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WINTER 2010 FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE VOL. 2 NO. 3

Advances in Autism Science

An Interagency Autism Coordinating Committee (IACC) Update

By Thomas R. Insel, MD, Director National Institute of Mental Health, Susan Daniels, PhD, Deputy Director and Erin Bryant, MJ, Office of Autism Research Coordination, NIMH

The Interagency Autism Coordinating Committee (IACC) is a federