion over the next five years to combat autism through research,

screening, intervention and education efforts, in effect doubling the current National Institute of Health's (NIH) autism funding. Information regarding this bill can be found www.westchestergov.com/mentalhealth.

Spano stressed the tremendous need for more funding and services. "Nobody knows what causes autism and there is no

cure anywhere on the horizon," he said. "Many of these families are on their own and coping with a life-long disability that requires special educational programs and additional support services. We want to let people know there are resources out there -- early intervention programs, family groups and support organizations." Spano noted that autism costs the nation over \$90 billion per year, a figure expected to double in the next decade, and receives less than 5% of the research funding of many less prevalent childhood diseases.

Dr. Jennifer Schaffer, the county's mental health commissioner, highlighted the "Speaking Out About Autism" site newly created to help families dealing with autism. The site, at www.westchestergov.com/mentalhealth, provides information on what autism is, addresses causes and treatment, summarizes the programs and services available, and includes a list of helpful resources. The Department of Community Mental Health collaborated with the Department of Health to ensure a comprehensive listing of services for children five and under. Early diagnosis and early intervention is crucial to helping children maximize their full potential.

For more information please call the Department of Community Mental Health (914) 995-5220. □

Using Therapeutic Socialization with Autistic Children

By Nancy Swanberg, MS, LMHC
The Friendship Network for Children

The emotional wellbeing of any child relies on authentic connections with others, and so it is for children on the autism spectrum. Yet by definition, these children have socialization and connection challenges. Typical interventions include repetition and rote memorization to "teach" socialization skills and manners. While this approach has varying success, we have to ask: Does this lead to authentic social connections?

As founder and Executive Director of The Friendship Network for Children, I have seen firsthand the isolation of children with social learning disabilities. Because they are unable to identify and express feelings in a meaningful way -- in a way that is meaningful to those around them -- their typical day is often a series of traumatic misunderstandings. All too often we try to "fix" these children instead of understanding them, as if we can help them be truly happy simply by training them to act the part.

At the Friendship Network our mission is to dig a little deeper, bringing psychotherapy to the table when addressing socialization. We build a "therapeutic bridge" that maximizes opportunities for self-understanding and expression while minimizing confusion and anxiety. In short, we put the child's happiness first, and let everything else fall into place.



Nancy Swanberg, MS, LMHC

How does a therapeutic approach to socialization work? We start by understanding how the child's neurological difficulties impact their view of the world. A short list of these difficulties includes pragmatic language problems, theory of mind deficits (inability to see from another's point of view), literal thinking, sensory integration issues, thinking in parts (not seeing the forest for the trees), missing social cues, and an inability to determine expectations. Can you imagine how challenging it is for a child with

these difficulties to navigate the social world that others take for granted? Daily confusion and disorientation gives rise to environmental anxiety and stress, and long-term stress has a negative impact on mental health. Given the potential for such a vicious cycle, it behooves us to get to know each child's world.

So we begin by addressing the child's anxiety with understanding and imagination. Our initial therapeutic message is: "You are fine just the way you are. Nobody is trying to change you or fix you." The clinician first meets the children individually, and learns to see the world from each child's perspective. This is almost like being a detective, looking for clues and insights in the child's behavior. Socialization groups of two to five children are then planned from this viewpoint.

The groups use creative activities to make socialization fun and desirable. We nurture authentic relationships by playing to each child's strengths. Rather than use a standard curriculum, each group is developed with the children's personalities and characteristics in mind. Every opportunity for an authentic connection is utilized by the clinicians, and because the activities fit the children's interests, the group social experience has special meaning that can carry over into other areas of their lives.

The following case illustrates the therapeutic socialization approach. Sara is a fourteen-year-old girl with high-functioning autism. She responds well to

visual schedules, therefore a visual schedule is used for each group. She has a difficult time sitting still, so she is allowed to stand without permission. Her favorite music was used in one of the sessions. Of course, similar consideration was given to the other group members as well.

All the children had anxiety about attending parties, so we built on previous successes, incorporating familiar and fun activities from earlier sessions into a successful group pizza party. Then came Sara's birthday, which happened to fall on a group day. By prior arrangement, Sara's parents brought a cake for the session. Sara does not like to be the center of attention, yet she was comfortable enough to allow the other children to sing "Happy Birthday" -- another child's idea, and a touching moment of true connection. As it turns out, this was Sara's first birthday party with friends. Her parents explained she had never wanted a party before, and that nobody outside the family had ever sung "Happy Birthday" to her.

Cases like this are very rewarding, and not atypical at the Friendship Network. It shows that social experiences can indeed be made accessible to children with an autism spectrum disorder, and that these special individuals can form friendships and enjoy such simple yet important everyday events.

The Friendship Network for Children is a nonprofit agency located in Northborough, MA and has a website at www.networkforchildren.org. □

Social Skills Training for Children with Asperger's Disorder

By Jo Hariton, PhD, Clinical Social Worker and Coordinator, Social Skills Program for Children and Adolescents, New York Presbyterian Hospital Westchester Division

Since the Social Skills Program for Children and Adolescents began in 1995, at New York Presbyterian Hospital, Westchester Division, there has been a steady increase in the number of children and adolescents referred who have Asperger's Disorder. Serious social difficulties and circumscribed interests characterize Asperger's Disorder. In addition there are no clinically significant delays in language or cognitive development and it is considered a high functioning autistic spectrum disorder.

These children and adolescents with significant impairment in social functioning can benefit enormously from social skills group therapy, which is the focus of the Social Skills Program. They learn friendship skills in the group and then can practice the skills with others who have similar problems. The program serves children from preschool through high school.

Although some schools in the community have also developed social skills groups, the need for services of this kind for children on the spectrum far exceeds the number of groups available. NYPH has filled a "niche" in this area. In fact, many of these children supplement the services they already receive in their schools with specialized help from this program.

Children who have a need for help in the development of social skills are not limited to those with Asperger's, and in fact the Social Skills Program benefits those who may have other diagnoses as well, such as anxiety disorders, learning disabilities, mood disorders, or ADHD. A common denominator for all of the children is a wish to do better with their peers.

It is a mistake to believe that the children with Asperger's do not have an interest in making friends. As Coordinator of the program I find that many of these chil-



Jo Hariton, PhD

dren are often lonely, and shy away from reaching out to their peers, in part because of past experiences that have left them feeling rejected and isolated. Sometimes they have not had the opportunity to meet others like themselves who may have similar interests. By learning ways to communicate better and pick up the nuances of social cues they become better able to feel that they belong.

The Social Skills Program tends to have between 16 - 18 groups during the school year. The groups run at after school times. There are generally 12 sessions in each group cycle. Most of the families utilizing the program continue to send their children for repeated cycles of the program. Since social skills are seen as the primary area of need for those with Asperger's Disorder, it is not unusual for families to continue to attend the program for several years. Families and children want support and receive it in this program.

We are now receiving referrals for the summer session. This is an abbreviated cycle of 7 sessions. Sessions for the summer cycle are held in the late afternoon,

which often does not interfere with day camp schedules. The summer cycle begins in July and runs through mid-August.

The Social Skills Program is held in the Child and Adolescent Outpatient Department of New York Presbyterian Hospital in White Plains. All children who attend have a child psychiatric evaluation session first. This allows the team to understand the developmental needs of the child and to carefully match the child with an appropriate group. The fact that this is a Behavioral Health outpatient department enables the children who attend to benefit from the special expertise of a team approach within a child psychiatric setting. Other services such as medication management, individual or family therapy, can be utilized as needed. Given that it is often difficult to find such specialized program in the community, the Social Skills Program will work with outside mental health providers who may follow these children individually and want this additional resource.

Two and sometimes even three group leaders generally lead our groups. These group leaders are generally social workers or psychologists, with co-leaders who are Child Psychiatry Residents, Postdoctoral Fellows in Psychology or Psychology Externs. The fact that it is a teaching hospital enables the program to have the luxury to draw from staff of different disciplines and to have an abundance of staff interested in leading these groups and in training others to do so. The combined Columbia - Cornell Child Psychiatry Training Program sends its Child Residents for four-month rotations through the Social Skills Program.

I provide ongoing consultation for all of the groups, and hold a group therapy seminar for clinicians within the program. By leading three groups myself, I am always directly involved, and often the person to make the match between the child and the group. Since children with Asperger's Disorder can sometimes become overwhelmed in large groups, I might sometimes suggest a "mini-group" as an ideal way to help them learn the communication and relationship building skills that can increase their confidence and self

esteem. Sometime the group is a duo therapy of two similarly matched children. This can help prepare the children for joining a larger group at a later date. Since the number of children and adolescents who are referred has expanded, the opportunity exists to make a well-suited match.

Even in the larger groups with 6-8 children, it is sometimes suggested to break the group in mini-groups for a brief period. Sometimes the larger group is too overwhelming for the child to be able to learn a skill and to practice it. A small group experience to practice first makes clinical sense.

Typical skills worked on these groups include Communication Skills, Interpersonal Perspective Taking, Problem Solving, Feelings Identification, Self Awareness, Increasing Frustration Tolerance, Good Sportsmanship, and the ability to be Flexible and able to Compromise.

Each group of children takes on its own personality and it is the job of the group leaders to pick the skills that need the most practice for any particular group. For children with Asperger's Disorder, picking up social cues and ascertaining the nuances of interpersonal communication is often difficult, and thus more time is generally spent on these skills. Role playing, stopping the action in the group to examine what has transpired, and understanding one's impact upon other members of the group, is often practiced and reinforced.

It can be tremendously reassuring for individuals with Asperger's Disorder to find others who face similar issues. Often these children have been isolated or rejected by their peers. Sometimes they can become stuck in roles at their own schools, which leads to avoidance in social situations. This can lead to further unhappiness, depression, and anxiety. The benefits of decreasing loneliness and increasing the prospects of friendship cannot be underestimated! By attending a program like this, renewed optimism and a wish to try again with their peers can be the outcome.

For those wishing to refer to the Social Skill Group Therapy Program, please contact Dr. Jo Hariton at 914 997-5957. □

Support Group for Parents and Advocates Responsible for High Functioning Adults on the Autism Spectrum

By Bonnie Kaplan & Judy Omidvaran Co-Facilitators

Two years ago, out of concern for the future of our adult children on the autism spectrum, frustration over the lack of appropriate services available to them and to us, and lacking any support group in our geographic area to meet our needs, we formed a support group. Our primary goal was to have a place and a group of people with whom we could share concerns, fears, frustrations, experiences and knowledge relating to our adult children's situations. Word spread quickly. We have a

steady group of approximately 15 attendees and frequently more people at our monthly meetings.

After gathering a few times, we realized that we were all looking for more information. The main topics that concern our group members are housing, employment, socialization, & mental health treatment for our adult children with autism. We are also concerned about legal and financial issues affecting our children now and in the future. Dealing with the OMRDD (Office of Mental Retardation and Developmental Disabilities) system is something that has frustrated some of our members. Our children have very specific needs, some the same and some very dif-

ferent from each other. However, most of them cannot be appropriately served by the traditional services available for people with other developmental disabilities.

To address the issues mentioned above we have invited many well-informed presenters to address our group. Attorneys, financial advisers, representatives of agencies that provide vocational, residential and recreational services to people with developmental disabilities, presenters from New York State Offices and others have met with us. They have shared much needed information and answered our many questions. Even those of us who have been involved in "the system" for some time have learned so much. Of

course we all provide support and are a source of information for each other, by sharing our experiences, both good and bad.

The many speakers who have addressed our group have also listened to us. We have tried to communicate to them what we feel is lacking in the way of services for our adult children with autism spectrum disorders. We have come to the conclusion that what is needed in the Westchester/Rockland Counties and surrounding area is an agency to serve families like ours. Such an agency could serve as a clearinghouse and provide information to families about services, conferences,

see Support Group on page 15

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Knock Knock: I'm looking for a 'Medical Home' for Autism

By John Harrington, MD
Associate Professor
New York Medical College

In the spring of 1997, I contemplated the fact that my son, who was 18 months old at the time, might have severe autism. Three months later, a neuro-developmental confirmed my findings. I was left with the sobering reality that, even as a pediatrician, I knew very little about diagnosing or treating a condition that profoundly affects communication and social relatedness. My residency and private practice training in Pediatrics had not prepared me for the task of raising and educating a child with autism. The one unmistakable lesson I learned early on was that there were very few evidenced based facts about what to expect as a parent of a child with autism and what to do as a physician for a child with autism.

Not Alone

In 2006, autistic spectrum disorders (ASD) are as common as 1 in 166 children. ASD, also called pervasive developmental delay (PDD), is generally considered a conglomeration of 5 subsets: 1. Aspergers' (high functioning autism), 2. Autism (classical), 3. Rett's syndrome, 4. Childhood Disintegrative Disorder, and 5.



John Harrington, MD

PDD-Not Otherwise Specified. The increase in prevalence of ASD over the last ten years has been referred to as an epidemic. The rapid increase in numbers of children being diagnosed has been confounded by several conflicting factors: finding appropriate data sets to compare, improved case reporting by practitioners, and a broadening of the 'spectrum' diagnosis itself. This has led to the belief, also postulated in the April edition of *Pediat-*

rics, that a diagnostic substitution of ASD for mental retardation has taken place. Regardless, the reality is that more children than ever are being diagnosed and will subsequently require continued medical care. In addition, children with ASD have complex medical and neuro-developmental problems. This makes them ideal candidates for the medical home paradigm espoused as a standard of care for children with chronic illnesses. In order to remain as a reliable source of information and advice for patients, primary care physicians and specialists need to familiarize themselves with the current beliefs and therapies available to parents of children with autism through various mediums such as; the internet, alternative health practitioners, and medical/informational meetings.

Where to Start

Initially, the most important function for primary care providers is to help parent's identify and confirm a diagnosis of autism and then gain access to intensive behavioral therapy as early as possible through early intervention. There is currently a quick screening test that can be utilized at 18 months. It is called the modified checklist for autism in toddlers or mCHAT. You can download a copy and how to score it from the website www.firstsigns.org. After the diagnosis

of autism is considered and confirmed through specialized testing, the next step for the pediatrician is to provide comprehensive care. This may include the following areas; genetic testing and assessing comorbid problems, keeping abreast of both conventional and non-conventional treatments, and providing local resources of information and advice for parents.

What Medical Tests, if any?

Testing is fairly limited and should follow specifically with your medical history and physical exam. Generally, testing that should be done on all patients with symptoms of ASD would be hearing/audiology, lead, and thyroid functions. A full psycho-educational assessment along with possible needs for physical and occupational therapy should be done. Children, who are confirmed to have an ASD, should undergo genetic testing with high resolution chromosomes along with Fragile X testing. Recent studies have also shown that children with ASD are much more likely to have medical complaints varying from gastro-intestinal and sleeping, to more neurologically based problems such as, attention deficit hyperactivity disorder and seizures. Obviously, each medical problem should be appropriately addressed based on symptoms and medical history.

see Medical Home on page 42

Addressing the Emotional Needs of Mothers of Children With Autism

By Theodore M. Roth, PhD

In my experience, the parent primarily responsible for taking care and managing the child with Autism is usually the mother. The mother rarely attends to her own emotional needs but rather tends to focus most of her energy on procuring the best services and developing the most complete treatment program for her child. Before the diagnosis and after the diagnosis has been made, she is the primary parent who deals with a slew of professionals including, developmental pediatricians, pediatric neurologists, child psychologists, and or psychiatrists, nutritionists, holistic healers, speech and language pathologists, physical therapists, occupational therapists, attorneys (to name a few) all of which is pretty overwhelming. The mother spends her day shuttling her child from one appointment to the next and her evenings trying to work out an effective behavioral management program at home. This hectic schedule leaves her with virtually no time for herself or for the other members of her family. This situation leads to increased conflict within and between family members, and emotionally damaging levels of anger, guilt, anxiety and depression. Spousal relationships, parent-child relationships, and sibling relationships are often fraught with tension and all suffer as a result.

What can be done about this? Individual, couple and/or family psychotherapy are all possibilities and indeed, may be very helpful in relieving some of these stressors. However, I would like to focus on what I feel is an extremely powerful intervention: a Therapeutic Support Group (TSG) for mothers of children with Autism. Fathers would also benefit from this type of intervention, but that is the subject of another article.

A TSG for mothers is facilitated by a trained professional and takes place in a group setting which allows for and encourages members with similar parenting demands to validate each other, to share with, support, and listen to one another, to offer different view points and suggestions, to more effectively problem solve, share information, develop strategies and brainstorm. The effect on each mother is often very healing.

Mothers of children with special needs have special needs too. It is essential for them to attend to their own emotional needs so that they can better take care of their children and families.

Mothers need a place to vent because internal pressure has built up to intolerable levels. This emotional venting is essential and in and of itself is cathartic, restorative, and allows the mothers to be strong and to deal with the overwhelming demands in her life and her anxiety and uncertainty about the future.



Theodore M. Roth, PhD

The group offers a safe place to cry, to scream, to laugh, to be scared, to feel heartbroken, to feel hopeless and then more hopeful, to learn how to better deal with herself and with others, to learn how to better advocate for herself, her children, and other family members.

The group setting allows for and encourages a discussion of some of the following issues.

- The shock of discovering that her child has Autism with all attendant feelings;
- The unrelenting self-blame which leads to depression and a life devoid of pleasure;
- The blame between spouses for "causing" the problem and not fixing it fast enough;
- The anxiety regarding an uncertain future for her child;
- The anxiety regarding selecting the most appropriate service providers for her child;
- The anxiety, anger and difficulties advocating for her child- how to deal more effectively with school systems to get all of the necessary services, i.e. CSE/CPSE, legal systems, school programs, specialized classes, self contained classes, inclusion settings, related services, etc;
- The painful embarrassment, anger and frustration evoked by her child's behavior in public settings and the hostile and un-accepting responses of others who do not understand and or accept children with Autism; and
- The anxiety, depression, and tension caused by strained relationships with

see Needs on page 41

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Federation of Organizations Opens New Supported Housing in Suffolk County

Staff Writer
Mental Health News

In Federation of Organizations' continuing effort to help people help themselves, the first community residence/single room occupancy building in Suffolk County was opened. The Irving Berkowitz Residence, named after Federation's President of the Board of Directors, can accommodate 42 residents with transitional housing and serve

eight people coming directly from psychiatric units in local hospitals.

"The residence was created to provide a better quality of life for individuals who have been diagnosed with a serious mental illness" said Doris Wagner, Federation's Deputy Executive Director. "This supported housing option gives people hope for their future by teaching them daily living skills while keeping with Federation's philosophy that, with additional supports and encouragement, people can live independently in the community." □



Barbara Faron, Executive Director; James Lupoli, NYS Office of Mental Health; Doris Wagner, Deputy Executive Director; Michael Newman, NYS Office of Mental Health

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The NARSAD Report

The National Alliance for Research on Schizophrenia and Depression

NARSAD's Research In Autism

By Constance E. Lieber, President
NARSAD



Constance E. Lieber

NARSAD has provided 16 years of funding for research in Autism. These years have surely been a period of more meaningful discoveries as to the nature of Autism than all of human history preceding it. We are pleased to have funded a number of the pioneers; 44 scientists, each of whom has brought an important part of modern technology and understanding in brain and behavior research to bear on the challenge of Autism.

NARSAD The Mental Health Research Association has just one issue — overcoming all the severe disorders of brain and behavior.

NARSAD funds Autism research as an important part of our mission to find better treatments and cures for the severe psychiatric disorders.

Our effort is extensive, the broadest of any donor-supported philanthropy. In 19 years NARSAD has awarded \$194.5 million to fund 2,901 grants to 2,264 scientists at 340 universities and medical research institutions worldwide.

NARSAD focuses on the broad spectrum of disorders recognizing that the cure for any one brain disorder may come from research in another.

The pioneers in Autism research have been funded by 16 years of NARSAD support for this field of medical science. A new generation of investigators are working effectively to provide the breakthroughs which are needed for Autism. The current NARSAD studies are centered in four areas — genes, which may be associated with Autism, brain anatomy variations in autistic spectrum disorders, the molecular biology of the brain, and pathophysiology and future design of drug studies in Autism.

NARSAD began funding Autism research in 1990 with support for **Christopher J. McDougle, M.D.**, then of Yale University. His was an early focus on differences in brain chemistry which might be vital to the understanding of Autism. We gave him additional grants in 1994, 1995 and again in 1997. His 1997 Award was supported by the Seaver Foundation. His

research focused on developing effective drug treatments for the interfering symptoms which accompany Autism. He reported that the NARSAD support was instrumental in allowing him to establish Risperidone as an effective treatment for severe Autism symptoms. The research results of that grant, when submitted to the NIMH, brought a five-year follow-up study funded by the NIMH.

Benjamin V. Siegel, Jr., M.D., of Mount Sinai, received a Young Investigator grant in 1991. His was a pioneering study about difficulties in attention and information processing. He was early in providing the observation that comparison of Autistic-to-Schizophrenic populations relates to differences and similarities in patterns of brain metabolic activity.

In 1992, NARSAD began funding **John L.R. Rubenstein, M.D., Ph.D.**, now of the University of California in San Francisco, as a Young Investigator. He was a pioneering student of the genetic mechanisms which regulate the development of the mammalian brain because he believed that in cases such as Autism, mental retardation and childhood Schizophrenia, there are abnormalities in brain development, many of which are due to genetic defects. His extraordinary research led Dr. Rubenstein to receive a NARSAD Distinguished Investigator award in 1997. His search for understanding of the mechanisms of Autism and potential treatment for it has led to determining the nature of molecular substrates of amygdala-dependent memory processes, among other analyses.

Christopher J. Stodgell, Ph.D., of the University of Rochester, has located biomarkers for Autism spectrum disorders.

Christopher A. Walsh, M.D., Ph.D., of Harvard University has developed a unique hunt for genes that predispose to Autism spectrum disorders. His study looks for Autism in families in which relatives such as first cousins have children together. Such marriages often bring out genetic diseases. He had led gene mapping in Turkey and Arab States which has provided strong evidence for linkage of an Autism spectrum gene to a single locus. **David Pauls, Ph.D.**, of Harvard University provided similar research for Finnish populations.

Innovative thinking and scientific technique characterized the NARSAD-funded research of **Eric Hollander, M.D.**, of Mount Sinai School of Medicine. He explored a unique monochromal antibody as a potential marker for susceptibility to Autism. He explored a "unique conceptual opportunity in that it is a novel and testable theory incorporating genetic and environmental factors in the pathogenesis and expression of Autism." His group found a particular anti-neural antibody in which a subgroup of Autistic individuals had extremely high levels. In research such as this, he led in the development of a consortium among Mount Sinai, Rockefeller, NIMH, Johns Hopkins and Columbia Universities in order to further study autoimmune issues in Autism and other illnesses.

J. Julius Zhu, Ph.D., at Cold Spring Harbor Research Laboratories, another

NARSAD investigator, described genetic defects of signaling molecules in brain receptors which can lead to Autism.

We are supporting research by one of the widely acknowledged leaders in neurobiology, **Richard J. Davidson, Ph.D.**, Director of the Keck Laboratory for Functional Brain Imaging and Behavior at the University of Wisconsin. Dr. Davidson received our Distinguished Investigator award for research on the functional neuroanatomy of affective dysfunction in Autism. He is using fMRI, eye-tracking and autonomic measures to probe dysfunctions in the processing of emotional stimuli in subjects with Autism. He is exploring functions of a vital section of the cortex in the brain, the anterior cingulate cortex in autistic and control subjects. Features of the core symptomatology of Autism, including communication deficits, gaze aversion, social withdrawal and shyness are presumed to arise from abnormalities in this central circuitry of emotion and emotion regulation.

We are also funding a young scientist working with him on this same project, **Mariana Lazar, Ph.D.**, of the University of Wisconsin-Madison. Her goal is to provide cutting edge new information on patterns of anatomical connectivity in the autistic brain.

Another Distinguished Investigator whose work is being funded by NARSAD is **David L. Pauls, Ph.D.**, Director of the Psychiatric and Neuro Developmental Genetics Unit of the Harvard Medical School Department of Psychiatry. He has undertaken to identify genes responsible for Autism and Asperger syndrome using a genetic mapping approach in the northern Finnish population. He states that although the genetic basis of Autism is well established, the mode of genetic transmission is not known. He has observed that a disease susceptibility gene should be detectable when a sizeable proportion of the patients share a common ancestor. That is why he has chosen an isolated population with common ancestors in northern Finland to provide an improved power for detection of Autism genes.

John B. Vincent, Ph.D., of the University of Toronto, has been described by a leading genetic scientist on our Council as "an outstanding Independent Investigator in an area of great importance to medical research: molecular genetic factors in complex psychiatric diseases." His intense interest in Autism over a period of years has already resulted in significant findings of genetic breakpoint regions in a number of Autism patients with chromosomal translocations. He has been funded by the NIH for a project on pharmacogenetics and neuroimaging of serotonin receptors in Autism with **Dr. Eric Hollander** of Mount Sinai and NARSAD Scientific Council member **Dr. James L. Kennedy** of the University of Toronto. Now, he is working to detect the position where a piece of chromosome breaks off and is transferred to a second chromosome and, thus, disrupting a gene crucial to normal development or specific brain function, which may lead to the impaired development and brain function as seen in Autism.

Moving to the study of the pathophysiology and the future design of drug studies in Autism, we support the research of **David J. Posey, M.D.**, of Indiana University. Dr. Posey is Chief of the Autism Clinic of that university, where he leads a large multidisciplinary group of clinicians which provides care for nearly 600 individuals with Autism and related disorders. In an earlier NARSAD award, he pursued pilot studies of glutamatergic function in Autism. Now he is building upon those insights to study whether a drug that affects an important subtype of the glutamate receptor has efficacy for the symptoms of social withdrawal in Autism.

An innovative and important critical study is being done by **Inge-Marie Eigsti, Ph.D.**, who is now at the University of Connecticut. She has noted that individuals with Autism have significant impairments in the ability to share their experience of an event or object with others by socially orienting. Such a social sharing of experience helps to provide a foundation for the development of cognitive and social skills. Until her work, there were no studies which related joint or social attention to the core attentional processes of the brain such as social orienting. She is making that study now in a sample of children with Autism at both the Autism Research Center of Columbia University and the Sackler Center at Cornell.

Pierre Lavenex, Ph.D., of the University of California at Davis, is studying the genes expressed during the development of hippocampus in the brain.

Ganeshwaran H. Mochida, M.D., M.M.Sc., of Harvard University, is studying genes involved in the development of the cerebral cortex, with a special focus on when the brain fails to achieve normal growth, is small and, thus, encounter disorders such as Autism.

Many grantees have used the NARSAD grants on Autism to obtain significant long-term funding from the NIMH. This brings increasing resources to the challenges we are addressing today.

Outstandingly, **Dr. Thomas R. Insel** built upon his NARSAD grant to obtain support from the NIMH at that time for a project called, "Developing a Center for Autism Research."

An important aspect of NARSAD's program is better recognition and understanding of psychiatric research achievements. NARSAD donors have provided the outstanding prize awards for **Lifetime Psychiatric Research Achievement**. For these awards in Autism research, the **Ruane Prize** for 2000 was given to **Professor Sir Michael L. Rutter** of the University of London, in 2001 to the late **Donald J. Cohen, M.D.**, of Yale University, and in 2005 to **Allan L. Reiss, M.D.**, of Stanford University.

Our remarkable grantee scientists are showing the way. These brief comments on this extraordinary variety of research efforts helps to show why NARSAD is so optimistic that the increasing breadth in Autism and related research will provide the answers we all seek. □

NARSAD

THE MENTAL HEALTH RESEARCH ASSOCIATION

Leading in Autism Research Grants

Ralph Adolphs, Ph.D., California Institute of Technology
Maricela Alarcon, Ph.D., University of California-Los Angeles
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Naama Barnea-Goraly, M.D., Stanford University
Ugo Borello, Ph.D., University of California-San Francisco
Marc G. Caron, Ph.D., Duke University
M. Inmaculada Cobos-Sillero, M.D., Ph.D., University of California-San Francisco
Kim M. Dalton, Ph.D., University of Wisconsin-Madison
Richard J. Davidson, Ph.D., University of Wisconsin-Madison
Adriana Di Martino, M.D., New York University
Catherine A. Dye, Ph.D., University of California-San Francisco
Inge-Marie Eigsti, Ph.D., University of Connecticut
Mohammad Ghaziuddin, M.D., University of Michigan
Joachim Hallmayer, M.D., Stanford University
Eric Hollander, M.D., Mount Sinai School of Medicine
Thomas R. Insel, M.D., Emory University
Alain Katic, M.D., Harvard University
Pierre Lavenex, Ph.D., University of California-Davis
Mariana Lazar, Ph.D., University of Wisconsin-Madison
James F. Leckman, M.D., Yale University
Jeffrey David Lewine, Ph.D., University of Utah
Linda J. Lotspeich, M.D., Stanford University

Russell L. Margolis, M.D., The Johns Hopkins University
Christopher J. McDougle, M.D., Yale University (2 grants)
Ganeshwaran H. Mochida, M.D., M.M.Sc., Harvard University (2 grants)
Sherie Lynn Novotny, M.D., Mount Sinai School of Medicine (2 grants)
Thomas G. O'Connor, Ph.D., Institute of Psychiatry/King's College London
David Pauls, Ph.D., Harvard University
Robert Philibert, M.D., Ph.D., University of Iowa
Jonathan Picker, M.D., Ph.D., Harvard University
Franck Polleux, Ph.D., University of North Carolina-Chapel Hill
David J. Posey, M.D., Indiana University (2 grants)
John L. R. Rubenstein, M.D., Ph.D., University of California-San Francisco (2 grants)
Gleb P. Shumyatsky, Ph.D., Columbia University
Benjamin V. Siegel, Jr., M.D., Mount Sinai School of Medicine
Christopher J. Stodgell, Ph.D., University of Rochester
Randy L. Stone, Ph.D., University of Michigan
Takuya Takahashi, M.D., Ph.D., Cold Spring Harbor Laboratory
Flora M. Vaccarino, M.D., Yale University
John B. Vincent, Ph.D., University of Toronto (2 grants)
Jacob A.S. Vorstman, M.D., University of Pennsylvania
Christopher A. Walsh, M.D., Ph.D., Harvard University
Chong-Bin Zhu, Ph.D., Vanderbilt University
J. Julius Zhu, Ph.D., Cold Spring Harbor Laboratory

Since 1987, NARSAD has awarded more than \$194 million to fund 2,901 research grants to 2,264 scientists at 340 universities and medical research institutions worldwide. Because NARSAD's administrative and fundraising expenses are underwritten by two family foundations, 100% OF ALL CONTRIBUTIONS GOES DIRECTLY TO SUPPORT RESEARCH.

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In Our House from page 1

door. Meeting someone in the halls, or especially in the elevator is a seemingly painful experience for her. Transitions are hard. I'm so used to giving a 5-minute warning and countdown to change activities that my husband will gently remind me sometimes that *she is at her grandparents' house* and he doesn't need one.

I tell my daughter over and over, when she is frustrated at some thing she wants to do that she cannot do yet including: when she is trying to keep up with the kids at the playground and she cannot, when the play outpaces her and she dissolves into tears, when one of her peers accosts me disbelievingly asking *how come she can read?*, when my daughter is trying to make sense of her world. I tell her, "people learn things in different ways at different times." It is my mantra. People learn things in different ways at different times.

One day after 2 weeks of fighting with my 5 yr old in the morning to get her out the door to go to preschool, "I don't want to go to school, Mommy," I use our family trainer's (a psychologist provided by the school district to help with behavior in the home and to ensure some continuity of care between home and school) advice and tell my daughter that school is her work. She explodes. "Work, work, work, that's all I get is work!!!"

I mumble something about play time. The explosion takes off. "PLAY," "DON'T YOU KNOW HOW HARD PLAY IS FOR ME?", and she collapses into tears. Later, when she is calm, I ask her, "What's hard about play?" and she

tells me, "choosing what to do is hard." And, "Pretend is very hard." And then I finally accept that this is asperger's. Asperger's from the inside, in five year old eyes. Don't you know how hard play is for me?

And a few days later, I take her in my arms and tell her, "mommy and daddy listened when you talked about how hard play is for you." She waits. "we talk lots about how people learn, don't we?" I ask. This next is hard. I swallow and continue. "There is a pattern to the way that you learn things." She looks up, intrigued. Patterns are something that she looks for in just about everything these days. "There is a name for the pattern of how you learn. That name is Asperger's." I reach behind me and take out a book, "Asperger's - what it means to me"*** She looks curiously at the cover. I turn to the table of contents. She skims down the pages and says to me, "mom, I have to turn to the Introduction."

She looks at the Introduction, closes the book, and gives me a hug. And that is that. She picks up her dinosaur off the floor and directs, "Mom, make it talk."

In our house, this is Aspergers. □

The OASIS Guide to Asperger Syndrome, Advice, Support, Insight, and Inspiration, Bashe and Kirby, Crown Publishers, New York. 2001. **The Developmental Neuropsychiatry Program is a joint program sponsored by New-York Presbyterian, Columbia University Medical Center, and the NY State Psychiatric Institute. *Asperger's - What does It Mean to Me?, Future Horizons, Inc. Arlington, TX, 2000*

Support Group from page 10

service providers, e.g. psychiatrists, psychologists etc., who specialize in treatment of adults with autism spectrum disorders in this geographical region. Another role of this agency should be to advocate for families so that necessary services are developed.

In our quest to disseminate information of interest to our group members we also maintain an e-mail list. Through this

list we announce our meetings and speakers and share pertinent information concerning autism. Our list now has 75 contacts and continues to grow.

Our support group meets monthly, usually the fourth Sunday of the month, at the Blythedale Children's Hospital in Valhalla, NY (Westchester County), from 10:30 a.m.- 12:30 p.m. For more information contact Bonnie at parent-talk04@yahoo.com or call Judy at 914-528-3871. □

See Page 4 - For the Mental Health News Upcoming Themes and Deadlines Calendar

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Some Tips for Management of Aggression in Autistic Spectrum Youth *By Stephanie Hamarman, MD*

In autistic spectrum youth, physical aggression is indeed a common problem disrupting life at home and at school. Often there is a reason for the behavior that can be addressed without medication. An environmental change may help. Here are some tips for parents.

Is the youth getting proper sleep? Sleep issues are very common in autistic spectrum youth and very frustrating to them. Good sleep hygiene is very important and easy to address. It requires behavioral changes not medication.

Have a physician do an evaluation looking for medical issues for example seizures or an infection irritating the child.

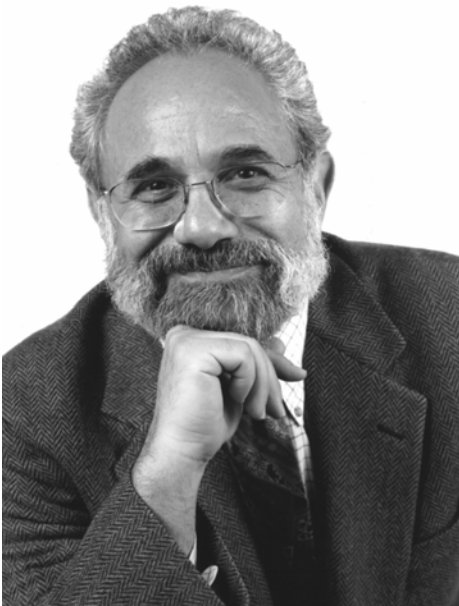
If medication becomes necessary side effects such as unusual movements, weight gain, effects on blood glucose and lipids, and foggy cognition are important to ask your doctor about. Your physician might suggest medicines that fall into three big classes: atypical antipsychotics, mood stabilizers, or serotonin reuptake inhibitors. □

Stephanie Hamarman, MD is a Clinical Assistant Professor of Psychiatry at SUNY, is a member of the APA Committee on Autism and is a child and adolescent psychiatrist specializing in autism.

POINT OF VIEW

Preserving Essential Mental Health Services If General Hospitals Close

By Michael B. Friedman, LMSW



Michael B. Friedman, LMSW

The Mental Health Associations of NYC and Westchester have become very concerned that The Commission on Health Care Facilities for the 21st Century could produce recommendations that inadvertently result in the loss of vital behavioral health services. With a grant from the New York Community Trust, we have formed a taskforce of over 25 umbrella organizations representing providers, professionals, families, consumers, and counties to call for a rigorous planning process regarding behavioral health services and to assure that vital services are preserved.

The Governor, with the support of the New York State Legislature, established the Commission in 2005. The Governor has characterized its goal as "rightsizing" the hospital and nursing home systems, leading to the Commission being nicknamed the "hospital closure commission." The Commission's Director maintains that this is a mischaracterization of its goal. Its goal, he says, is to assure access to health care in New York State while also holding down Medicaid costs.

This is certainly a sensible goal. But many of us have become concerned that behavioral health services will be neglected by the Commission as they focus on big ticket cost items. Because mental health and substance abuse services constitute less than 10% of hospital costs, they are a minor matter from the standpoint of those looking for big savings.

From the standpoint of the mental health system however, general hospitals are anything but minor. In fact they constitute 37% of all spending on public mental health in NYS and provide 65% of psychiatric hospital beds. They also provide crisis services, outpatient services, case management, assertive community treatment and more for many thousands of New Yorkers each year.

It is also important to keep in mind that while overall utilization of beds in general hospitals hovers around 65%, utilization of psychiatric beds is closer to 90%--nearly full utilization. There are quite a number of hospitals in NYS with very low utilization of medical-surgical beds but high utilization of psychiatric beds. Thus, decisions based on overall utilization of hospitals rather than on utilization of behavioral health services could result in significant losses of heavily utilized psychiatric facilities.

The fact of the matter is that New York's general hospitals are a key element of the system of community-based services that was devised in the late 1970's in response to the failures of deinstitutionalization. Over five years starting in 1968, NYS went from 80,000 beds in state psychiatric hospitals to 40,000. The result was disastrous for tens of thousands of people, many of whom moved into squalid and dangerous single room occupancy apartments in very poor neighborhoods or into adult homes unprepared to serve them. It was also very tough on the thousands of families who took their relatives in.

In 1978, New York State responded to the failures of deinstitutionalization by introducing the community support program. Housing, rehabilitation, case management, and other community supports were put in place to help people with psychiatric disabilities lead tolerable lives in the community. Outpatient services were expanded in community mental health agencies, state psychiatric centers, and general hospitals. The state also approved expansion of psychiatric beds in local general hospitals in preference to maintaining beds in overcrowded, low quality, often dangerous state hospitals. This policy also allowed the state to replace state dollars with federal Medicaid dollars.

In essence NYS created a tripartite structure for community based mental health, a structure composed of expanded community mental health agencies, smaller and much improved state psychiatric centers, and general hospitals. This fundamental structure remains in place

today, and there has been no indication that the state is preparing to change it by reducing its reliance on general hospitals.

Many of us have come to the fairly obvious conclusion that before the Commission makes recommendations, there must be a rigorous, public process of review of all proposals that would result in the loss of behavioral health services. We believe that the Commission and the NYS Office of Mental Health should jointly cast a plan that takes into account possible closures of general hospitals and nursing homes and assures that adequate alternatives will be in place before general hospitals providing vital behavioral health services are closed or people with mental disorders are discharged from nursing homes.

The plan should be based on specific answers to specific questions about specific facilities including:

- What behavioral health services does the facility provide? Crisis? Inpatient? Outpatient? Case management? Etc.
- What populations does the facility serve: children, adults, and older adults?
- What is the inpatient and outpatient capacity of the facility?
- What is the utilization over the past two years?
- How many admissions are there annually?
- What is the average length of stay?
- What are the hospital's referral sources?
- Where will they refer if the hospital closes?
- What are the current discharge patterns?
- How many patients are discharged to shelters, nursing homes, or adult homes?
- Can current capacity be transferred to another facility in the local community?
- How far away is it?
- To what extent will changes in systems other than mental health increase or decrease need for the services currently provided by the facility? (For example, The Administration for Children's Services in NYC has been reducing residential treat-

ment slots. Will this create additional demand for psychiatric inpatient services for children?)

- What training programs currently use the facility as a training site?
- How many people are trained annually?
- What professions? What specialties?
- Will training be discontinued? If so, what will be the loss in the development of well-trained mental health personnel?
- If training will be continued elsewhere, what is the plan?
- What will be the operating cost savings?
- What impact will closure have on paying off bonds and mortgages?
- If the services are moved elsewhere, how much will the new costs be? How much will renovations and new construction cost? (Capital costs and debt service?)
- How much will the net savings be?
- Can the land and buildings of closed hospitals be used to provide housing and community services for people with mental illnesses?

Just to be clear, many of us believe that it may be possible for NYS to meet its people's behavioral health care needs with fewer hospitals and nursing homes. But responsible closures require rigorous planning and the development of adequate alternatives before closures take place.

Over the past quarter century NYS has made considerable progress towards building a decent community-based mental health system. General hospitals have been an essential element of that system. It is frightening to think that so much of the progress of the past 25 years could be undone if this Commission does not devote appropriate attention to behavioral health needs.

That is why we hope to be able to work collaboratively with the Commission and with OMH to do the kind of rigorous planning that is needed when making major changes. □

Michael B. Friedman is Director of the Center for Policy and Advocacy of the Mental Health Associations of The Mental Health Associations of NYC and of Westchester. Mr. Friedman can be reached at center@mhaofnyc.org. The Center's website is www.mhawestchester.org/advocates/metcenter.asp.

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The NYSPA Report

**By Barry B. Perlman, MD, President
New York State Psychiatric Association
and Richard Gallo, Government
Relations Advocate**

This article presents NYSPA's position in opposition to the proposed civil commitment of sexual offenders at the conclusion of their sentences, an alternative approach to the matter, and those elements which NYSPA believes must be addressed by any legislation which may become law.

The goal of civilly committing sexually violent predators (SVP) in New York State at the completion of their terms of incarceration, which had long been a "back burner" issue, jumped to the fore with the publication of an article in The New York Post during the summer of 2005. The Post article informed that, using current civil commitment laws, "The Pataki administration had quietly begun locking up dangerous sex fiends in a Manhattan mental institution after they complete their prison terms..." As I read The Post article, I was aghast to learn that many of the "monsters," as they were referred to, had received sentences of only 3 1/2, 4 1/2, 6, & 7 years. It seemed an affront that such heinous crimes had been so lightly punished. The New York Times of November 16, 2005 contained 2 related articles. One told of a repeat sex offender being sentenced to 50 years to life for the murder of a 12 year old boy in 1998. The other informed that a judge had ruled that NYS was illegally holding 12 convicted sex offenders in a mental hospital after they had served their prison sentences. It is the position of NYSPA that the former, imprisonment, is the better way to go rather than the latter, civil commitment.

The controversy regarding the use of civil commitment at the end of terms of imprisonment has been an issue of national concern since 1989 when it was first utilized by the State of Washington and 1997 when the U.S. Supreme Court upheld Kansas' SVP law. From the time the debate was first joined the American Psychiatric Association has taken a clear and unambiguous position in opposition to such use of civil commitment. The APA filed an amicus curiae brief in the U.S. Supreme Court case *Kansas v.*



Barry B. Perlman, MD

Hendricks. At that time Richard J. Ciccone, M.D., a NYSPA member, was quoted as saying that the Kansas law does not refer to a mental disease or disorder which would allow for civil commitment but rather to a mental abnormality which it defines "as having been convicted of committing or attempting to commit a sexual crime and being likely to commit the act again based on a preponderance of the evidence. In 1998 the APA's Board of Trustees approved a report by its Council on Psychiatry and the Law addressing sexually dangerous offenders. At that time Paul Appelbaum, M.D., who had been Chair of the APA task force which addressed this issue said, "We were concerned that psychiatry was being used to preventively detain a class of people for whom confinement rather than treatment was the real goal. This struck many people as a misuse of psychiatry."

Despite many states having adopted statutes similar to that of Kansas, NYSPA has continued to reject the use of civil commitment in these situations as being poor public policy since it first wrote a memorandum of opposition in 1998 to Senate Bill S-751. Today NYSPA opposes proposed legislation which would permit the civil commitment of SVPs at the end of their term of incarceration for a number of reasons. First, it creates an

unwarranted link between persons with mental illness and sexually predatory behavior. We believe this is a retrogressive step in the face of NYSPA's work along with that of other groups which advocate on behalf of those with mental illness to erase the stigma which often accompanies the condition. Second, the cost of "housing and treating" SVPs would likely rise to close to a half billion dollars per annum within a decade. (It is estimated that it would cost \$200,000 per year in today's dollars to house and treat an SVP. It is projected that approximately 200 SVP would enter the system annually. Thus in a decade the cost of the program would rise beyond \$400 million per year.) We are concerned that those funds will be attributed to the cost of providing publicly funded mental health care in NYS which will then be said to be too expensive and subject to unwarranted cuts. At the bottom line the SVP program will become an unstoppable competitor for community treatment dollars to the detriment of the latter. Third, we remain concerned about using the public mental health (MH) system in an expedient manner to solve a problem inherent to the criminal justice system. While making use of the mental health system for what appear to be political ends may not seem like a "big deal" to many, it alarms psychiatrists who have seen governments misuse mental health systems in other countries with terrible consequences for the public's trust of our profession and the MH system. The definition of a SVP is a judicial finding not a psychiatric diagnosis. No psychiatric diagnosis is contingent on the presence of an individual having committed a specific class of felony. Finally, we question why those convicted of sexual offender felonies if deemed mentally ill receive no targeted treatment during their term of incarceration. It would seem disingenuous, given the expression of concern, to initiate treatment only at the conclusion of their sentences.

While NYSPA will continue to raise its concerns about and oppose the passage of SVP bills as presently proposed, we do recognize society's legitimate concern for securing public safety. In recognition of that concern we offer an alternate approach based in the State's past use of civil commitment when it created the Narcotic Addiction Control Commission

(NACC) in 1966 for those suffering with addictions who had been arrested or convicted for related felonies or misdemeanors. (Despite some success that program was ended due to being too hastily made operational and its being poorly administered and implemented.) However, the NACC precedent is worthy of consideration. The creation of either a new agency or one under the auspice of the Department of Correction which purchased treatment services from either an outside vendor or the NYS Office of Mental Health to "treat" SVPs would offer several advantages over the current proposals. It would avoid identifying SVPs with persons diagnosed with and requiring traditional psychiatric care and would be less likely to engender an inadvertent mistrust of the public MH system. It would assure that SVPs were not mixed with persons being treated in the state psychiatric centers for usual psychiatric disorders, an expressed concern of many advocates for persons with mental illness. It would separate the budget for the SVP program from the budget of the NYS Office of Mental Health and thus avoid a contest for scarce resources among the several divisions of the agency.

If legislation is passed NYSPA believes it should incorporate several provisions. These include: necessary protection from liability for psychiatrists participating in the process and acting in good faith, treatment of costs consequent to the establishment of the program outside of the state's mental health budget, inclusion of an alternative program of intensive community monitoring and "treatment," indeterminate sentences requiring mandatory indefinite parole, and evaluation of those convicted as sexual offenders at the time of incarceration in order that they receive "treatment" while in prison.

NYSPA opposes the currently proposed which aims at civilly committing SVPs to psychiatric hospitals at the end of their term of incarceration and stands ready to work with lawmakers to the end of satisfying both their concerns about public safety and NYSPA's concerns about the impact of such a law on our profession and its relation to society. We urge other advocates for those with mental illness to join us in opposing the presently proposed SVP commitment legislation. □



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Helping Families: White Paper

By J. David Seay, Esquire
Executive Director
NAMI-New York State



J. David Seay, Esquire

The biggest news from NAMI New York State is the recent release of the document *"Helping Families to Help Their Loved Ones with Serious Mental Illness: A White Paper of the National Alliance on Mental Illness of New York State."* The white paper, principally authored by NAMI-NYS Deputy Director Jeff Keller, with input from NAMI leaders from within all levels of the movement as well as other experts, is part of collaboration with the New York State Office of Mental Health and the Family Institute of Education, Practice and Research at the University of Rochester. Its picks up on the observation by the President's New Freedom Commission on Mental Health that "services and treatments must be consumer and family friendly." This paper will, I believe, be a landmark contribution to the field and is a must read by elected officials at all levels, government policy makers and mental health professionals as well as families and consumers of mental health treatment and other services.

I take the liberty of quoting from the paper's Introduction:

"Although the family is the basic social and cultural unit of every society, it has not been until very recently that families have been appreciated for the role they play in the recovery process of their loved ones with a serious mental illness. For the best part of the last century, families were shamelessly accused of being the root cause of their loved ones' condition. Until the science of the brain put such theories to rest, autism was thought to be the result of cold rejecting professional women and "schizophrenogenic mothers" were accused of causing schizophrenia in their children. If it wasn't schizophrenogenic mothers, it was pathological communications in families.

Once the biological basis of serious

mental illness was established, such theories were, for the most part, discarded. The witch-hunting slowly ended. But families faced a new set of challenges. Under the "medical model" that emerged, the role of families simply was not acknowledged. In the eyes of the treatment establishment, families went from perpetrators to bystanders and bill-payers. What help they received has been mostly self-help, epitomized by NAMI.

The times have finally begun to change, however. Providers now have a bio-social, rather than just a biological model to work with, the central importance of families is no longer being ignored, and research has now indisputably shown that the more families acquire the ability to take care of their loved ones (and also themselves) the better everyone's outcomes will be.

Recently, the proven, A-level, evidence-based best practice of multifamily psychoeducation has begun to be provided throughout the state by the New York State Office of Mental Health (OMH) as well as the family education provided by NAMI-NYS. Also, the Family Institute for Education, Practice and Research has been established by OMH and the University of Rochester to inform providers how to effectively provide family services to individuals with mental illness and their families. These efforts are underway because it has been recognized that providing these services can pay off dramatically.

Family services are still too few and far between in New York State, however. Many gaps exist in the kinds of help that are offered, and there is no systematic means to provide that help according to individual family needs. Families have strengths that should be developed, weaknesses that should be mitigated, needs that should be met and limits that, once they have been reached, require someone else to take over. They are often "secondary consumers" as well as primary providers of care. They should be able to participate in an integrated system that takes these facts into account and provides services accordingly.

This white paper is meant to be a working document upon which an ongoing partnership to systematically establish family services can be based. It is part of a collaborative effort with the Family Institute and the Office of Mental Health to bring a unified program of family services to providers across New York State."

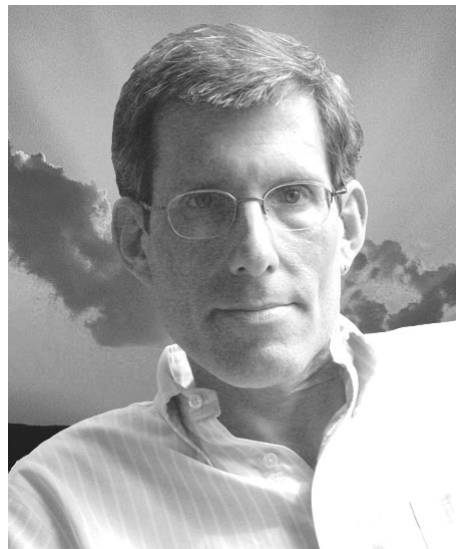
The paper serves as a lead-in to a collaborative effort among NAMI-NYS, OMH, the Family Institute and the New York Conference of Local Mental Hygiene Directors to identify, promote and make widely available a full "spectrum of family services" available from different auspices across the state, including NAMI-NYS, our 58 local affiliate organization,

see *White Paper* on page 40

A Voice of Sanity: A Consumer Advocacy Column

A Spoonful of Sugar

By Joshua Koerner
Executive Director
CHOICE



Joshua Koerner

It was a moment of journalistic synchronicity, life imitating art, the punch line to a joke arriving before the set up. In a recent issue of *The Onion*, a newspaper that is to fake print journalism what *The Daily Show* is to fake broadcast journalism, a headline declared "Wonder Drug Inspires Deep, Unwavering Love of Pharmaceutical Companies." A few days later, in the business section of the *New York Times*, there was this major story: "Take Your Pills, All Your Pills; Drug Makers Nag Patients to Stay the Course." The fake news was that "The Food and Drug Administration today approved the sale of the drug PharmAmorin, a prescription tablet developed by Pfizer to treat chronic distrust of large prescription-drug manufacturers." The real news is that pharmaceutical companies, losing billions of dollars because so many people don't take their medications, have developed programs in which nurses call up patients to remind them.

How often aren't people taking their prescription medications? A 2002 survey by Harris Interactive of 9,290 patients indicated that in the year prior to the survey, 18% hadn't filled a prescription, 26% had delayed in filling a prescription, 14% had taken a medication in a smaller dosage than prescribed, 30% less often than prescribed, and 21% stopped taking it sooner than prescribed. The reasons? 24% just forgot. 20% didn't want the side effects. 17% said they cost too much. 14% didn't think they needed it. And 10% couldn't get the prescription filled, picked up, or delivered.

Do the math: that's a lot of meds that a lot of people aren't taking, and the drug companies see it as a ton of lost revenue. It is also a legitimate public health issue, because of all the clinical benefits people are failing to derive from medications they take improperly or not at all.


What to do? Let's force 'em. Let's set up elaborate legal mechanisms to make sure that people do what's in their best interests. Oh, wait, we only do that with mental patients. You know the response of the mental health system to "I forgot": You're resistant! If you object to side effects you're deluded. "PharmAmorin, available in 100-, 200-, and 400-mg tablets, is classified as a critical-thinking inhibitor, a family of drugs that holds great promise for the estimated 20 million Americans who suffer from Free-Thinking Disorder." That is a joke, but the darker joke is that people with a mental illness diagnosis are presumed to lack the capacity to think critically.

The topper? Another recent article in the *New York Times* with news of a study questioning the efficacy of treating schizophrenia with medication. This is not new news, merely another study to confirm what the World Health Organization has known for years: that, when it comes to the treatment of schizophrenia, "a substantial body of evidence shows a more benign course and better outcomes in developing countries." Places, in other words, where they can't afford the latest high-tech pharmaceutical products to treat mental illness. Why are the treatment outcomes better in the third world? The World Health Organization says that "the factors that underlie higher improvement rates in developing countries remain ill-defined, although better tolerance of the sick role, availability of suitable jobs, supportive family attitudes and extended family networks have been suggested as explanation." All of which are factors associated with recovery, rehabilitation and rights, rather than forced treatment.

Force, intimidation and legislation aren't used on people being treated for cancer, or diabetes, or heart disease, so drug companies have had to fall back on persuasion and education. Novartis started a program called BP Success Zone, for users of its blood pressure meds. Customers can interact on a web site, through E-mail, via US mail or at the pharmacy. Participants get discounts on refills, and benchmarks to give them a sense that they are successfully managing their high blood pressure. Other companies are providing 24 hour call-in centers, or nursing staff that will call and see how you're feeling and whether you're remaining adherent. In a way, it's just what is already working in countries like Columbia and India, in which ongoing support is an organic function of extended family networks.

But in mental health, support isn't our first instinct. We start at coercion and frequently go no further. "If it saves one life" is the mantra that is so often repeated, ignoring the net loss of life because people avoided a system they were rightfully afraid would snatch them up without warning. The idea that we don't

see *Spoonful* on page 40




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The Mental Health News New York City Section

Autistic Children and Reading

By Roxanne Lanquetot, MA, MS

This article describes the way in which reading was taught to three nonverbal autistic children, the motivation used, and the children's adaptation to the learning situation.

Teaching reading to autistic children is unlike teaching reading to other children. Their learning follows no apparent rules of cognition, and it varies from child to child. However, most of the children have excellent visual discrimination and visual memory, capabilities which can be used in their education. If even only one activity can be found in which nonverbal, autistic children can achieve, they should be taught to exercise that skill, and their special visual abilities can be valuable in learning to read. Once these skills are progressing well, other behaviors may be modified without further special developmental training.

Following are three brief case studies illustrative of autistic behavior, cognition, and reading ability. The children in the studies were diagnosed autistic after their admission to the therapeutic nursery of Bellevue Psychiatric Hospital, New York City, where they remained for three months following a structured program and participating in a drug study. At the end of the study, some of the children



Roxanne Lanquetot, MA, MS

were selected on the basis of age and academic potential for transfer to the special education school located in the hospital. According to evaluations by the professional staff, their academic potentials were high relative to the functional level of the average autistic nursery patient. It is not surprising that these children could learn to read since they were selected for this purpose.

VICKIE

Vickie was a Black albino girl first seen at age 6 ½. She was admitted to the nursery for evaluation and placement in a special class in a day school. Although she had been diagnosed autistic at age 2, she was later certified legally blind so that she could attend a nursery school for the blind, the only school available. The girl was myopic and had impaired peripheral vision, which in no way interfered with her performance, except that she had to hold printed material close to her eyes. She was decertified blind at Bellevue.

A psychological assessment on the Gesell Developmental Schedule (1940) showed that Vickie was functioning on a third year level in motor skills and a two and half year level in language. She was in the fourth year in adaptive skills and in the middle of the third year level in personal and social development. (Due to the child's age the Gesell scores were only estimates.) She was in the severely retarded range in language, moderately retarded in motor development, and from 2 ½ to 3 years behind her age level in adaptive, personal, and social skills. The child adapted well to a group of three children although there was no real socialization with peers in play. When I worked with one of her classmates, she played by herself, putting puzzles together, tracing her name, or drawing pictures with crayons.

As soon as I began to work with an autistic child, I tried to establish a relationship by rewarding all positive efforts. Although I started working with Vickie using a modified reward system, it was soon obvious that rewards were not necessary. Lessons with an adult she liked and knowing she was progressing in her academic work were sufficient motivation. She seemed aware of her scholastic achievements when she interrupted her work to turn to me, smile, and thrust up her cheek to be kissed. After this display of affection, she snuggled up closer and redirected her attention to the task.

Speech and language were Vickie's areas of lowest functioning. Although she had a relatively large nominal vocabulary and learned new words easily, she uttered only a few words and phrases spontaneously. Some of these phrases were "Go to lunch!" "Bathroom, go bathroom," or "Coat," which signified that it was time to take the school bus home. The main part of her speech consisted of both functional and immediate echolalia. In spite of intensive training during her eight months at Bellevue, she continued to echo, even when she understood a question and could give the proper answer. An example of echolalia follows:

see Reading on page 41

What Parents Should Know About Expediting Diagnosis and Treatment When an Autism Spectrum Disorder (ASD) is Suspected

By Richard Perry, MD
Clinical Professor of Psychiatry
NYU School of Medicine

A mother called me recently to request that I evaluate her fourteen year old son. Actually, the request came after a ten to fifteen minute discussion during which she said that her son was diagnosed with Asperger's Disorder but that she is not sure if the diagnosis is correct nor does she know what to do about her son remaining in a school or program in the community or being placed in a boarding school. He had serious behavioral problems. She was a single parent and was burdened by the importance of her decisions. She told me that the diagnosis was done after the psychiatrist spent twenty minutes with her, fifteen minutes with her son and zero time to discuss planning. This is not the way it should happen whether a two year old or sixty year old is being evaluated for an ASD. After some

preliminary comments about the ASDs, I will propose what I think should happen.

ASDs, otherwise known as Pervasive Developmental Disorders (PDDs), have received much increased attention over the past two decades. However, knowledge about the disorders go back to the 1940s with the seminal papers of Leo Kanner and Hans Asperger. Dr. Kanner described children who today would be pretty closely meet the criteria of Autistic Disorder whereas Dr. Asperger, of course, described children that today are diagnosed with the disorder carrying his name. The increased attention given to the ASDs over the past two decades, appears to me to derive from the better treatments that were first described in the 1980s for those diagnosed with Autistic Disorder and the inclusion of Asperger's Disorder in the Diagnostic and Statistical Manual-4th. Edition in 1994. Better treatments, which required early diagnosis and rapid implementation sparked increased attention to the ASDs and the inclusion of Asperger's Disorder resulted in a great increase in the

diagnosis of individuals having milder forms of ASDs. During the 1970s and 1980s, the prevalence of ASDs was thought to be between 4 and 10 per ten thousand. Today, estimates go up to 60 per ten thousand.

I have been closely involved with individuals diagnosed within the autistic spectrum since 1979. There has always been a concern with delayed diagnosis and efforts to expedite it and treatment efforts. However things have changed. In the 1980s, many parents came to me months or even years after a diagnosis could have been made complaining that they continue to have grave concerns about their child's lack of relatedness and/or communication deficits and/or their odd interests and behaviors and they keep getting reassurances or comments that they worry too much. There is less of this today. Most of the frustration that I encounter today is about the older, more mildly impaired child who is having increasingly severe interpersonal and/or behavioral problems and is a diagnostic dilemma. Referrals

today for diagnostic evaluations does not end with school children. I and others get referrals for diagnostic evaluations from the parents of adolescents, from the parents of adult children who complain about their children's difficulties in interpersonal relations and in the workplace. Then there are adults who seek an evaluation. Their motivation for evaluation comes solely from themselves and/or from significant others in their lives.

Many young children will be referred for evaluation to an expert in the ASDs, by a pediatrician, school staff or by someone in the parent's social network. My opinion is that the initial referral should be made to either a psychiatrist or pediatric neurologist who has much experience with individuals within the autistic spectrum. Parents should expect in such an evaluation that it is sufficiently comprehensive so that they feel confident that the evaluator is basing his/her opinions on sufficient knowledge of the child. This

see Expediting on page 42

Understanding Sensory Integration Dysfunction (SID)

By Benjamin R. Sher, MA, LMSW
Director, Training and Staff Development
Institute for Community Living

When you were growing up, maybe you hated to wear t-shirts with labels on them, or maybe you knew someone who had a lot of trouble in large social settings, complaining that it was too noisy or over-stimulating. I remember for myself the “feeties” of blanket pajamas drove me crazy. As the science of the brain has progressed in understanding, we no longer define these reactions to certain stimuli as “unusual” or “different”. We now understand that they may be parts of a larger reaction to sensory issues known as Sensory Integration Dysfunction (SID). This article attempts to shed light on this phenomenon.

Though sometimes referred to as “sensory integration disorder,” “sensory processing disorder (SPD),” “sensory integrative dysfunction,” “sensory modulation disorder,” and even “dysfunction of (or dysfunctional) sensory integration (DSI),” the most simple term to use is “SI dysfunction” or “SID”. SID, of course, has nothing to do with SIDS (sudden infant death syndrome). Sensory integration has to do with how people use the information provided by all the sensations coming from within the body and from the external environment. Because the senses often work together to give us a reliable picture of the world and our place in it, someone with SI dysfunction has difficulty using this information to integrate a sensible picture of their world, or their sense may be diminished in one or more areas, so that they need to take in very large amounts of stimulus to experience a reaction.

SI dysfunction can be as simple as the examples listed in the first paragraph, where scratchy clothing labels or loud rock concerts overload the sense of feel or the sense of hearing, or they can be as dramatic as where you feel nauseated and sick from even the whiff of someone’s cologne. Again, people with SI dysfunction can also experience underdeveloped responses to stimuli. Here, the person may need heavy bodily contact or complete death-defying activities to *feel* and *experience* their environment.

To some extent, many of us have certain sensory tolerances and preferences. For example, when you know that you are in for a long lecture, do you bring gum to chew on or “fidgets” to play with to keep from being bored? Or, do you hate using goopy suntan lotion because you don’t like the way it feels on your body? Do you prefer spray-on lotions? These things may indicate your sensory preferences; you like auditory and visual stimulation, or you prefer a light touch to a heavy lotion on your body. When the issue moves in to the area of *dysfunction* is when the situation interferes with daily activities and learning. For example:

- Oversensitivity or undersensitivity to touch, sights, sounds, movements, tastes, or smells
- High distractibility, with problems



Benjamin R. Sher MA, LMSW

paying attention and staying focused on a task

- An unusually high or low activity level
- Frequent tuning out or withdrawing
- Intense, out-of-proportion reactions to challenging situations and unfamiliar environments
- Impulsiveness, with little or no self-control
- Difficulty transitioning from activity to activity or situation to situation
- Rigidity and inflexibility at times
- Clumsiness and carelessness
- Discomfort in group situations
- Social or emotional difficulties
- Developmental and learning delays and acting silly or immature
- Awkwardness, insecurity, or feeling “stupid” or “weird”
- Trouble handling frustration, tendency to tantrum longer and more intensely than other children do, and more difficulty returning to a calmed state
- Problems transitioning from an alert, active state to a calm, rested state (for example, difficulty falling asleep or waking, or doing a quiet activity after being very active and vice versa).

SI dysfunction is generally diagnosed in early childhood. As the body and senses develop, parents, teachers, and other individuals in the child’s life may begin to observe maladaptive responses to certain experiences. Most parents are familiar with the “terrible twos” or even “troublesome threes”. Children at this age struggle with making sense of their physical and emotional world at the same time that they are learning to become separate and individuated from their parents or guardians. SI dysfunction speaks more to continuous maladaptive responses to everyday situations, such as consistently showing behaviors that are not age-appropriate and that *cannot* be just dismissed as a “phase” of development.

Children with SI dysfunction have inconsistent responses to sensory information. Some children may be oversensitive (*hypersensitive*) to certain types of sensory input and undersensitive (*hyposensitive*) to other types of input. For example, a child who experiences auditory hypersensitivity may hate the sound of his aunt’s shrill

voice, while at the same time being hypersensitive to the low tone sounds of the lawn mower – he may love this sound. Sometimes, there is inconsistency in reactions to sensory input; one day a child may love splashing in the bath, and the next day, detest it vehemently. Is this the same child? Yes. A disorganized nervous system is just that, disorganized. Therefore, there may seem like no “rhyme or reason” to a child with SI dysfunction to various sensory stimulation.

Autism and SI Dysfunction

SID is a stand-alone diagnosis that is separate from the pervasive developmental disorder (PDD) spectrum of developmental disabilities. It can be seen as a symptom of autism; it is often chained with other childhood disorders, such as ADD, and it can be a diagnosis in and of itself. Simply because a child has sensory issues does not mean that they are necessarily autistic. Also, many of the interventions that are appropriate for a child who is autistic may not be so for the SID child, with the exception of the targeting of the sensory issues that they have in common. Childhood autism is a complex diagnosis of social interaction and responsiveness issues, communication challenges, and odd behaviors, interests, and activities. A child with autism may also have unusual responses to sensory stimuli that mirror SID; therefore, it is important that a qualified health professional (such as a pediatrician or a developmental neurologist) conduct a differential diagnosis to rule out a PDD.

The Causes of SI Dysfunction

There are no clear answers as to what causes SI dysfunction, only theories and correlations. SID is a dysfunction, not a disease. It can occur in conjunction with autism, or as a stand alone problem. It can be moderate, mild, or severe. It is usually seen in early childhood, and early intervention outcomes are quite positive. Some possible causes of SID include wiring in the developing brain, genetics, premature birth, or birth trauma and hospitalization. Let’s look closer at each issue.

The developing brain of an infant is an incredibly complex organ. As the brain is developing, millions of neurons and connections that carry reactions and expressions of thought are connecting and growing in the brain. It is amazing to think of the complexities associated with brain development, and a primary brain development function is myelination, or the developing of the protective sheath around neurons. Research is beginning to show that some children with SI dysfunction have under-developed myelinated areas of their brain, and their sensory problems are often linked to these areas. Some sensory problems are also related to an abnormal cerebellum, which seems to act as the “volume control” for sensory input.

Genetics may also play a part in SID. Sensory issues tend to cluster in families, as do the developmental problems that related to SID, such as autism or ADD. Though no twin studies have been done to examine the genetic relation of sensory

integration dysfunction, there are many anecdotal stories of an uncle who could not ride a bike, or a difficult child cousin who could tantrum for hours and hours.

There is some evidence that premature births lead to an increased risk for SI dysfunction. The developing fetus gets to spend a lot of time in a warm environment with much muted sounds, such as the beating of a mother’s heart. Premies are exposed to stimulus their nervous system may not be ready to handle; such as buzzing equipment and 24/7 room lighting. These experiences may “mark” the growing child’s nervous system, affecting how s/he reacts to stimuli later in life.

Birth trauma may also place a baby at increased risk for sensory issues, as may a prolonged hospitalization at a young age. These experiences again may imprint themselves on the growing nervous system of the infant, such as tactile defensiveness from being pricked by many needles, or having to spend time bedridden, away from usual childhood experiences.

Other issues may also affect sensory development, such as adoption, exposure to heavy metals, or a lack of sensory stimulation. In summary, many biological and environmental conditions can contribute to the problem of SID. Many parents or guardians may review these birth or infancy issues and wish that they could change the past. Unfortunately, what has occurred in the past is immutable; however, given early intervention and treatment, the prognosis for SID is quite good.

Treatment of SID

SID can be treated through occupational, physical and environmental changes. Children with SID generally experience challenges in one or more sensory areas; tactile, vestibular, and/or proprioceptive. Tactile issues relate to challenges in the area of touch. Children with SID in this area may experience oversensitivity, such that even the lightest touch sets their senses afire. Other children with tactile issues may crave touch; they love being piled under cushions or under heavy blankets. Touch can also relate to sensitivity to vibrations, to temperature changes, or even to sensations of pain.

Vestibular challenges relate to our position of our bodies in space. Gravity is constantly trying to pull us down; vestibular reception gives us the sensory information that we need to maintain our balance and to coordinate our movements as we move. Children that struggle with vestibular dysfunction may have difficulty in organizing more complex movement activities, such as riding a bike or even going down a slide. Other children may be vestibular junkies; they ride the swings for dear life or seek out the greatest thrills on the monkey bars, such as constantly hanging upside down.

Proprioception is the internal sense that tells us where our bodies are in space. It is the information that travels along the nervous system about our body positioning, such that we are not even aware of it. For example, as you read this article, your attention is focused on the concepts and

see SID on page 42

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Autism and the Sensory Diet

**Denise Lalande, Assistant Director
FEGS Manhattan Developmental Day
Treatment Program**

Jeffrey, a middle aged man with a diagnosis of Autism, is not interested in group activities and occasionally gets into power struggles with his peers. He prefers to do things his own way and lacks the expressive skills to make his needs known. Most of his communication is through gestures, including rocking back and forth and finger flicking. But once he joins the cooking group at the FEGS Manhattan Developmental Day Treatment Program and is given the right utensil and the vegetables that he needs his need for order becomes a useful strength. Jeffrey is one of the stars of the cooking group. Cooking is where Jeffrey can be part of the group, where his peers can compliment him and where his exquisite attention to detail, in this case chopping vegetables, is a real strength. When the time is right, Frank, another cooking group member, will say "Jeffrey, time for the vegetables" and he will pass them to the mixer. Being the 'prep-cook' for the weekly cooking group offers him the opportunity to participate with his peers, in a group setting, creating a shared meal.

Loving a dog, dicing and slicing vegetables, dancing to show tunes—any of these activities can make the day for a person with developmental disabilities and a diagnosis of Autism. It isn't an easy task to serve people with a primary diagnosis of profound to severe mental retardation and a secondary diagnosis of Autism spectrum disorder. In order to do so effectively, service providers need to put aside some aspects of traditional programming and services and employ more imaginative techniques to allow our participants to express themselves as individuals. Our programs and services can then function as a conduit for creativity in a structured setting, the conduit for an individual's sensory diet. This is especially important for people who have sensory issues that impede daily living.

What is the sensory diet?

Environmental factors both at home and at day program, set the tone for the day. If the room is too bright and the climate is not comfortable, an individual might react aversively or defensively to the stimuli. Sensory diets, which include auditory, visual, olfactory, tactile, and vestibular systems, contribute to how a person is going to react. Knowing an individual's sensory diet is crucial in making a multi-sensory experience both positive and productive. This can only be accomplished by really knowing the individual well, including their history, their likes and their dislikes.

Staff and management at the FEGS Manhattan Day Treatment Program are making a concerted effort each day to offer programming and services based on individuals' sensory diets. We offer revolving group and individual activities that build self-esteem and develop skills in a non-judgmental environment for our adults, aged 25-75, who have a diagnosis of Autism.

The Music and Dance Groups

The sensory diet can involve hearing, touch, and sight, all working together. On a

weekly basis, a group of individuals with varying levels of abilities, move, wiggle, sing or hum, and certainly laugh to their favorite songs with a our choreographer, from Hospital Audiences, Inc., who is sensitive to the participants' personal preferences. Mark, a man with Autism, prefers only to touch objects that are the colors he likes; he enjoys moving a blue scarf back and forth to Frank Sinatra's "New York, New York". The dance therapist who leads the group is aware of his sensory diet, making sure to have the blue scarves available for him when he chooses to join the group. Through these sessions, the dance therapist guides the participants through soothing movements and rhythms that invoke pleasurable feelings.

The Pet Therapy Group

The sensory diet can also involve interacting with pets. Angela, who is tactile defensive due to her diagnosis of Asperger's, usually does not like to be around others and avoids being touched. Most of her day is spent in doing her own activities, rarely socializing with others. After some coaxing and encouragement, she joined the pet therapy group and the day program staff realized that she likes to feel fur with her hands. Through New York Animal Hospital and the ASPCA, volunteer dogs visit our site with their owners as a part of a pet therapy group. Once in the group, Angela will stroke Chuck, the volunteer dog's black fur with gentle repetition and care. Angela's sensory diet involves avoiding touch and gravitating to quiet activities, so she enjoys the pet therapy group because it does not offend her sensibilities. Not only is she enjoying time spent with the dog, but the activity helps to activate the less rigid areas of her personality.

Knowing one's sensory diet and personal preferences and learning how to better adapt to one's environment are basic Snoezelen concepts. Snoezelen is an artificially created multi-sensory environment based on "Controlled Sensory Input". This concept was defined in the late 1970s by a therapist of Dutch descent while working with people with disabilities. With this in mind, we have incorporated at our site various pieces of sensory equipment to induce a state of relaxation. This stimulates primary areas including the auditory, visual, olfactory, tactile, and vestibular systems. This space is specially designed to provide choice, interaction, and relationship building in a soothing environment. In addition, it can also be effective in a short-term behavioral crisis. This is especially important for those with a diagnosis of Autism spectrum disorder as these individuals are often isolated from others and frequently misunderstood.

In our experience at FEGS, providing effective services to participants with a diagnosis of Autism Spectrum disorder means that staff must be in tune with client needs, preferences, and desires. Additionally we feel the program must take a holistic view of participants and value activities that encourage self-expression. Identifying individual abilities and preferences is key to any effective individualized service plan; when working with individuals with a diagnosis of Autism Spectrum Disorder, individual preference takes on even greater meaning. □

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JBFCFS Helps Children In The Early Years

By Marian Davidson-Amodeo, LCSW
Director of Child Development Center

When a family is faced with a diagnosis of autism, an array of questions, emotions and responses can surface for parents: "Why did my child develop this disorder?" "How will we care for our child?" "I feel like I lost my dream of a 'normal' family."

Through its Child Development Center, the Jewish Board of Family and Children's Services (JBFCFS) helps families of preschool children with this diagnosis. Autism is a general term for a continuum of developmental disorders of childhood that have become grouped under the phrase Autism Spectrum Disorders (ASD). JBFCFS also has a division of developmental disabilities that helps older children and young adults with severe autism that can co-exist with mental retardation.

ASD appears in a child's early years. "Typically by the time a child reaches the second birthday, surely by the third, the diagnosis has already been made. Earlier diagnosis leads to earlier intervention; intervention that can create new connections in the brain that enable communication and relationship with others," explains Dr. Bruce Grellong, our Chief Psychologist and Director of the JBFCFS Center for Child Development and Learning.

ASD is a neurological disorder of relating and communicating. The disorder affects a child's processing system for all the senses (seeing, hearing, touch, movement, etc.), language and social relationships. The symptoms are varied and will be different for each child, but typical behavior can include delayed language, repetitive actions like rocking back and forth, which can be a child's way of self-soothing, or "scripted language." Scripted language is an ability to use language to



Margo Bayroff, MEd, LCSW
and Marian Davidson Amodeo

recite stories by memory yet an inability to understand a parents' simple explanation like "we won't go to the park now, we'll go after lunch." Or a child may show great proclivity for numbers or sight reading words but lacks understanding of quantity or meaning. Parents often think such behavior suggests that the child may be advanced when, in fact, the child is displaying splintered skills that are symptomatic of the disorder.

Because children with ASD cannot negotiate language skills and can be very sensitive to receiving touch or hugs, these children can be difficult to parent.

These children are very attached to their parents, yet they may not give the affectionate social feedback to Mom and Dad that other kids typically do. These children can exhibit excessive temper tantrums that won't be easily soothed by parents' words or hugs.

"These children can require a lot of adult care to get their needs met," says Dr. Grellong. "All of this becomes stressful for a marriage. Parents need a lot of support and talking to other parents in similar

circumstances can be helpful. They also need information about the developmental delays and strategies and methods of intervention—both what we know and what we don't know. And they need the opportunity to grieve the diagnosis, that the disorder was not what they expected when they planned to have a family."

The JBFCFS Child Development Center (CDC) offers family therapy to help parents work through these issues. What's unique about CDC programs is the focus on the whole family, not just the children's needs. We spend a lot of time understanding how a family is organized because services have to be tailored both to what the child requires and what the family can provide. Parents are our partners and together we design a treatment plan that will support the parents as well as the child.

CDC offers an Early Intervention parent-child program five mornings a week with eight families and a program for four families three afternoons a week. Children start at age 2 or 2 1/2 and stay one academic year, September through mid-August. This program is funded and regulated by the New York City Department of Health and Mental Hygiene. Most of the children will continue the following year in the CDC therapeutic nursery school which is a funded by the New York City Department of Education, Committee on Pre-School Education.

The nursery school has 24 children who have developmental delays; almost half the children are diagnosed with ASD. There are three classes with each staffed by a New York State licensed, masters-level special educator and two assistants, typically in graduate programs in education. The school provides a team approach with an interdisciplinary staff of special educators, social workers, psychologists, speech and language pathologists, occupational therapists, physical therapists, music therapists and consulting psychiatrists.

Family participation is considered an essential part of the team approach.

Our nursery school children have significant sensory vulnerabilities. We work with the children so that they become more comfortable with their environment and typical pre-school experiences. We have children who disliked noise now able to participate in music and singing time or children who were reluctant to touch sand now able to play at a sand table.

The digital camera has proved to be a very effective curriculum aide for working with the children in the program. Staff can help children by creating meaningful materials to help them process information. That same child who had a script to follow from rote memory can instantly have photographs that concretely and vividly represent their experience. Teachers and therapists use these photos to help support the child's language by creating a narrative, strengthening their sequencing skills, and as aides for helping the child relate their experience to others.

When children become too old for the nursery school and are ready to move to another school, CDC offers the family and children much needed support through that process. Applying to another program is stressful. Often the children participate in as many interviews as a high school student applying for college. It is also a trying time for parents because they may want their child to go to a particular school, and the school may have a limited number of places for children.

At CDC, we're committed to helping families receive the services and support that meets their individual needs. Our team approach and focus on the family is our trademark in the field. □

For more information about the Child Development Center programs or other programs of the Center for Child Development and Learning, please call 212 632-4499.

Mental Health For Individuals With ASD's

By Valerie Gaus, PhD

In recent years, mental health issues have gained more attention with an estimated 54 million people in the nation suffering from mental disorders. According to a 2001 study by the World Health Organization, mental health ranks first in terms of causing disability in the United States, Canada, and Western Europe (WHO, 2001). The study also found that mental illness — including depression, bipolar disorder, and schizophrenia — accounts for 25 percent of all disability across major industrialized countries. For individuals with autism spectrum disorders (ASD's), the risk of developing mental illness is no less than it is for the general population. For their parents and caregivers, mental illness presents yet another challenge to add to the list of social, educational and behavioral issues they have to contend with. The intent of this article is to address some of

the most common questions parents and caregivers pose about mental illnesses in individuals with ASD's, as well as to offer strategies that will allow them to successfully advocate for quality treatment.

What is mental health and how is it defined for people with ASD's?

Can a person with an autism spectrum disorder be "mentally healthy?" Before that question can be answered, we must define "mental health" and what it means for any person, whether neurotypical or on the autism spectrum. There are endless debates in the psychological literature about this question, but for the purposes of this article, I will offer Dosen's (1993) idea. Mental health is achieved when one has: limited stress in daily living, a place of one's own and a role in his/her surroundings, and achieved functioning in accordance with one's own abilities.

A person with ASD may need help in tackling obstacles that can potentially

interfere with the attainment of the above criteria. However, with the necessary help, persons with ASD can achieve and/or maintain mental health.

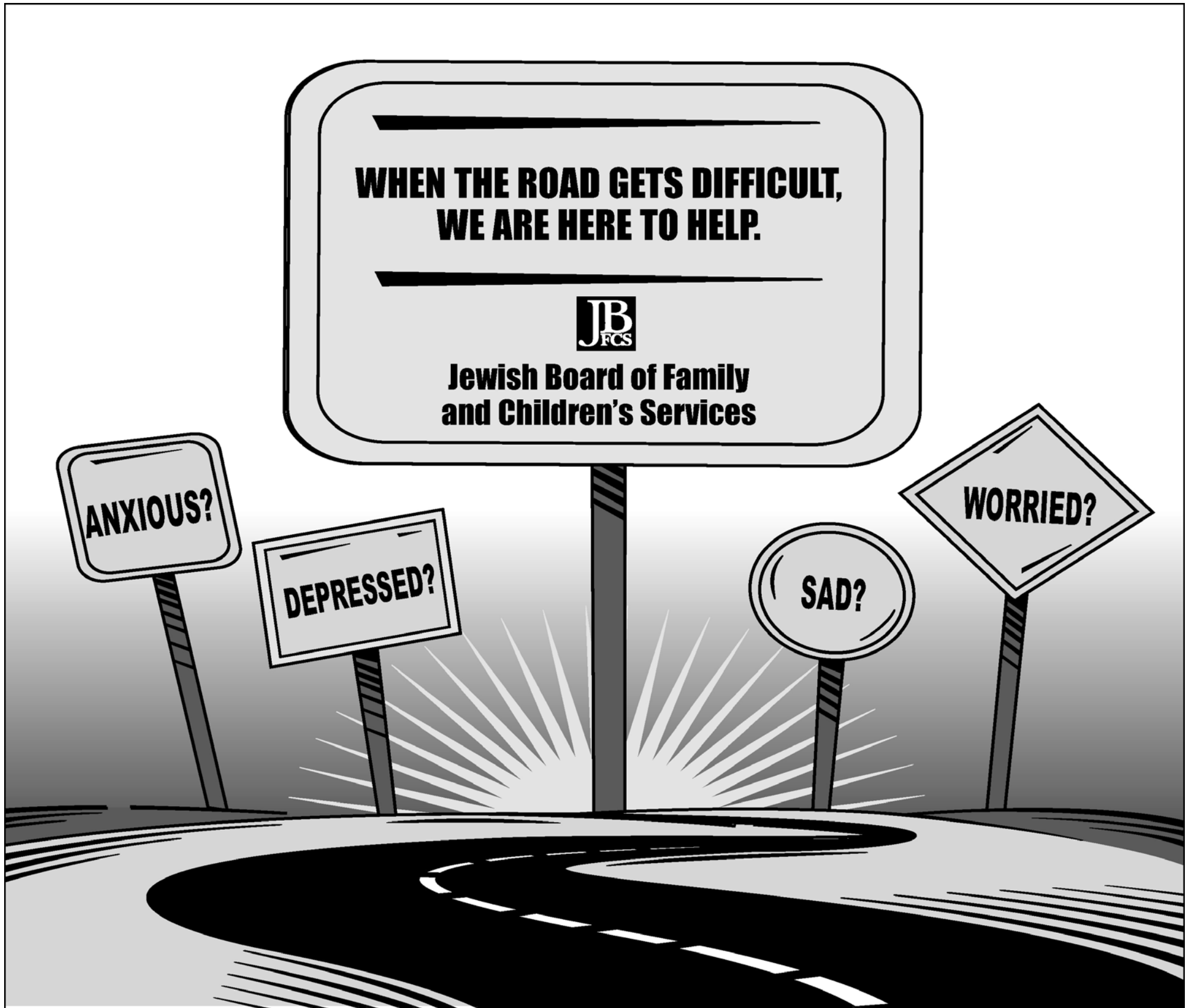
Can a person with an ASD have a mental health problem too?

Throughout the lifespan, there are many things that can lead any person to develop a mental health problem. These issues do not necessarily cause mental illness, but simply increase a person's vulnerability. Some risk factors for the neurotypical population are:

- poor social support,
- presence of central nervous system damage,
- low expectations for success,
- sense of helplessness,
- limited economic resources,
- high levels of stress in family,
- presence of physical disability,
- a chronic medical problem,
- and a family history of mental illness.

Unfortunately, there have not been any thorough studies on the prevalence of mental health disorders in the ASD population. Most studies on "comorbidity," or the co-existence of a psychiatric condition with ASD, have been based only on case reports (Gillberg & Ehlers, 1998). Preliminary studies have suggested that for some disorders, the incidence is higher for people with ASD than would be found in the general population. For example, Klin & Volkmar (1997) found in a sample of 99 individuals with ASD that 28 percent also met criteria for ADHD, 19 percent showed obsessive-compulsive disorder and 15 percent had depression. DeLong & Nohria (1994) reported a higher incidence of bipolar mood disorder in persons with ASD and within their families than found in the general population. Conversely, psychotic disorders (e.g., schizophrenia) do not appear to be more prevalent in people with ASD (Tantam, 2000), and may

see Mental Health on page 33



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MHA of NYC A Partner in City's Heightened Focus on Depression

**By Giselle Stolper, Executive Director
The Mental Health Association
Of New York City**



Giselle Stolper

In 2004 the New York City Department of Health and Mental Hygiene (DOHMH) launched its groundbreaking public health campaign, Take Care New York, which encourages New Yorkers to take important but simple steps to improve their health of New Yorkers. These 10 steps included getting help for depression and living free of drugs and alcohol. This year, DOHMH is putting the spotlight on depression. The Mental Health Association of New York City (MHA of NYC) is pleased to assist.

A recent study issued by DOHMH puts the issue of depression in a new light. Three quarters of a million New York City adults reported experiencing frequent mental distress last year, according to new data from DOHMH. Nearly 1 in 7 adults (13 percent) living in the five boroughs reported frequent mental distress in 2005, compared with approximately 1 in 10 adults in New York State and the nation.

These data were collected in DOHMH's annual Community Health Survey from 2003 and 2005, an annual phone survey of 10,000 New York City adults. Individuals who reported that their mental health (including stress, depression or problems with emotions) was "not good" on 14 or more days of the past month were classified as having frequent mental distress. Among the barriers to treatment included both stigma, and a lack of knowledge about the symptoms of depression and then, how to get help. That

is where the MHA of NYC can provide a much needed service.

During Mental Health Month in May, the MHA of NYC teamed up with DOHMH and the Citywide Children's Committee to coordinate Children's Depression Screening Day, which provided depression screenings and literature to hundreds of individuals and families at multiple sites throughout the five boroughs.

There is also great need to address high rates of depression in New York City among older adults, where DOHMH and the New York City Department for the Aging (DFTA) estimate that over 400,000 of our seniors suffer from the illness. Many older adults struggle because they believe that feeling depressed is a natural part of the aging process, or they are ashamed or afraid to seek help for experiencing the symptoms of depression: feeling sad, listless or sleepless, uninterested in friends, family or activities they used to enjoy.

Depression in older persons is closely associated with physical illness, social isolation, bereavement, and dependency. It not only causes suffering for individuals, caregivers, and families, it can result in suicide as well. Yet getting older and becoming depressed do not go hand-in-hand. Far from it! Depression can be effectively treated, often with as much or more success than treatment of other medical conditions -- for example, the effectiveness of treatment of mild depression can be between 60 and 80 percent.

To address high rates of depression in older New Yorkers, the MHA of NYC, in partnership with DOHMH and DFTA, is coordinating free depression screenings in English and Spanish -- as well as referrals -- for older adults in 23 senior centers, reaching approximately 1,000 older adults, through South and Central Bronx.

DOHMH is also providing education to primary care practitioners to help identify symptoms of depression. In February, approximately 50,000 healthcare practitioners throughout the five boroughs received a newsletter detailing information about symptoms and treatment for depression. In the Bronx specifically, 200 primary care physicians received comprehensive detailing kits, and more than 200 case workers, senior center staff and home health aides were trained about depression and other types of mental illness among older adults.

In May, DOHMH also launched a new campaign that encourages New Yorkers to be aware of signs and symptoms of depression and if they have concerns, to reach out to their primary care physicians or call 1-800-LIFENET, the multicultural, mental health crisis, information and re-

ferral hotline which the MHA of NYC operates under a contract with DOHMH. Posters are appearing on subways, on the outside of buses, and check cashing sites in the 3 high-need neighborhoods in NYC, South Bronx, North Central Brooklyn and Harlem. The MHA of NYC is monitoring LifeNet call volume and will present data for DOHMH to evaluate the campaign's reach.

We are very pleased to partner with DOHMH on such an important initiative. This depression screening program is a significant step toward helping New Yorkers live healthier, longer lives.

If you or a friend or relative feels the symptoms of depression, help through LifeNet is just a phone call away. Call 1-800-LIFENET for information and referrals to nearby services. □



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GET HELP FOR DEPRESSION:
A Key Step to a
Healthier New York

YAI/NIPD Network and Mount Sinai Join Forces To Further Quality of Care for People with Autism

Staff Writer
Mental Health News

The YAI/National Institute for People with Disabilities (YAI/NIPD) Network and The Seaver and New York Autism Center for Excellence at the Mount Sinai School of Medicine, announced an affiliation today to offer enhanced programs and greater access to diagnostic treatment and services for children and adults with Autistic Spectrum Disorders (ASD).

"The need for the provision of treatment and services for people with Autism Spectrum Disorder has never been greater," said Dr. Joel M. Levy, CEO, YAI/NIPD, during the organization's 27th Annual International Conference. "We are certain that the YAI/NIPD Network's partnership with Mount Sinai School of Medicine and The Seaver and New York Autism Center for Excellence will play a pivotal role in addressing this pressing need."

"The goal of this endeavor is to create a premier autism center in New York. Mount Sinai's expertise in research and evaluation and the YAI/NIPD's Network's capacity and reputation in services and treatment will create a unique program," said Kenneth L. Davis, MD, Presi-

dent and C.E.O., The Mount Sinai Medical Center and Dean, Mount Sinai School of Medicine. "We believe this combined venture will serve as a model for other programs throughout the country."

The Mount Sinai School of Medicine has been at the forefront of autism treatment and research for several years, translating scientific discovery into better diagnostic tools and treatment. In 2003, Mount Sinai's Seaver and New York Autism Center of Excellence was named a Center of Excellence by the National Institutes of Health and awarded a grant as part of the Studies to Advance Autism Research and Treatment (STAART) Centers Program initiative. Mount Sinai is one of only eight such centers around the country. The YAI/NIPD Network has been a leader in the field, providing programs for people with autism and other developmental disabilities for nearly 50 years. The partnership will bring the highest levels of quality care and access to state-of-the-art evaluation, diagnosis, treatment and services for patients with ASD.

"I am so pleased to be a part of this journey," said Eric Hollander, MD, Chairman of Psychiatry and Director of the Seaver and New York Autism Center for Excellence at Mount Sinai. "Combining forces with the YAI/NIPD Network will

benefit many patients and families dealing with this disease. Both institutions are equally committed to furthering a singular mission, to provide the highest quality of care and access to evaluation, diagnosis treatment and services for all patients with ASD."

Individuals served within the YAI/NIPD Network's, including patients at Premier HealthCare, a medical practice with doctors, dentists and specialists trained to treat this population, will have access to Mount Sinai's nationally acclaimed evaluation services and opportunities to participate in their internationally recognized research programs which produce vital information on ASD.

Mount Sinai patients will have access to the coordinated services available through Premier HealthCare, cited by the U.S. Surgeon General as a national model for the provision of health care for people with developmental disabilities.

"We are very proud of our new affiliation with the YAI/NIPD Network," said Eric Hollander, M.D., Director of the Seaver and NY Autism Center of Excellence, and Esther and Joseph Klingenstein Professor and Chair of Psychiatry at Mount Sinai School of Medicine. "This is an important step in increasing research, enhancing services and bridging the gap between outstanding academic research

centers and treatment providers. The autism community as a whole will greatly benefit from this partnership."

"We have a long history of collaboration with the YAI/NIPD Network and we believe that this will be yet another success," said Robert Southwick, Associate Dean of the Mount Sinai School of Medicine. "You have bright people caring for a challenging population matched with experts from a world-renowned autism center. This is a great fit for the two organizations; the synergy draws upon the assets of both."

Dr. Ilana Slaff will serve as an Autism Fellow, dividing her time and professional duties between both organizations. Dr. Slaff will perform clinical work, facilitate patient referral and coordination of care, share up-to-date ASD information with clinical staff, and contribute to newsletter articles and presentations at YAI/NIPD Network conferences and lecture series.

"This partnership creates an extraordinary opportunity for both organizations and for the thousands of individuals and families we serve," said Dr. Philip H. Levy, President of YAI/NIPD.

For more information about autism services available through the YAI/NIPD Network, please call 1-866-2-YAI-LINK or visit yai.org. □

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- Have trouble making friends or maintaining a relationship?

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GCO #01-1295; IRB approved through 4/30/2007



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- ▶ Do you have trouble making friends or maintaining a relationship?
- ▶ Did you have any difficulties with language development as a young child?

If you have answered yes to any of these questions and are between the ages of 18-65, you may qualify for a no-cost evaluation with participation in a medication treatment study or neuroimaging study for Autism Spectrum Disorders at the Seaver and New York Autism Center of Excellence, Mount Sinai School of Medicine, New York, NY. Our studies are conducted to see if certain medications may be helpful in the treatment of behavioral symptoms associated with autism. The medications we use in our studies are approved by the FDA for treatment of other conditions, not autism.

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GCO# 04-1106 IRB approved through 1/3/07

Silver Hill Hospital Introduces Dialectical Behavior Therapy

Staff Writer
Mental Health News

Silver Hill Hospital has introduced a dedicated Dialectical Behavior Therapy (DBT) program with a clinical staff trained in DBT. Each DBT patient's treatment program will be planned and coordinated by a treatment team of psychiatrists, social workers and nurses who have had specialized training.

DBT is a proven treatment for people with a history of impulsive behaviors including attempts at suicide and other forms of self-harm. DBT at Silver Hill will be tailored to benefit a broad spectrum of problems including: difficulties with impulsive behaviors, poorly regulated emotions, unstable relationships, substance abuse and eating disorders.

Silver Hill's program will focus on DBT skills training groups and coaching. In addition to skills training, each patient will meet with their individual therapist weekly. Their therapist and members of their treatment team will



Sigurd Ackerman, MD

coach them on how to apply the skills they are learning to specific situations they are experiencing in their lives.

Skills training will include:

- Mindfulness: Skills to help patients be aware, without judgment, of life as it

is, yourself as you are, other people as they are via direct and immediate experience. Mindfulness helps people get better at enduring pain, solving problems, not creating misery for themselves and participating fully in the moments of life that are joyful.

- Emotion Regulation: Skills allowing patients to learn how to turn down their "emotional temperature" and become less reactive to people and situations in their lives. Emotion Regulation skills enable patients to better understand their emotions, decrease suffering and to increase their experience of positive emotions.

- Interpersonal Effectiveness Skills: Skills helping patients learn how to nurture relationships, meet their own needs and keep their self respect.

- Distress Tolerance: This module allows patients to learn how to survive a crisis with grace and wisdom. It is a part of what DBT calls an "acceptance strategy", helping patients learn to tolerate unavoidable losses without hurting

themselves or others.

The Silver Hill Hospital campus includes both inpatient treatment facilities as well as residential Transitional Living Programs. Patients can benefit from DBT skills training as part of their inpatient treatment program designed to focus on rapid evaluation, relief from symptoms of illness, and, if indicated, detoxification from substances of abuse.

Once a patient is stabilized they can continue their DBT program in Transitional Living at Silver Hill. Patients who have received hospitalization somewhere else to stabilize their symptoms can directly enter Silver Hill's DBT program in Transitional Living.

DBT requires a minimum 28-day stay although some patients may stay longer.

Dr. Sigurd Ackerman, President and Medical Director of Silver Hill Hospital, explains that "the great advantage of living in a DBT-focused residence is the opportunity to generalize the skills learned during treatment sessions to the entire 24-hour day. For many patients this is the most powerful recovery experience they will ever encounter." □

At the Children's School at Westchester Arc Early Intervention and Pre-School Can Change Lives

Staff Writer
Mental Health News

Westchester Arc Executive Director, Ric Swierat explains, "Our Children's School for Early Development is celebrating its 50th anniversary this year, and we have made an important difference in the lives of thousands of youngsters, many of whom have had autism." The school has been teaching children with autism for two decades, and in 2004 was recognized by the Westchester Foundation for Autism and Related Delays (WFA) for its innovative and caring approach.

The pre-school itself serves children from the ages of three to five in both center-based and community settings, but its early intervention services, available from birth to the age of three, are seen as critical to realizing a child's potential.

"Research has shown that the brain is a sponge from birth to five," explains service coordinator Isabel Leach. "If there are any delays, that's the best time to address them."

Depending upon an individual child's profile, speech, occupational and/or physical therapy may be involved. Occupational therapy involves fine motor skills such as picking up a pencil or reactions to stimuli from the environment. For instance, a child with autism might refuse to walk on grass or wear socks. Physical therapy, on the other hand, involves gross motor skills such as walking, balancing or sitting up.



Ric Swierat

At three, attention shifts to learning skills, although all other supports may continue, depending on a child's needs. "Autism requires very intensive educational techniques that differ from those used to teach children with other developmental disabilities," explains Developmental Psychology Consultant Ann-Marie Sabrsula. "For some time, we have been using ABA/VB (Applied Behavior Analysis/Verbal Behavior), which focuses on observable speech and language behaviors." The pre-school's staff is trained by Dr. Vincent Carbone, interna-

tionally recognized for his research on teaching children with autism how to communicate.

The school's center-based classes in Hawthorne are very structured and intensive, with each child's curriculum combining one-to-one instruction with "natural environment" learning. The majority of the pre-school's students, however, learn alongside typically developing youngsters in community settings. Almost half of the children who begin in "contained" settings move to community classes at some point during their pre-school years.

"Our center-based classes concentrate more on language, while the inclusion classes focus more on social skills," explains Helga Coiro, who teaches one of the Hawthorne groups. "The children who come to me don't have many words. They may point or cry when they want something. They may not know how to put a doll into a bed or a spoon into a cup." The young students first learn signs and gestures, then build upon those skills, eventually acquiring words.

Catherine M. began attending classes in Hawthorne during fall 2004. She had no language or play skills. "She would just line up her dolls," explains her mother, Theresa. "She had a lot of difficulty with transitions—you couldn't change things."

Now she can share a dollhouse with classmates. She knows her colors and can even spell her name. "She must still be prompted to use words," says Theresa, "but when I ask her what my name is, she says, *Mommy*."

The Children's School's inclusion classes are held in conjunction with 12 pre-schools throughout Westchester County. There children with autism learn alongside and from their typically developing peers. Westchester Arc's pre-school was the first in the county to offer specialized, day-long inclusion classes to children with autism.


"The kids love it, and they would never do so well in contained settings," says Dona Delohery a teacher at Mascia Day Care in Tarrytown. "A child will go home and announce, 'I have a best friend!'"

Often, the children in inclusion settings have begun in self-contained classes, then transitioned to mixed playgroups and, finally, to community-based classes. In order to attend inclusion classes, they must already know how to learn in a larger group of peers, follow directions and accept the greater noise and activity level of a typical day care setting.

Inclusion classes concentrate on social skills—sharing, taking turns, learning that they won't always win—but occupational, physical and speech therapy continue. Like all pre-schoolers, the children learn their alphabet, numbers and how to classify things—"Name a vegetable." Everyone has "jobs." They might hand out napkins, be line leader or weather helper. It's a naturally reinforcing environment.

The typical children are very accepting. Delohery describes a situation in which a three-year-old boy had trouble hanging his coat in his cubby.

see Pre-School on page 38

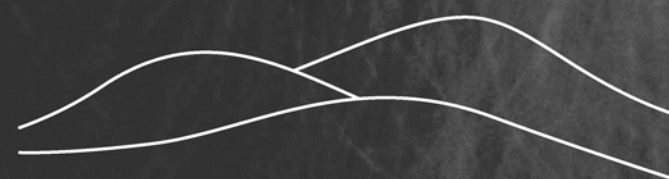


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United Kingdom, Europe, and Asia. Prevalence estimates range from 2 to 6 per 1,000 children. This wide range of prevalence points to a need for earlier and more accurate screening for the symptoms of ASD. The earlier the disorder is diagnosed, the sooner the child can be helped through treatment interventions. Pediatricians, family physicians, daycare providers, teachers, and parents may initially dismiss signs of ASD, optimistically thinking the child is just a little slow and will "catch up." Although early intervention has a dramatic impact on reducing symptoms and increasing a child's ability to grow and learn new skills, it is estimated that only 50 percent of children are diagnosed before kindergarten.

All children with ASD demonstrate deficits in 1) social interaction, 2) verbal and nonverbal communication, and 3) repetitive behaviors or interests. In addition, they will often have unusual responses to sensory experiences, such as certain sounds or the way objects look. Each of these symptoms runs the gamut from mild to severe. They will present in each individual child differently. For instance, a child may have little trouble learning to read but exhibit extremely poor social interaction. Each child will display communication, social, and behavioral patterns that are individual but fit into the overall diagnosis of ASD.

Children with ASD do not follow the typical patterns of child development. In some children, hints of future problems may be apparent from birth. In most cases, the problems in communication and social skills become more noticeable as the child lags further behind other children the same age. Some other children start off well enough. Oftentimes between 12 and 36 months old, the differences in the way they react to people and other unusual behaviors become apparent. Some parents report the change as being sudden, and that their children start to reject people, act strangely, and lose language and social skills they had previously acquired. In other cases, there is a plateau, or leveling, of progress so that the difference between the child with autism and other children the same age becomes more noticeable.

Possible Indicators
of Autism Spectrum Disorders:

- Does not babble, point, or make meaningful gestures by 1 year of age
- Does not speak one word by 16 months
- Does not combine two words by 2 years
- Does not respond to name
- Loses language or social skills

Some Other Indicators:

- Poor eye contact
- Doesn't seem to know how to play with toys
- Excessively lines up toys or other objects
- Is attached to one particular toy or object
- Doesn't smile
- At times seems to be hearing impaired

Social Symptoms

From the start, typically developing infants are social beings. Early in life, they gaze at people, turn toward voices, grasp a finger, and even smile.

In contrast, most children with ASD seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interaction. Even in the first few months of life, many do not interact and they avoid eye contact. They seem indifferent to other people, and often seem to prefer being alone. They may resist attention or passively accept hugs and cuddling. Later, they seldom seek comfort or respond to parents' displays of anger or affection in a typical way. Research has suggested that although children with ASD are attached to their parents, their expression of this attachment is unusual and difficult to "read." To parents, it may seem as if their child is not attached at all. Parents who looked forward to the joys of cuddling, teaching, and playing with their child may feel crushed by this lack of the expected and typical attachment behavior.

Children with ASD also are slower in learning to interpret what others are thinking and feeling. Subtle social cues—whether a smile, a wink, or a grimace—may have little meaning. To a child who misses these cues, "Come here" always means the same thing, whether the speaker is smiling and extending her arms for a hug or frowning and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering. To compound the problem, people with ASD have difficulty seeing things from another person's perspective. Most 5-year-olds understand that other people have different information, feelings, and goals than they have. A person with ASD may lack such understanding. This inability leaves them unable to predict or understand other people's actions.

Although not universal, it is common for people with ASD also to have difficulty regulating their emotions. This can take the form of "immature" behavior such as crying in class or verbal outbursts that seem inappropriate to those around them. The individual with ASD might also be disruptive and physically aggressive at times, making social relationships still more difficult. They have a tendency to "lose control," particularly when they're in a strange or overwhelming environment, or when angry and frustrated. They may at times break things, attack others, or hurt themselves. In their frustration, some bang their heads, pull their hair, or bite their arms.

Communication Difficulties

By age 3, most children have passed predictable milestones on the path to learning language; one of the earliest is babbling. By the first birthday, a typical toddler says words, turns when he hears his name, points when he wants a toy, and when offered something distasteful, makes it clear that the answer is "no."

Some children diagnosed with ASD remain mute throughout their lives. Some infants who later show signs of ASD coo and babble during the first few months of life, but they soon stop. Others may be delayed, developing language as late as age 5 to 9. Some children may learn to use communication systems such as pictures or sign language.

Those who do speak often use language in unusual ways. They seem unable to combine words into meaningful sentences. Some speak only single words, while others repeat the same phrase over and over. Some ASD children parrot what they hear, a condition called echolalia. Although many children with no ASD go through a stage where they repeat what they hear, it normally passes by the time they are 3.

Some children only mildly affected may exhibit slight delays in language, or even seem to have precocious language and unusually large vocabularies, but have great difficulty in sustaining a conversation. The "give and take" of normal conversation is hard for them, although they often carry on a monologue on a favorite subject, giving no one else an opportunity to comment. Another difficulty is often the inability to understand body language, tone of voice, or "phrases of speech." They might interpret a sarcastic expression such as "Oh, that's just great" as meaning it really IS great.

While it can be hard to understand what ASD children are saying, their body language is also difficult to understand. Facial expressions, movements, and gestures rarely match what they are saying. Also, their tone of voice fails to reflect their feelings. A high-pitched, sing-song, or flat, robot-like voice is common. Some children with relatively good language skills speak like little adults, failing to pick up on the "kid-speak" that is common in their peers.

Without meaningful gestures or the language to ask for things, people with ASD are at a loss to let others know what they need. As a result, they may simply scream or grab what they want. Until they are taught better ways to express their needs, ASD children do whatever they can to get through to others. As people with ASD grow up, they can become increasingly aware of their difficulties in understanding others and in being understood. As a result they may become anxious or depressed.

Repetitive Behaviors

Although children with ASD usually appear physically normal and have good muscle control, odd repetitive motions may set them off from other children. These behaviors might be extreme and highly apparent or more subtle. Some children and older individuals spend a lot of time repeatedly flapping their arms or walking on their toes. Some suddenly freeze in position.

As children, they might spend hours lining up their cars and trains in a certain way, rather than using them for pretend play. If someone accidentally moves one of the toys, the child may be tremendously upset. ASD children need, and demand, absolute consistency in their environment. A slight change in any routine—in mealtimes, dressing, taking a bath, going to school at a certain time and by the same route—can be extremely disturbing. Perhaps order and sameness lend some stability in a world of confusion.

Repetitive behavior sometimes takes the form of a persistent, intense preoccupation. For example, the child might be obsessed with learning all about vacuum cleaners, train schedules, or lighthouses. Often there is great interest in numbers, symbols, or science topics.

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Rare Autism Spectrum Disorders

Rett Syndrome

Rett syndrome is relatively rare, affecting almost exclusively females, one out of 10,000 to 15,000. After a period of normal development, sometime between 6 and 18 months, autism-like symptoms begin to appear. The little girl's mental and social development regresses—she no longer responds to her parents and pulls away from any social contact. If she has been talking, she stops; she cannot control her feet; she wrings her hands. Some of the problems associated with Rett syndrome can be treated. Physical, occupational, and speech therapy can help with problems of coordination, movement, and speech.

Scientists sponsored by the National Institute of Child Health and Human Development have discovered that a mutation in the sequence of a single gene can cause Rett syndrome. This discovery may help doctors slow or stop the progress of the syndrome. It may also lead to methods of screening for Rett syndrome, thus enabling doctors to start treating these children much sooner, and improving the quality of life these children experience.*

Childhood Disintegrative Disorder

Very few children who have an autism spectrum disorder (ASD) diagnosis meet the criteria for childhood disintegrative disorder (CDD). An estimate based on four surveys of ASD found fewer than two children per 100,000 with ASD could be classified as having CDD. This suggests that CDD is a very rare form of ASD. It has a strong male preponderance.** Symptoms may appear by age 2, but the average age of onset is between 3 and 4 years. Until this time, the child has age-appropriate skills in communication and social relationships. The long period of normal development before regression helps differentiate CDD from Rett syndrome.

The loss of such skills as vocabulary are more dramatic in CDD than they are in classical autism. The diagnosis requires extensive and pronounced losses involving motor, language, and social skills.*** CDD is also accompanied by loss of bowel and bladder control and oftentimes seizures and a very low IQ.

*Rett syndrome. NIH Publication No. 01-4960. Rockville, MD: National Institute of Child Health and Human Development, 2001. Available at <http://www.nichd.nih.gov/publications/pubskey.cfm?from=autism>

**Frombonne E. Prevalence of childhood disintegrative disorder. *Autism*, 2002; 6(2): 149-157.

***Volkmar RM and Rutter M. Childhood disintegrative disorder: Results of the DSM-IV autism field trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 1995; 34: 1092-1095.

Education and Psychosocial Rehabilitation for Children and Adults with a Diagnosis of Autism

**By Martin Gittelman,
Clinical Professor, Dept of Psychiatry
NYU Medical School**

In the lifetime of some of us there has been a sea change in how children with severe behavior disorders are viewed. Fifty years ago there was little dispute about the issue of autism. Such children were considered part of a group of children termed childhood schizophrenics and the etiology was considered to be their mothers. The mothers were seen as "detached and cold" and termed, "schizophrenogenic mothers" and were given treatment to assist them to become less detached and cold towards their children.

Many of us entering the field disbelieved such conventional wisdom. With Herbert Birch and Mike Rutter and Carl Fenichel we set to work studying these youngsters. Regarding etiology (See Gittelman and Birch, Archives of General Psychiatry, 1967 Childhood Schizophrenia) we found no evidence for parentogenesis. Rather we found overwhelming evidence for etiology as a result of perinatal complications--80% of the children had perinatal complications and many had classical neurological signs. Moreover when we studied the siblings of these children we found that our cohort resembled the distribution of children with normal developmental course. Clearly, our index children had developmental problems due to cerebral dysfunction.

The next issue to be tackled was that of appropriate intervention. British colleagues, Neil O'Connor and Beate Hermelin; and those in America: Rick Heber and Carl Fenichel had shown that such children required

special education to develop to their full potential. Education was most important prerequisite to prepare these youngsters for life and work. The problem was that such education was unavailable for such children with special needs. In America in the 1960's and early 1970's few school districts accepted seriously behaviorally disturbed children. They were excluded. A few cities and states offered "vouchers" to families to assist in paying for private school placement. New York State passed the Greenberg Law which provided \$2000. for each child excluded from public education. With funds available, many private schools were initiated and which accepted seriously behaviorally disturbed children. However, because of the enormous need and the paucity of schools, tuition costs quickly rose much beyond the amount given by the Greenberg Law. To solve that problem people such as Irving Blumberg, Carl Fenichel, Senator Edward Kennedy, Bernard Rimland and the Association for the Help of Retarded Children and other family groups pressed and lobbied Congress and finally won the Federal funding for the "Education for All Handicapped Children" Act. The law provided for federal funds for locally provided public special education for all handicapped children regardless of handicap, but only to the age of 16.

Prior to the organization of families of the disabled and passage of the law, disabled children were simply excluded from public education.

With passage, some school districts began to offer appropriate special education for these children based on extensive evaluation of their needs. It was clear from the outset that class size was important and as Carl Fenichel had demonstrated at the League School, effective education

required that these children with complex disabilities required a ratio of one teacher for each four children.

Today, as we look at the situation for children diagnosed with Autism we see that many of the same challenges remain. What is needed?

First, strong family associations to advocate for the needs of these children on a local, State and federal level. Without a strong family advocacy organization, lone families will not have their child's needs met.

Second, better educational programs for these youngsters. Today there is a scarcity of quality special educational programs in many communities, especially those in low income areas.

Third, it needs to be stressed that children grow quickly and as young adults, they require vocational opportunities. Substantial compensation and tax benefits for employers who hire the disabled, sheltered work, on the job training and especially the availability of special education until each child reaches a mental age of 14 years.* Such education is available in all of Scandinavia and in many European countries. Incidentally, it is important for family associations to have contact with European Family associations and also possibly arrange for educational seminars in Europe where education and services are advanced.

In the 1950's Denmark required all new residential construction to reserve some residential units for the aged and also for the handicapped and disabled. Finally, it is important that we have accurate epidemiological and population surveys to learn whether vaccines or other factors have indeed caused increased incidence of Autism and /or other childhood

behavioral disorders. This is an important issue and family associations will need to press for restoration of the funds recently cut from budgets for the Centers for Disease Control and National Institute of Mental Health.

A mental age of fourteen years has been found the minimum mental age maturity for employment in northern Europe. Mental age differs from chronological age in that it is based on intelligence testing. A child who is chronologically 16 years old may have an IQ of 50, indicating such a child is developing at 50% of usual development. Such a child would require special education until he or she (autism has a 4:1 ratio for boys) reaches the chronological of 28 years. To promote independent functioning and the possibility of employment, free public education is provided in Europe for educable youngsters, eg, with an IQ of at least 50 or above. In most States in America public education is now only provided until the chronological age of 16 years.

Countries such as Denmark have found the policy of continuing education until a mental age of 14 is achieved is cost effective since it promotes employment and reduces long term handicap and dependency. □

Martin Gittelman is a Clinical Professor in the Department of Psychiatry, at NYU Medical School, and is past President, of the American Association for Psychosocial Rehabilitation (an NGO with the World Health Organization and UNESCO. Readers may be interested in descriptions of European Programs for children which can be found in the back issues of the International Journal of Mental Health (ME Sharpe, Inc., 80 Business Park, Armonk, NY. Martin Gittelman serves as Editor.

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even be *over-diagnosed* in higher-functioning ASD because the individual's willingness to inappropriately verbalize thoughts can be mistaken as psychosis (Martin, Patzer & Volkmar, 2000).

All of this data must be interpreted cautiously because, as Martin, Patzer & Volkmar (2000) point out, it is difficult at this stage to determine whether symptoms are really part of a separate disorder, or are part of the ASD itself. Also, there is still so much controversy over the precise way in which to define ASD that clear prevalence studies will not be possible until there is more agreement among scientists and practitioners over definitions.

Without accurate statistics, however, we can at least assume that the prevalence of mental disorders would be no *less* than the general population. In other words, there is no reason to believe that a person with ASD would be less likely than neurotypicals to develop, for example, problems with depression or anxiety. When one examines the above risk-factors, it is easy to imagine how the presence of ASD may actually increase the stress and strain on an individual and his/her family, making mental health needs all the more important for early detection and state-of-art treatment.

Do people with ASD have access to the same quality of mental health services?

Despite the increased risk mentioned above, individuals with ASD and other devel-

opmental disabilities (DD), including mental retardation, cerebral palsy, epilepsy and traumatic brain injury have received inadequate mental health treatment throughout most of the 20th century (see Butz, Bowling, & Bliss, 2000; Dosen, 1993, 2002; MacLean, 1993; Nezu, Nezu & Gill-Weiss, 1992 for more comprehensive reviews). There are many reasons the mental health needs of people with DD were neglected. From the 1950s to the early 1970s, the majority of people in the United States with multiple disabilities lived in institutional settings where all treatment and educational needs were inadequately addressed. As people with DD were moved out of institutions and into the community during the 1970's and early 1980's, medical and educational/rehabilitative services improved, but mental health needs continued to be ignored. This is largely due to the fact that mental health professionals were not trained to deal holistically with people with DD and therefore had a very narrow focus on treatment. Clear symptoms of mental health problems were wrongly seen as part of the DD. This type of error is now called "diagnostic overshadowing" (Leviton & Reiss, 1983; Reiss, 1993), which happens when the primary diagnosis of a developmental disorder actually overshadows or masks the presence of a secondary problem. Symptoms that were expressed overtly (e.g., through physical aggression) were labeled as "behavior problems." Symptoms expressed in subtler ways (e.g., with-

drawal, changes in sleep habits, gradual skill regression) often went unnoticed.

Treatment for "behavior problems" relied heavily on pharmacological approaches aimed at reducing problem behavior (e.g., "chemical restraint"). They were applied without a comprehensive assessment of the individual's psychiatric status. Therefore, significant mental health diagnoses and more appropriate drug options were overlooked. Non-pharmacological approaches were limited to "behavior modification" (Alford & Locke, 1984), systems of rewards and punishments designed to reduce problem behavior. Unfortunately, these approaches were sometimes designed by professionals who were not properly trained in Applied Behavior Analysis (ABA) and learning principles. The resulting contingency systems in these cases were not addressing the true function of an individual's behavior. In addition, the types of treatments that were known to help non-disabled people with various mental health problems, especially "talk" therapies, were not being offered to people with DD. For various reasons, people with DD were not viewed as candidates for counseling or psychotherapy.

Thankfully, within the past 10 years, there is a greater emphasis on using multi-modal, multi-disciplinary approaches to treatment planning, which includes consideration of the subjective experiences and information-processing styles of individuals (Dosen, 2002; Gardner & Sovner, 1994), as well as the neu-

robiology and medical factors behind problem behavior. Also, the old view that psychotherapy is not a viable treatment option for people with ASD and other DD's has been strongly refuted by several authors (Butz, Bowling & Bliss, 2000; Lynch, 2000; Prout & Strohmer, 1994). For higher-functioning people with ASD, psychotherapy is more naturally considered with these newer attitudes toward people with disabilities (Gaus, 2000, 2002.)

When is it time to get a consultation with a psychiatrist?

There can be any number of signs that a person needs a psychiatric assessment. Below are the most common examples:

- There is a dramatic decrease in functioning level compared to the individual's previous level of ability; a loss of skills.
- There is ongoing maladaptive behavior that disrupts his/her functioning. It persists even after there has been a thorough assessment and multiple assessment-based interventions designed by a qualified applied behavior analyst.
- The individual is functioning poorly despite being on multiple psychiatric medications without a clear rationale or diagnosis.
- The individual is verbalizing increased distress (e.g., reporting feelings of loneliness, anger, suicidal thoughts).

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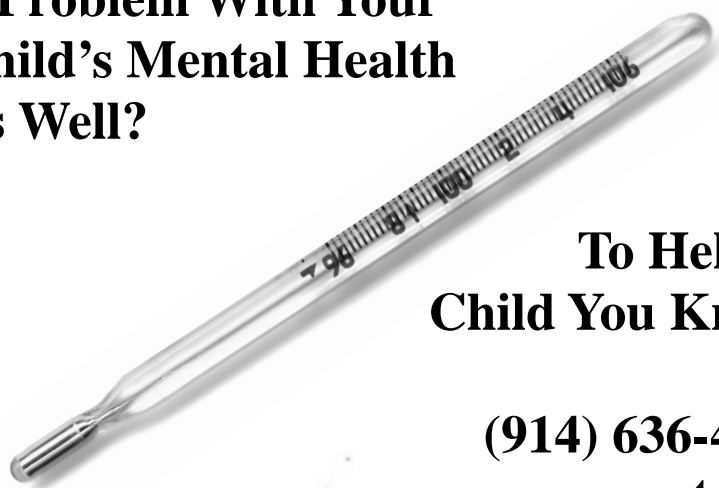
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THE GUIDANCE CENTER

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Problems That May Accompany ASD

Sensory problems. When children's perceptions are accurate, they can learn from what they see, feel, or hear. On the other hand, if sensory information is faulty, the child's experiences of the world can be confusing. Many ASD children are highly attuned or even painfully sensitive to certain sounds, textures, tastes, and smells. Some children find the feel of clothes touching their skin almost unbearable. Some sounds—a vacuum cleaner, a ringing telephone, a sudden storm, even the sound of waves lapping the shoreline—will cause these children to cover their ears and scream.

In ASD, the brain seems unable to balance the senses appropriately. Some ASD children are oblivious to extreme cold or pain. An ASD child may fall and break an arm, yet never cry. Another may bash his head against a wall and not wince, but a light touch may make the child scream with alarm.

Mental retardation. Many children with ASD have some degree of mental impairment. When tested, some areas of ability may be normal, while others may be especially weak. For example, a child with ASD may do well on the parts of the test that measure visual skills but earn low scores on the language subtests.

Seizures. One in four children with ASD develops seizures, often starting either in early childhood or adolescence. Seizures, caused by abnormal electrical activity in the brain, can produce a temporary loss of consciousness (a "blackout"), a body convulsion, unusual movements, or staring spells. Sometimes a contributing factor is a lack of sleep or a high fever. An EEG (electroencephalogram—recording of the electric currents developed in the brain by means of electrodes applied to the scalp) can help confirm the seizure's presence.

In most cases, seizures can be controlled by a number of medicines called "anticonvulsants." The dosage of the medication is adjusted carefully so that the least possible amount of medication will be used to be effective.

Fragile X syndrome. This disorder is the most common inherited form of mental retardation. It was so named because one part of the X chromosome has a defective piece that appears pinched and fragile when under a microscope. Fragile X syndrome affects about two to five percent of people with ASD. It is important to have a child with ASD checked for Fragile X, especially if the parents are considering having another child. For an unknown reason, if a child with ASD also has Fragile X, there is a one-in-two chance that boys born to the same parents will have the syndrome. Other members of the family who may be contemplating having a child may also wish to be checked for the syndrome.

Tuberous Sclerosis. Tuberous sclerosis is a rare genetic disorder that causes benign tumors to grow in the brain as well as in other vital organs. It has a consistently strong association with ASD. One to 4 percent of people with ASD also have tuberous sclerosis.

The Diagnosis of Autism Spectrum Disorders

Although there are many concerns about labeling a young child with an ASD, the earlier the diagnosis of ASD is made, the earlier needed interventions can

begin. Evidence over the last 15 years indicates that intensive early intervention in optimal educational settings for at least 2 years during the preschool years results in improved outcomes in most young children with ASD.

In evaluating a child, clinicians rely on behavioral characteristics to make a diagnosis. Some of the characteristic behaviors of ASD may be apparent in the first few months of a child's life, or they may appear at any time during the early years. For the diagnosis, problems in at least one of the areas of communication, socialization, or restricted behavior must be present before the age of 3. The diagnosis requires a two-stage process. The first stage involves developmental screening during "well child" check-ups; the second stage entails a comprehensive evaluation by a multidisciplinary team.

Screening

A "well child" check-up should include a developmental screening test. If your child's pediatrician does not routinely check your child with such a test, ask that it be done. Your own observations and concerns about your child's development will be essential in helping to screen your child.⁷ Reviewing family videotapes, photos, and baby albums can help parents remember when each behavior was first noticed and when the child reached certain developmental milestones.

Several screening instruments have been developed to quickly gather information about a child's social and communicative development within medical settings. Among them are the Checklist of Autism in Toddlers (CHAT),⁸ the modified Checklist for Autism in Toddlers (M-CHAT), the Screening Tool for Autism in Two-Year-Olds (STAT), and the Social Communication Questionnaire (SCQ) (for children 4 years of age and older).

Some screening instruments rely solely on parent responses to a questionnaire, and some rely on a combination of parent report and observation. Key items on these instruments that appear to differentiate children with autism from other groups before the age of 2 include pointing and pretend play. Screening instruments do not provide individual diagnosis but serve to assess the need for referral for possible diagnosis of ASD. These screening methods may not identify children with mild ASD, such as those with high-functioning autism or Asperger syndrome.

During the last few years, screening instruments have been devised to screen for Asperger syndrome and higher functioning autism. The Autism Spectrum Screening Questionnaire (ASSQ), the Australian Scale for Asperger's Syndrome,⁹ and the most recent, the Childhood Asperger Syndrome Test (CAST), are some of the instruments that are reliable for identification of school-age children with Asperger syndrome or higher functioning autism. These tools concentrate on social and behavioral impairments in children without significant language delay.

If, following the screening process or during a routine "well child" check-up, your child's doctor sees any of the possible indicators of ASD, further evaluation is indicated.

Comprehensive Diagnostic Evaluation

The second stage of diagnosis must be

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comprehensive in order to accurately rule in or rule out an ASD or other developmental problem. This evaluation may be done by a multidisciplinary team that includes a psychologist, a neurologist, a psychiatrist, a speech therapist, or other professionals who diagnose children with ASD.

Because ASDs are complex disorders and may involve other neurological or genetic problems, a comprehensive evaluation should entail neurologic and genetic assessment, along with in-depth cognitive and language testing. In addition, measures developed specifically for diagnosing autism are often used. These include the Autism Diagnosis Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS-G). The ADI-R is a structured interview that contains over 100 items and is conducted with a caregiver. It consists of four main factors—the child's communication, social interaction, repetitive behaviors, and age-of-onset symptoms. The ADOS-G is an observational measure used to "press" for socio-communicative behaviors that are often delayed, abnormal, or absent in children with ASD.

Still another instrument often used by professionals is the Childhood Autism Rating Scale (CARS). It aids in evaluating the child's body movements, adaptation to change, listening response, verbal communication, and relationship to people. It is suitable for use with children over 2 years of age. The examiner observes the child and also obtains relevant information from the parents. The child's behavior is rated on a scale based on deviation from the typical behavior of children of the same age.

Two other tests that should be used to assess any child with a developmental delay are a formal audiologic hearing evaluation and a lead screening. Although some hearing loss can co-occur with ASD, some children with ASD may be incorrectly thought to have such a loss. In addition, if the child has suffered from an ear infection, transient hearing loss can occur. Lead screening is essential for children who remain for a long period of time in the oral-motor stage in which they put any and everything into their mouths. Children with an autistic disorder usually have elevated blood lead levels.

Customarily, an expert diagnostic team has the responsibility of thoroughly evaluating the child, assessing the child's unique strengths and weaknesses, and determining a formal diagnosis. The team will then meet with the parents to explain the results of the evaluation.

Although parents may have been aware that something was not "quite right" with their child, when the diagnosis is given, it is a devastating blow. At such a time, it is hard to stay focused on asking questions. But while members of the evaluation team are together is the best opportunity the parents will have to ask questions and get recommendations on what further steps they should take for their child. Learning as much as possible at this meeting is very important, but it is helpful to leave this meeting with the name or names of professionals who can be contacted if the parents have further questions.

Available Aids

When your child has been evaluated and diagnosed with an autism spectrum disorder, you may feel inadequate to help

your child develop to the fullest extent of his or her ability. As you begin to look at treatment options and at the types of aid available for a child with a disability, you will find out that there is help for you. It is going to be difficult to learn and remember everything you need to know about the resources that will be most helpful. Write down everything. If you keep a notebook, you will have a fool-proof method of recalling information. Keep a record of the doctors' reports and the evaluation your child has been given so that his or her eligibility for special programs will be documented. Learn everything you can about special programs for your child; the more you know, the more effectively you can advocate.

For every child eligible for special programs, each state guarantees special education and related services. The Individuals with Disabilities Education Act (IDEA) is a Federally mandated program that assures a free and appropriate public education for children with diagnosed learning deficits. Usually children are placed in public schools and the school district pays for all necessary services. These will include, as needed, services by a speech therapist, occupational therapist, school psychologist, social worker, school nurse, or aide.

By law, the public schools must prepare and carry out a set of instruction goals, or specific skills, for every child in a special education program. The list of skills is known as the child's Individualized Education Program (IEP). The IEP is an agreement between the school and the family on the child's goals. When your child's IEP is developed, you will be asked to attend the meeting. There will be several people at this meeting, including a special education teacher, a representative of the public schools who is knowledgeable about the program, other individuals invited by the school or by you (you may want to bring a relative, a child care provider, or a supportive close friend who knows your child well). Parents play an important part in creating the program, as they know their child and his or her needs best. Once your child's IEP is developed, a meeting is scheduled once a year to review your child's progress and to make any alterations to reflect his or her changing needs.

If your child is under 3 years of age and has special needs, he or she should be eligible for an early intervention program; this program is available in every state. Each state decides which agency will be the lead agency in the early intervention program. The early intervention services are provided by workers qualified to care for toddlers with disabilities and are usually in the child's home or a place familiar to the child. The services provided are written into an Individualized Family Service Plan (IFSP) that is reviewed at least once every 6 months. The plan will describe services that will be provided to the child, but will also describe services for parents to help them in daily activities with their child and for siblings to help them adjust to having a brother or sister with ASD.

Treatment Options

There is no single best treatment package for all children with ASD. One point

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The Adolescent Years

Adolescence is a time of stress and confusion; and it is no less so for teenagers with autism. Like all children, they need help in dealing with their budding sexuality. While some behaviors improve during the teenage years, some get worse. Increased autistic or aggressive behavior may be one way some teens express their newfound tension and confusion.

The teenage years are also a time when children become more socially sensitive. At the age that most teenagers are concerned with acne, popularity, grades, and dates, teens with autism may become painfully aware that they are different from their peers. They may notice that they lack friends. And unlike their school-mates, they aren't dating or planning for a career. For some, the sadness that comes with such realization motivates them to learn new behaviors and acquire better social skills.

that most professionals agree on is that early intervention is important; another is that most individuals with ASD respond well to highly structured, specialized programs.

Before you make decisions on your child's treatment, you will want to gather information about the various options available. Learn as much as you can, look at all the options, and make your decision on your child's treatment based on your child's needs. You may want to visit public schools in your area to see the type of program they offer to special needs children.

Guidelines used by the Autism Society of America include the following questions parents can ask about potential treatments:

- Will the treatment result in harm to my child?
- How will failure of the treatment affect my child and family?
- Has the treatment been validated scientifically?
- Are there assessment procedures specified?
- How will the treatment be integrated into my child's current program? Do not become so infatuated with a given treatment that functional curriculum, vocational life, and social skills are ignored.

The National Institute of Mental Health suggests a list of questions parents can ask when planning for their child:

- How successful has the program been for other children?
- How many children have gone on to placement in a regular school and how have they performed?
- Do staff members have training and experience in working with children and adolescents with autism?
- How are activities planned and organized?
- Are there predictable daily schedules and routines?

- How much individual attention will my child receive?
- How is progress measured? Will my child's behavior be closely observed and recorded?
- Will my child be given tasks and rewards that are personally motivating?
- Is the environment designed to minimize distractions?
- Will the program prepare me to continue the therapy at home?
- What is the cost, time commitment, and location of the program?

Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. Mental Health: A Report of the Surgeon General states, "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior." The basic research done by Ivar Lovaas and his colleagues at the University of California, Los Angeles, calling for an intensive, one-on-one child-teacher interaction for 40 hours a week, laid a foundation for other educators and researchers in the search for further effective early interventions to help those with ASD attain their potential. The goal of behavioral management is to reinforce desirable behaviors and reduce undesirable ones.

An effective treatment program will build on the child's interests, offer a predictable schedule, teach tasks as a series of simple steps, actively engage the child's attention in highly structured activities, and provide regular reinforcement of behavior. Parental involvement has emerged as a major factor in treatment success. Parents work with teachers and therapists to identify the behaviors to be changed and the skills to be taught. Recognizing that parents are the child's earliest teachers, more programs are beginning to train parents to continue the therapy at home.

As soon as a child's disability has been identified, instruction should begin. Effective programs will teach early communication and social interaction skills. In children younger than 3 years, appropriate interventions usually take place in the home or a child care center. These interventions target specific deficits in learning, language, imitation, attention, motivation, compliance, and initiative of interaction. Included are behavioral methods, communication, occupational and physical therapy along with social play interventions. Often the day will begin with a physical activity to help develop coordination and body awareness; children string beads, piece puzzles together, paint, and participate in other motor skills activities. At snack time the teacher encourages social interaction and models how to use language to ask for more juice. The children learn by doing. Working with the children are students, behavioral therapists, and parents who have received extensive training. In teaching the children, positive reinforcement is used.

Children older than 3 years usually have school-based, individualized, special

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education. The child may be in a segregated class with other autistic children or in an integrated class with children without disabilities for at least part of the day. Different localities may use differing methods but all should provide a structure that will help the children learn social skills and functional communication. In these programs, teachers often involve the parents, giving useful advice in how to help their child use the skills or behaviors learned at school when they are at home.

In elementary school, the child should receive help in any skill area that is delayed and, at the same time, be encouraged to grow in his or her areas of strength. Ideally, the curriculum should be adapted to the individual child's needs. Many schools today have an inclusion program in which the child is in a regular classroom for most of the day, with special instruction for a part of the day. This instruction should include such skills as learning how to act in social situations and in making friends. Although higher-functioning children may be able to handle academic work, they too need help to organize tasks and avoid distractions.

During middle and high school years, instruction will begin to address such practical matters as work, community living, and recreational activities. This should include work experience, using public transportation, and learning skills that will be important in community living.

All through your child's school years, you will want to be an active participant in his or her education program. Collaboration between parents and educators is essential in evaluating your child's progress.

Dietary and Other Interventions

In an effort to do everything possible to help their children, many parents continually seek new treatments. Some treatments are developed by reputable therapists or by parents of a child with ASD. Although an unproven treatment may help one child, it may not prove beneficial to another. To be accepted as a proven treatment, the treatment should undergo clinical trials, preferably randomized, double-blind trials, that would allow for a comparison between treatment and no treatment. Following are some of the interventions that have been reported to have been helpful to some children but whose efficacy or safety has not been proven.

Dietary interventions are based on the idea that 1) food allergies cause symptoms of autism, and 2) an insufficiency of a specific vitamin or mineral may cause some autistic symptoms. If parents decide to try for a given period of time a special diet, they should be sure that the child's nutritional status is measured carefully.

A diet that some parents have found was helpful to their autistic child is a gluten-free, casein-free diet. Gluten is a casein-like substance that is found in the seeds of various cereal plants—wheat, oat, rye, and barley. Casein is the principal protein in milk. Since gluten and milk are found in many of the foods we eat, following a gluten-free, casein-free diet is difficult.

A supplement that some parents feel is beneficial for an autistic child is Vitamin B6, taken with magnesium (which makes the vitamin effective). The result of research studies is mixed; some children

respond positively, some negatively, some not at all or very little.

In the search for treatment for autism, there has been discussion in the last few years about the use of secretin, a substance approved by the Food and Drug Administration (FDA) for a single dose normally given to aid in diagnosis of a gastrointestinal problem. Anecdotal reports have shown improvement in autism symptoms, including sleep patterns, eye contact, language skills, and alertness. Several clinical trials conducted in the last few years have found no significant improvements in symptoms between patients who received secretin and those who received a placebo.

Medications Used in Treatment

Medications are often used to treat behavioral problems, such as aggression, self-injurious behavior, and severe tantrums, that keep the person with ASD from functioning more effectively at home or school. The medications used are those that have been developed to treat similar symptoms in other disorders. Many of these medications are prescribed "off-label." This means they have not been officially approved by the FDA for use in children, but the doctor prescribes the medications if he or she feels they are appropriate for your child. Further research needs to be done to ensure not only the efficacy but the safety of psychotropic agents used in the treatment of children and adolescents.

A child with ASD may not respond in the same way to medications as typically developing children. It is important that parents work with a doctor who has experience with children with autism. A child should be monitored closely while taking a medication. The doctor will prescribe the lowest dose possible to be effective. Ask the doctor about any side effects the medication may have and keep a record of how your child responds to the medication. It will be helpful to read the "patient insert" that comes with your child's medication. Some people keep the patient inserts in a small notebook to be used as a reference. This is most useful when several medications are prescribed.

Anxiety and depression. The selective serotonin reuptake inhibitors (SSRI's) are the medications most often prescribed for symptoms of anxiety, depression, and/or obsessive-compulsive disorder (OCD). Only one of the SSRI's, fluoxetine, (Prozac®) has been approved by the FDA for both OCD and depression in children age 7 and older. Three that have been approved for OCD are fluvoxamine (Luvox®), age 8 and older; sertraline (Zoloft®), age 6 and older; and clomipramine (Anafranil®), age 10 and older. Treatment with these medications can be associated with decreased frequency of repetitive, ritualistic behavior and improvements in eye contact and social contacts. The FDA is studying and analyzing data to better understand how to use the SSRI's safely, effectively, and at the lowest dose possible.

Behavioral problems. Antipsychotic medications have been used to treat severe behavioral problems. These medications work by reducing the activity in the brain of the neurotransmitter dopamine. Among the older, typical antipsychotics,

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on the recent discovery of the existence and extent of the high variability of the human genome. Dr. Sebat will examine gene sequence data in order to identify genes and other genomic elements that have either been deleted (micro deletions) or repeated (some many times over). These extensive gene alterations may contribute to the range of Autism Spectrum Disorders.

The Emory project seeks to explore forms of familial inheritance through the X chromosome — because more males than females are diagnosed with autism. Zwick will use a highly innovative technology with great promise for DNA sequencing. It is hoped that this study might lead to insights into autism and a related disorder, Fragile X syndrome.

These new initiatives complement a large autism genetics project funded by NIMH earlier this year and awarded to Johns Hopkins University for research led by Aravinda Chakravarti, Ph.D. This effort employs state-of-the-art gene chips to study variation across the

genome in children with autism. This study has already yielded interesting results that point to candidate genomic regions on chromosomes 7, 10, and 19. These signals will provide important clues to the three new genetics projects funded by the consortium.*

These studies would not be possible without the support of the NIMH Human Genetics Initiative** and its large data and sample repository which is available to investigators who study the genetics of autism. It is the largest such facility for mental disorders in the world and collects data and blood samples, makes cell lines, stores DNA and clinical data for autism and other mental disorders. □

*For more information on Autism Spectrum Disorders, visit <http://www.nimh.nih.gov/healthinformation/autismmenu.cfm>. *For information about similar projects in genetic research on autism, visit <http://www.nimh.nih.gov/press/autismgenetics.cfm>. **For more information about the NIMH Human Genetics Initiative, visit www.nimhgenetics.org.*

Court from page 6

disorders who are involved in the criminal justice system. The program has focused particularly on linguistic, cultural and clinical competency for the Hispanic and African American Bronx community. The Court includes mentally ill defendants who are charged with felony offenses or who are persistent misdemeanants, within an alternative-to-incarceration, deferred sentencing paradigm. Clients may be referred by the community, by the jails, by defense or prosecuting attorneys or by the court system. Within the mental health court, the clinical team provides comprehensive diagnosis, treatment, and risk assessment evaluation to facilitate diversion into individualized services.

Mental health courts are a promising strategy for communities seeking to improve the response to people with mental illness in the juvenile justice system. Their number in the United States has grown exponentially over the past decade: In 1997 there were four known mental health courts in the country; by January 2004 the number had grown to 70 courts in 29 states, and by March 2006 there were over 120 known courts in 35 states.

Selected through a rigorous review implemented by the Council of State Governments, BJA's partner in the project, experts in mental health and court operations who participated in the selection process determined that the Bronx Mental Health Court is well-suited to provide peer to peer assistance to policymakers and practitioners nationwide. □

Autism Internet Resources of Interest

Autism Research

- Autism Research Network (National Institute of Health website)
- National Alliance for Autism Research (NAAR)
- Association for Science in Autism Treatment
- Clinical Trials
- Medline
- M.I.N.D. Institute
- Seaver Center for Autism Research and Treatment – Mount Sinai School of Medicine
- CAN (Cure Autism Now)
- Yale Developmental Disabilities Clinic
- The Columbia Developmental Neuropsychiatry Program at New York-Presbyterian Hospital
- Organization for Autism Research (OAR)

Educational Support

- Autism Society of America
- The Association of Behavior Analysis
- The Doug Flutie Foundation
- Journal of Applied Behavior Analysis
- NYSABA – New York State Association for Behavior Analysis
- FEAT – Families for Early Autism Treatment
- Autism/PDD Resources
- Cody Center for Autism
- NAAD (National Alliance for Dual Diagnosis)
- Herbert G. Birch Services
- CARD (Center for Autism & Related Disorders)
- Resources for Children with Special Needs
- Young Adult Institute
- Future Horizons (conference information)
- Division TEACCH (University of North Carolina)
- COSAC (The New Jersey Center for Outreach and Services for the Autism Community)

Aspergers Syndrome

- FAAS (Families of Adults with Asperger's Syndrome)
- University Students with Autism and Asperger's Syndrome
- Asperger Syndrome International
- O.A.S.I.S.
- Tony Attwood
- Aspen of America

Support Groups

- Advocates for Individuals with High Functioning Autism, Asperger's Syndrome and Pervasive Developmental Disorders
- Westchester ParentLink
- Connecticut Autism Spectrum Resource Center
- Greenwich Autism Program
- New York Families for Autistic Children (NYFAC)
- GRASP

Government & Legal

- Council for Exceptional Children
- New York State Office of Mental Health
- Westchester County Department of Community Mental Health
- IDEA (The Individuals with Disabilities Education Act)
- Wrights Law
- NYSACRA (NY State Association of Community and Residential Agencies)
- New York State Education Department (NYSED)
- VESID (Vocational and Educational Services for Individuals with Disabilities)
- OMRDD (Office of Mental Retardation & Developmental Disabilities)
- NICHCY (The National Information Center for Children & Youth with Disabilities)
- NYSARC

List provided by Judy Omidvaran

Mental Health from page 33

Too many labels?
Isn't the ASD diagnosis enough?

Unfortunately, it is still true in our society that having a mental health diagnosis can be stigmatizing in some situations. There continues to be fear and negative attitudes toward disability and mental illness that is largely based on ignorance. In addition, being *incorrectly* diagnosed can have devastating affects when inappropriate treatment is applied. In the face of this, it is all the more important to correctly identify a mental health problem when there is one present. Ignoring psychiatric symptoms in an age when psychiatry and neuroscience are making so many advances can be equally devastating if it means a good treatment is withheld from someone who needs it.

The true purpose of diagnosis is *not* to label people; rather it is to label the behavior pattern that is problematic for the individual. Why is that important? If behavior can be classified, then it can be linked to *similar behavior patterns that have been documented by other mental health professionals*. If the behavior is similar enough to one of these well-documented behavioral phenomena, then the caregivers and professionals are given important short-cuts to viable treatment options that have already been shown to be helpful

for other people with the same problem. Without this, doctors would have to start from scratch and provide "shot in the dark" treatments with every single new patient.

If you are a caregiver involved in the process of diagnosing a mental health problem in a person with ASD, here are some things to keep in mind to avoid stigma:

- You are helping to classify behavior, not the individual.
- Labeling the behavior helps the individual access treatment that has been supported by research.
- Accurately naming the behavior improves the quality of the ongoing assessment process by enhancing communication between professionals on the treatment team.

Are patients getting appropriate mental health treatment?

Many times caregivers ask how they can tell if their doctor is prescribing the right type of treatment. Though they can't tell the doctor what to do, parents want to properly advocate when they go to mental health appointments. There are two important principles for success in advocating for good quality treatment:

Knowing what questions to ask: Here are

continued on next column

from previous column

some good quality assurance questions that all caregivers should ask regularly when visiting psychiatrists and psychotherapists (adapted from Sovner & Hurley, 1985):

- Has there been a thorough assessment, including a medical exam to rule out possible medical causes for the problem behavior?
- What is the theory on what is causing the problem behavior?
- What is the psychiatric diagnosis as listed in the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV)?
- What evidence was used to arrive at the diagnosis?
- What are the goals of treatment?
- How will the treatment be carried out?
- Is the treatment plan based on the theory of what is causing the problem?
- Is the treatment based on the research literature; is it similar to the treatment that would be offered to non-disabled individuals who have the same mental health diagnosis?
- How are the effects of treatment going to be monitored?
- What signs and symptoms should the caregiver be documenting at home?
- Are there too many pharmacological agents involved?
- Is the individual being over-medicated?
- Is the individual being under-medicated?
- Is drug therapy being changed too rapidly?
- Are doses given on an emergency basis or given as on as-needed basis being used excessively?
- What are the criteria for discharge from treatment?

Practicing good communication: You don't have to be a doctor to seek and share information, which is a large part of what caregivers do on mental health visits. Good communication is a 50/50 process. Both you and the doctor need to be open to an ongoing collaboration in order to help the individual being treated. Because of a mental health professional's obligation to keep treatment *confidential*, your involvement as a caregiver will vary according to the functioning level and age of your child. Listed below are good communication practices for each party:

Psychiatrist or Therapist

- educate patient and caregiver about target signs and symptoms;
- ask patient and caregiver to keep track of changes and report back;
- offer and explain treatment options and discuss supporting research;
- use language that is understandable to a

layperson;

- be open to questions and answer them respectfully;
- direct patient and caregiver to resources that will enhance treatment;
- and coordinate treatment with all other providers in patient's life by communicating with them on a regular basis (e.g., other therapists, teachers, case managers, other physicians).

Patient and Caregiver

- ask the quality assurance questions listed above on a regular basis;
- make requests of the doctor to ensure he/she is practicing the above;
- ask for clarification if you do not understand a term used by the doctor;
- initiate discussions about changes you have observed at home, don't wait for the doctor to ask you and be prepared to report something at each visit;
- when reporting to the doctor, try to be concise and objective. Keep it short and to the point, using descriptive terms about what you saw or heard; avoid using vague terms that you can't back up with evidence.

Conclusion

It can be a very confusing and intimidating process to interface with the mental health service delivery system. By practicing the guidelines listed above, you can be more confident that you are advocating for the best treatment for your child's problem. Remember, *you don't have to be a doctor to ask lots of questions!*

For more information and resources on this topic, contact the National Association for Dual Diagnosis (NADD), www.thenadd.org, an organization for persons with developmental disabilities and mental health needs. □

Valerie Gaus, Ph.D., is a licensed clinical psychologist with 12 years of experience working with individuals with developmental disabilities. She works at YAI-National Institute for People with Disabilities, a private non-profit agency based in New York City. She provides psychotherapy services and supervision in their outpatient clinic, Premier HealthCare, where she focuses on issues related to dual diagnosis, high functioning autism/Asperger's Syndrome, posttraumatic stress disorder, and other stress and anxiety-related problems. Dr. Gaus also maintains a private practice on Long Island, serves on the board for the New York Metro chapter of NADD, and is on the adjunct faculties at Nassau Community College and Long Island University/C.W. Post.

This article is reprinted with permission from OAR, The OARacle, The Monthly E-Newsletter of the Organization for Autism Research: "Research and Resources That Help Families Today!" www.researchautism.org, August 2004.

Pre-School from page 30

"I'll be his big brother," announced a little friend.

The parents of typical children are similarly content. They welcome the additional state-certified instructors that The Children's School supplies, and they value the lessons that the kids learn about diversity.

Marc Damon, nearly 15, used The Children's School's services between the ages of two and five. At that time, he lacked social skills and was not expressive. He couldn't point and had to be taught how to pick up Cheerios. He was extremely sensitive to light, sound and textures.

Each day, his parents and school staff shared information about his progress in a notebook that passed back and forth. He slowly began picking up words, and once he started speaking, he never stopped. Since leaving the pre-school, he has at-

tended regular classes in his neighborhood school. This year he began attending Fordham Prep, where he's a strong student.

"He was on the bowling team this year, and they won a division championship," says his mom. "Now he's helping to manage the baseball team. His goal is to go to Notre Dame and to become a sportscaster."

How do you define success for a child with autism? Teacher Helga Coiro talks about a parent who put his child on the bus daily with "I love you" as a send off. One day, she turned back to him and answered, "I love you." □

Westchester Arc is the largest agency in the county serving children and adults of all ages who have developmental disabilities.

Mental Health News wishes to thank Cathy Bahan, Director of Marketing & Public Affairs at Westchester Arc, for her assistance in preparing this article.

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such as haloperidol (Haldol®), thioridazine, fluphenazine, and chlorpromazine, haloperidol was found in more than one study to be more effective than a placebo in treating serious behavioral problems. However, haloperidol, while helpful for reducing symptoms of aggression, can also have adverse side effects, such as sedation, muscle stiffness, and abnormal movements.

Placebo-controlled studies of the newer "atypical" antipsychotics are being conducted on children with autism. The first such study, conducted by the NIMH-supported Research Units on Pediatric Psychopharmacology (RUPP) Autism Network, was on risperidone (Risperdal®). Results of the 8-week study were reported in 2002 and showed that risperidone was effective and well tolerated for the treatment of severe behavioral problems in children with autism. The most common side effects were increased appetite, weight gain and sedation. Further long-term studies are needed to determine any long-term side effects. Other atypical antipsychotics that have been studied recently with encouraging results are olanzapine (Zyprexa®) and ziprasidone (Geodon®). Ziprasidone has not been associated with significant weight gain.

Seizures. Seizures are found in one in four persons with ASD, most often in those who have low IQ or are mute. They are treated with one or more of the anti-convulsants. These include such medications as carbamazepine (Tegretol®), lamotrigine (Lamictal®), topiramate (Topamax®), and valproic acid (Depakote®). The level of the medication in the blood should be monitored carefully and adjusted so that the least amount possible is used to be effective. Although medication usually reduces the number of seizures, it cannot always eliminate them.

Inattention and hyperactivity. Stimulant medications such as methylphenidate (Ritalin®), used safely and effectively in persons with attention deficit hyperactivity disorder, have also been prescribed for children with autism. These medications may decrease impulsivity and hyperactivity in some children, especially those higher functioning children.

Several other medications have been used to treat ASD symptoms; among them are other antidepressants, naltrexone, lithium, and some of the benzodiazepines such as diazepam (Valium®) and lorazepam (Ativan®). The safety and efficacy of these medications in children with autism has not been proven. Since people may respond differently to different medications, your child's unique history and behavior will help your doctor decide which medication might be most beneficial.

**Adults with
an Autism Spectrum Disorder**

Some adults with ASD, especially those with high-functioning autism or with Asperger syndrome, are able to work successfully in mainstream jobs. Nevertheless, communication and social problems often cause difficulties in many areas of life. They will continue to need encouragement and moral support in their struggle for an independent life.

Many others with ASD are capable of employment in sheltered workshops under the supervision of managers trained in working with persons with disabilities. A

nurturing environment at home, at school, and later in job training and at work, helps persons with ASD continue to learn and to develop throughout their lives.

The public schools' responsibility for providing services ends when the person with ASD reaches the age of 22. The family is then faced with the challenge of finding living arrangements and employment to match the particular needs of their adult child, as well as the programs and facilities that can provide support services to achieve these goals. Long before your child finishes school, you will want to search for the best programs and facilities for your young adult. If you know other parents of ASD adults, ask them about the services available in your community. If your community has little to offer, serve as an advocate for your child and work toward the goal of improved employment services. Research the resources listed in the back of this brochure to learn as much as possible about the help your child is eligible to receive as an adult.

**Living Arrangements for the Adult with
an Autism Spectrum Disorder**

Independent living. Some adults with ASD are able to live entirely on their own. Others can live semi-independently in their own home or apartment if they have assistance with solving major problems, such as personal finances or dealing with the government agencies that provide services to persons with disabilities. This assistance can be provided by family, a professional agency, or another type of provider.

Living at home. Government funds are available for families that choose to have their adult child with ASD live at home. These programs include Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid waivers, and others. Information about these programs is available from the Social Security Administration (SSA). An appointment with a local SSA office is a good first step to take in understanding the programs for which the young adult is eligible.

Foster homes and skill-development homes. Some families open their homes to provide long-term care to unrelated adults with disabilities. If the home teaches self-care and housekeeping skills and arranges leisure activities, it is called a "skill-development" home.

Supervised group living. Persons with disabilities frequently live in group homes or apartments staffed by professionals who help the individuals with basic needs. These often include meal preparation, housekeeping, and personal care needs. Higher functioning persons may be able to live in a home or apartment where staff only visit a few times a week. These persons generally prepare their own meals, go to work, and conduct other daily activities on their own.

Institutions. Although the trend in recent decades has been to avoid placing persons with disabilities into long-term-care institutions, this alternative is still available for persons with ASD who need intensive, constant supervision. Unlike many of the institutions years ago, today's facilities view residents as individuals with human needs and offer opportunities for recreation and simple but meaningful work.

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NIMH Reviews ASD from page 39**Research into Causes and Treatment of Autism Spectrum Disorders**

Research into the causes, the diagnosis, and the treatment of autism spectrum disorders has advanced in tandem. With new well-researched standardized diagnostic tools, ASD can be diagnosed at an early age. And with early diagnosis, the treatments found to be beneficial in recent years can be used to help the child with ASD develop to his or her greatest potential.

In the past few years, there has been public interest in a theory that suggested a link between the use of thimerosal, a mercury-based preservative used in the measles-mumps-rubella (MMR) vaccine, and autism. Although mercury is no longer found in childhood vaccines in the United States, some parents still have concerns about vaccinations. Many well-done, large-scale studies have now been done that have failed to show a link between thimerosal and autism. A panel from the Institute of Medicine is now examining these studies, including a large Danish study that concluded that there was no causal relationship between childhood vaccination using thimerosal-containing vaccines and the development of an autism spectrum disorder, and a U.S. study looking at exposure to mercury, lead, and other heavy metals.

Research on the Biologic Basis of ASD

Because of its relative inaccessibility, scientists have only recently been able to study the brain systematically. But with the emergence of new brain imaging tools—computerized tomography (CT), positron emission tomography (PET), single photon emission computed tomography (SPECT), and magnetic resonance imaging (MRI), study of the structure and the functioning of the brain can be done. With the aid of modern technology and the new availability of both normal and autism tissue samples to do postmortem studies, researchers will be able to learn much through comparative studies.

Postmortem and MRI studies have shown that many major brain structures are implicated in autism. This includes the cerebellum, cerebral cortex, limbic system, corpus callosum, basal ganglia, and brain stem. Other research is focusing on the role of neurotransmitters such as serotonin, dopamine, and epinephrine.

Research into the causes of autism spectrum disorders is being fueled by other recent developments. Evidence points to genetic factors playing a prominent role in the causes for ASD. Twin and family studies have suggested an underlying genetic vulnerability to ASD. To further research in this field, the Autism Genetic Resource Exchange, a project initiated by the Cure Autism Now Foundation, and aided by an NIMH grant, is recruiting genetic samples from several hundred families. Each family with more than one member diagnosed with ASD is given a 2-hour, in-home screening. With a large number of DNA samples, it is hoped that the most important genes will be found. This will enable scientists to learn what the culprit genes do and how they can go wrong.

Another exciting development is the Autism Tissue Program (<http://www.brainbank.org>), supported by the

Autism Society of America Foundation, the Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.) Institute at the University of California, Davis, and the National Alliance for Autism Research. The program is aided by a grant to the Harvard Brain and Tissue Resource Center (<http://www.brainbank.mclean.org>), funded by the National Institute of Mental Health (NIMH) and the National Institute of Neurological Disorders and Stroke (NINDS). Studies of the postmortem brain with imaging methods will help us learn why some brains are large, how the limbic system develops, and how the brain changes as it ages. Tissue samples can be stained and will show which neurotransmitters are being made in the cells and how they are transported and released to other cells. By focusing on specific brain regions and neurotransmitters, it will become easier to identify susceptibility genes.

Recent neuroimaging studies have shown that a contributing cause for autism may be abnormal brain development beginning in the infant's first months. This "growth dysregulation hypothesis" holds that the anatomical abnormalities seen in autism are caused by genetic defects in brain growth factors. It is possible that sudden, rapid head growth in an infant may be an early warning signal that will lead to early diagnosis and effective biological intervention or possible prevention of autism.

The Children's Health Act of 2000: What It Means to Autism Research

The Children's Health Act of 2000 was responsible for the creation of the Interagency Autism Coordinating Committee (IACC), a committee that includes the directors of five NIH institutes—the National Institute of Mental Health, the National Institute of Neurological Disorders and Stroke, the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Institute of Child Health and Human Development (NICHD), and the National Institute of Environmental Health Sciences (NIEHS)—as well as representatives from the Health Resource Services Administration, the National Center on Birth Defects and Developmental Disabilities (a part of the Centers for Disease Control), the Agency for Toxic Substances and Disease Registry, the Substance Abuse and Mental Health Services Administration, the Administration on Developmental Disabilities, the Centers for Medicare and Medicaid Services, the U.S. Food and Drug Administration, and the U.S. Department of Education. The Committee, instructed by the Congress to develop a 10-year agenda for autism research, introduced the plan, dubbed a "matrix" or a "roadmap," at the first Autism Summit Conference in November 2003. The roadmap indicates priorities for research for years 1 to 3, years 4 to 6, and years 7 to 10.

The five NIH institutes of the IACC have established the Studies to Advance Autism Research and Treatment (STAART) Network, composed of eight network centers. They will conduct research in the fields of developmental neurobiology, genetics, and psychopharmacology. Each center is pursuing its own particular mix of studies, but there also will be multi-site clinical trials within the STAART network.

see NIMH Reviews ASD - next column

NIMH Reviews ASD from left column

The STAART centers are located at the following sites:

- University of North Carolina, Chapel Hill
- Yale University, Connecticut
- University of Washington, Seattle
- University of California, Los Angeles
- Mount Sinai Medical School, New York
- Kennedy Krieger Institute, Maryland
- Boston University, Massachusetts
- University of Rochester, New York

A data coordination center will analyze the data generated by both the STAART network and the Collaborative Programs of Excellence in Autism (CPEA). This latter program, funded by the NICHD and the NIDCD Network on the Neurobiology and Genetics of Autism, consists of 10 sites. The CPEA is at present studying the world's largest group of well-diagnosed individuals with autism characterized by genetic and developmental profiles.

The CPEA centers are located at:

- Boston University, Massachusetts

Spoonful from page 18

take our meds because we're too mentally ill to be reasoned with is bigotry and an out for a system too lazy to come up with new solutions.

I'm sure a lot of very well-meaning people in the mental health field secretly wish for a miracle pill that made people remember to take their psych meds. Thing is, you would need another pill to remember to take that pill, and so on, and so on. You can't drug people into recovery. People need to transform themselves from the inside out, and decide for themselves whether to take medication and what part it will play in their recovery.

Because the mental health system relies so heavily on force and coercion, no one ever takes the time or the imagination to look for other ways to induce people to embrace self-care. I remember when I was young and very noncompliant: the more medication was shoved down my throat – or in my butt – the less I wanted to take it. How much more willing might I have been had some incentives been added: say, a sultry voice providing a half hour worth of phone sex every time I took my meds, or even just a coupon for some free pizza might have worked a lot

- University of California, Davis
- University of California, Irvine
- University of California, Los Angeles
- Yale University, Connecticut
- University of Washington, Seattle
- University of Rochester, New York
- University of Texas, Houston
- University of Pittsburgh, Pennsylvania
- University of Utah, Salt Lake City

The NIEHS has programs at:

- Center for Childhood Neurotoxicology and Assessment, University of Medicine & Dentistry, New Jersey
- The Center for the Study of Environmental Factors in the Etiology of Autism, University of California, Davis □

This article comes courtesy of: NIH Publication No.04-5511, April 2004.

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better, and engendered a great deal less resistance. I probably went years longer than necessary un- or self-medicated, all because no one wanted to take the time and effort necessary to make medication more, not less, attractive.

The 12-step movement understands that people in early recovery need incentives: when you say you have gone 15 days without using, the group applauds. When was the last time anyone heard applause in a mental health clinic? 12-step programs have key chains, anniversary celebrations, coins for every year of recovery (I carry my coin like a talisman), symbolic rewards for working the program. We never bother with any of that in mental health. Instead we have psychiatrists who make pronouncements from on high, and if that doesn't work, threats, legal proceedings, and, for those of us unfortunate enough to be on inpatient status, take downs, seclusion, and restraints.

Now I have a ton of incentive: a good job, a mortgage, a niece, a place in the community. A have a lot of good reasons to take care of myself. The system needs to use a lot more honey and a lot less vinegar; it needs to become a system of attraction, not compulsion. □

White Paper from page 18

OMH and other sources. We are very pleased that OMH Commissioner Carpinello is making this project a priority. The white paper makes it clear in no uncertain terms how families help, why families need help, what help families need and how family services should best be provided.

Members of NAMI-NYS will be receiving copies in the mail before too long and others make obtain copies by contact-

ing the NAMI-NYS office at (518) 462-2000 or toll free in New York at (800) 950-FACT.

Please mark your calendars to attend the NAMI New York State's 24th Annual Meeting and Educational Conference at the Crowne Plaza Hotel in White Plains, New York. It will be held November 3-5, 2006. This event is shaping up to be the best ever, so plan to be there. Brochures with a full description of the conference, topics and speakers will be going out this summer. □

Reading from page 21

Teacher: Good morning, Vickie!

Vickie: Good morning, Vickie!

Teacher: What's my name? (I took her hand and placed it on my arm as I said, "Roxanne.")

Vickie: (With a smile of recognition.) Roxanne.

Teacher: Very good. I'm Roxanne. (Pointing at myself, I asked again.) What's my name?

Vickie: What's my name?

Vickie knew 15 letter names when she began to attend class. In comparison to normal kindergartners, she did not learn the letter names rapidly and required frequent review. However, once she began to learn to read, she acquired sight words with little effort. Any attempt to teach her phonics was a failure. She never understood the relationship between letters and sounds.

I tested comprehension by asking Vickie questions about the stories in her pre-primer and pointed to the pictures accompanying the texts. I had to continually simplify the questions until they were comprehensible. This system worked for the pre-primers where there is a one-to-one word-picture correspondence, but it became confusing as the stories increased in complexity. Eventually it became necessary to simplify the questions to the point where the child understood, but the questions were no longer based on the stories. To solve this problem I printed special reading cards with statements she understood. "Open the door. Sit down. Wash your hands. Brush your hair. Give me the paper, etc." As soon as Vickie learned to read the cards, she was able to follow the directions written on them and pantomime the actions. When she could read and understand more than 30 cards, I was certain she understood what she was reading and not just mouthing meaningless words.

I tried to improve the girl's comprehension by teaching her to read stories she made up from photographs and pictures cut out of magazines. Vickie dictated the following description from a soup advertisement. "This is a picture of a little boy. The boy has a red hat. The boy is eating soup and crackers."

I made a communication board for Vickie with common phrases useful in daily life to facilitate communication with her family. I taught her to read the phrases and use the board properly by having her imitate me—I had an identical board. For example, when I pointed to a square on the board and said, "Good morning!", Vickie pointed to the same square on her board and said, "Good morning!" The answers to the questions were written below. "How are you?" "Fine." As soon as a question was asked, it was covered up, leaving only the answer visible. Then, the question was covered on Vickie's board, and I would point to the answer to further encourage correct responding. The board was designed to replace echolalia as a means of communication, but it was a long process to teach her the correct responses. Each response had to be taught separately, and there seemed to be no generalization.

ROSA

Rosa was an attractive 6-year-old Spanish girl. She did not enter my class until 8 months after admission to the Bellevue nursery as an outpatient because of her difficulties in adapting to new situations. Even after several weeks in class, she still had frequent crying spells and was inconsolable unless she was permitted to perseverate aimless block play or listen to music. Her psychological assessment on the Gesell Developmental Schedules showed development quotient scores of 57 in motor skills, 61 in adaptive skills, 30 in language, and 44 in personal and social skills.

Before beginning academic work, it was necessary for Rosa to stop crying, adapt to class, and establish a relationship with me. Since she didn't like candy or cookies, these items were useless as rewards. However, she loved music, particularly a recording of Spanish children's songs sung in Spanish, and she would accompany the singer. By promising Rosa to play the record after she finished her schoolwork, I could motivate her. If she refused to cooperate and started to cry, she stopped after I showed her the record. When I visited Rosa's home several months after her discharge, she refused to talk but made the motion of the revolving record with her arm.

Rosa could count to 10, both in English and Spanish, and always read the numerals on the elevator panel out loud. Standing by herself in a corner of the elevator, she chanted the number as the elevator reached the floor, much to the amusement of the other passengers, whose greetings she ignored. In class she learned to match numbers to groups of objects and add and subtract numbers from 1 to 5.

During the 2 months that Rosa attended class while awaiting placement in a special class in a public school outside of the hospital, she learned to read the names of the letters of the alphabet and 15 sight words. She learned without effort, and while she was reading out loud she had an expression of beatitude on her face as if she were performing a miracle.

TOMMY

Tommy, a handsome, well coordinated 9-year-old black boy, came to class during his third admission to Bellevue. Since he was quite limited intellectually, Tommy had attended the nursery program previously, but by then he was too big and strong to be allowed to play with the nursery children. With this admission, his mother agreed to the psychiatrist's suggestion for residential treatment, as she felt she could no longer manage her son. Tommy had been diagnosed autistic on his first admission. He scored 37 on the Stanford Binet during his third admission, giving him a mental age of 3 years and 6 months. He was more limited intellectually than the other children in class, but I have included him to illustrate how even low functioning autistic children can be taught to read. The boy's special abilities consisted of a sense of rhythm, good coordination, and ability to learn the words of songs. He amused the older students by singing and dancing uninhibitedly to rock music. He recognized pictures of rock stars

see Reading on next column

Reading from previous column

and called out their names when he saw them.

At the time Tommy joined the class, his two classmates were beginning to read. Since Tommy seemed unready for scholastic activities, he was given readiness materials while his classmates had their reading lesson. He needed more training in social skills than in academics. Then, one day about 3 months after admission Tommy called out "city" as the flash card was presented to a classmate, and I realized that he also might be able to learn to read. Teaching reading to autistic children seemed to depend less on their intelligence than their visual discrimination. Tommy's recognition of rock stars was proof of his visual discrimination. Motivated by participation in a reading group with peers, Tommy began to learn the names of the letters of the alphabet, which were made more concrete by attaching the names of Tommy's friends to the letters, T for Tommy, R for Rosa, S for Superman, M for his mother Mary. The boy also learned to place cardboard letters of his name in the correct sequence by himself after practicing for 3 months matching the letters to those of his name printed on a sheet of paper. He never learned to write his name alone.

Tommy continued his alphabet lessons for the next 2 months and learned the names of 12 letters before discharge. He did not continue his "reading" lessons after transfer to a residential treatment center, where he was placed in a class for low functioning children with an emphasis on social skills.

DISCUSSION

These three case studies illustrate the facility with which some autistic children can learn beginning reading and the importance of such an accomplishment. Vickie and Rosa learned to read in the effortless way typical of autistic children described by Wolff and Chess (1965) and Cobrinik (1974). Even Tommy, who functioned on a much lower level than the girls, was able to learn letter names. The children acquired reading skills because of their superior visual discrimination and recall. In view of the major cognitive defects in other areas, it seems important that the children be taught to read to allow them to experience positive feelings from their achievement.

Hewett (1964) described long and tedious techniques of operant conditioning, which he considered the only effective means of working with autistic children. However, I found that once a child began to learn, he or she progressed easily. The crucial factor that initiated the learning process was the relationship with me, the teacher, and my task was to make the children believe they were capable of achieving. I had to discover ways of developing trust. After the relationship was established and the children experienced positive experiences, the learning became self-motivating.

Contrary to the view that reading by autistic children is rote reading without comprehension (Cobrinik, 1974), I found that the children were able to understand when they read as long as the texts were geared to each child's experience and level of understanding. The teacher is obliged to design special reading material for each child in order for understanding to increase concurrently with reading skills. □

Roxanne Lanquetot is a family member, writer, and retired psychologist/teacher who worked with young children on the Inpatient Children's Service of Bellevue Psychiatric Hospital, New York, N.Y., for over 27 years.

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Needs from page 12

her spouse, her special needs child, and with the siblings of her special needs child.

Finally, the TSG offers the mother an opportunity to give back to herself so she can be available for others. It is an opportunity for the mother to forgive herself because it is not her fault. It is okay and absolutely necessary

for a mother of a child with Autism to attend to herself, to allow herself to have pleasure in her life, to forgive herself, and live without so much self-inflicted emotional punishment and guilt for her feeling overly responsible for her child's Autism. □

Theodore M. Roth, PhD, is a New York State Licensed Psychologist, with private practices in Westchester and Long Island, New York.

Medical Home from page 12**Conventional & Non-conventional Therapies**

Conventional therapies for autism generally refer to intensive behavioral therapies such as; Applied Behavioral Analysis (ABA), Greenspan's Floortime model, or Treatment and Education of Autism and Related Communication Handicapped Children (TEACHH). All these treatments work through the theory that the child with autism needs to be directly engaged. Eye contact and social reciprocity needs to occur in order for learning to begin. Many of the other therapies familiar to early intervention are also helpful based on need. As alluded to earlier, physical therapy, especially for children with low tone and gross motor problems can be helpful. Additionally, occupational therapy may be helpful for poor penmanship and difficulty manipulating objects in space.

Non-conventional therapies are actually too numerous to count and I will try and highlight the most common ones that a practitioner is likely to come across. I usually separate them into three categories; dietary/supplements, biological treatments, and complementary alternative medicines. Dietary strategies usually in-

volve some type of restriction. The most common restriction diet is based on the gluten and casein free diet used for patients suffering from celiac disease. The theory is that gluten and casein cause inflammation in the gut and this allows neuro-toxic compounds to "leak" through the gut and travel up to the brain, thus causing the manifestations seen in autism. Supplements are much more plentiful and in many cases cause no harm, but are generally expensive and difficult to measure what they are doing. A list of some common supplements include; essential fatty acids (omega-3, etc.), multivitamins, carnitine, digestive enzymes, and pro-biotics such as lactobacilli.

Biological treatments for autism are also plentiful and may have side-effects that may be harmful. Chelation therapy to remove heavy metals is one therapy that is utilized where children are actually given intravenous, intramuscular, or oral chelators that can cause electrolyte abnormalities and even death. These therapies should be cautioned against until some type of research is done to prove they have any benefit. Secretin was an interesting therapy because at the end of the 1990s, after a well publicized anecdotal success in the media, it was being used quite frequently as an intravenous drug.

Soon randomized trials were done with a sugar water placebo versus a \$250 injection of secretin and they were found to be equivalent in the treatment for autism. Other common biological treatments include; anti-fungals to clean out the gut, glutathione to improve detoxification, and melatonin to improve the sleep cycle.

Complementary therapies are a little more elaborate in their theoretical ability to improve the symptoms of autism. For example, sensory integration techniques such as auditory integrative therapy or AIT, require an intricate understanding of retraining the receptive hearing of the patient so that they can improve cognition. There are actually no well designed randomized studies showing any improvement with this therapy, yet it is very popular in the autism community. Recently some local articles have surfaced looking at hyperbaric oxygen as a treatment for autism. At present, other than anecdotal reports from parents who are paying \$8,000 for a set of 40 treatments, no other evidence exists for its use. Obviously having an illness like autism, where there is no known etiology, creates a vulnerable population of families to unproven therapies. Unfortunately, they may be spending their money on short term possibilities, instead of proven long term gains.

Keeping the Lines of Communication Open

The primary care giver's role in the diagnosis of autism should be to recognize and screen for ASD and be pro-active and informative to parents by sharing their earliest concerns regarding autism. To sustain an open, trusting relationship with parents of children with autism, practitioners should inquire about parental beliefs concerning etiology and learn what treatments the children are receiving. Simple testing based on medical history and physical exam will allow the practitioner to address treatable problems. Providing local resources and evidenced based support will allow the parent to view their practitioner as a partner in the treatment of their child. Using a non-judgmental tone will maximize a physician's chances of uncovering critical information needed to avert potentially harmful practices, and provide a safe and practical 'medical home' for parents and their children with autism. □

Dr. John Harrington is an Associate Professor at New York Medical College and has a private practice at 19 Bradhurst Avenue in Hawthorne, New York.

SID from page 22

ideas that are presented. You may filter out the noise of the subway as you read. Or you are having a cup of coffee while you are reading. You barely have to think as to where your mouth is to take a sip of your hot beverage. Proprioception helps us to stay stable in space and to balance ourselves. Children with SI dysfunction in this area may have body awareness problems. They may constantly bump into other children, or push, bite or hit, even though they are not known to be overly aggressive children. Or they may have to closely watch their feet as they walk, or even enjoy jumping, crashing, banging or pulling activities.

So how do we treat these challenges? By first observing and knowing our children, and getting to learn what their sensory needs are. We can create a sensory-filled environment, or one that "feeds their needs" – a sensory diet. This is best done in consultation with an occupational therapist trained in sensory integration issues, but may include weighted blankets for children who love deep pressure activities, an opportunity to swing everyday for the child who loves vestibular stimulation, or putting the child who has a poor sense of spatial boundaries always at the front of the line as the "line leader", so s/he cannot bump into everyone as s/he walks.

It is wonderful to know that our awareness of the issues of SI dysfunction have grown by leaps and bounds over the years. We really have to thank the early pioneers of autism research and treatment for this work; as they learned more about the symptom of sensory challenges faced by children with autism or PDD, our work with children with all sorts of generalized sensory challenges has grown exponentially. Early intervention works best. If a child begins to display some of the issues described in this article, it is best if they get help during their pre-school years. More and more occupational and physical therapists are aware of SID, and they can do wonders to help set up a home and school environment that meets

the sensory needs of any child.

The question will arise as to whether to have a child identified as SID for services in the public school system. This is a decision best left to parents, legal guardians, as well as treating doctors and therapists who work with the family. Having the child identified as SID through an Individualized Education Plan (IEP) or 504 Plan is a decision that should be made with thought, consultation, and an evaluation of the pros and cons. Identifying the child as special needs opens the doors to treatment, pre-schools for children with special needs, and an array of services. It can also lead to labeling, misunderstanding, and an over-emphasis on disability. Luckily, there are some good resources on the internet and at the local library to help with making this decision. Ask for or search for resources on Sensory Integration Dysfunction.

Sensory Integration Dysfunction as a disorder is not without controversy. Maybe some of you read this article and thought, "I hate the ear-splitting noise of loud places and I do just fine in life!" That may certainly be true. SID may simply be a developmental challenge that we all face, and we all have our own ways of dealing with the numerous sensory stimuli that we are faced with every day. What SID does help us to realize is that certain childhood sensory behaviors we used to label as odd or unusual, such as covering one's ears on a bus, or refusing to eat certain foods, or even spinning like mad on a swing, may have some underlying neurological explanation. Learning about SID helps us to discriminate our home, school, and social environments to the best of our abilities for each child, and empowers us to stay focused on the needs of children that can often be overlooked. □

A major resource for this article was Raising a Sensory Smart Child: The Definitive Handbook for Helping Your Child with Sensory Integration Issues, by Lindsey Biel, MA, OTR/L, and Nancy Peske (2005). The book is available from Penguin Books, NY, NY.

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includes a detailed history, an interview of the individual, speaking, when indicated, with others involved with the child like pediatricians and school staff and then discussion of the findings with the parents. This discussion should include recommendations for any indicated further evaluations, like audiological or neuropsychological testing and recommendations for any treatment or intervention that can begin immediately. Not every individual has to be administered every sort of test to arrive at a diagnosis and extensive testing, although helpful to tease out the specific problems of a child may be unnecessary to make a diagnosis. Delay of diagnosis in a young child may delay the implementation of treatment and keep parents in a suspended state of heightened anxiety about the status of their children. The expert should also be available to advocate for the child and parents. This includes, when necessary, participating in getting further evaluations or services for the child.

If an individual expert is not available to a parent, one can start the evaluative process through early intervention (EI) services for children less than three years of age. Information about EI is available over the Internet. EI puts children through a number of evaluations which takes some time. Beside this, I have been disappointed at times with children, who are clearly in the autistic spectrum to not be diagnosed as such after EI evaluations. The children may receive some needed services but not the more crucial ones for autistic spectrum disorders.

Mental health professionals should enlighten parents to the fact that the precision of a psychiatric diagnosis will vary from one case to another. There is much overlap with the symptoms of different categories of disorder. The individual who clearly meets the criteria in one or two categories and does not have some symptoms of other disorders is the excep-

tion, not the rule. One can be relatively more precise in diagnosing a young child who has all the characteristics of Autistic Disorder. On the other end, one diagnosed with a milder form of ASD may have been diagnosed with, or at least make an evaluator think of ADHD, Obsessive Compulsive Disorder, an anxiety disorder etc. Notwithstanding this, in most cases, the evaluator can arrive at what appears to be the primary diagnosis or diagnoses and an approach at treatment. In those cases where it remains unclear if an individual has or does not have an ASD, and only further time or evaluation will help clarify the situation, I believe that it is better for a parent to be told this rather than to be told that a child definitely is not in the autistic spectrum. Parents should also know that there are no biological markers that confirm a diagnosis of an ASD like some genetic marker, blood test or brain imaging finding. Research is being conducted in all of psychiatry to come up with these markers for all disorders. The brain, due to its complexity, and the limitations on how we may probe into how it works, gives up its secrets more slowly than other organs.

I am hopeful that these words will be of help to parents and others as they navigate through the process of getting evaluations and treatments. A last word is that they and, I think evaluators, should come together in the spirit of a collaboration. Parents know their children best in the sense that they observe and interact with them day in and day out. The evaluator knows best how to diagnose and recommend a course of action. Both parties should be able to question each others' opinions with the aim of arriving at a consensus as to how best to proceed in getting help for the child. □

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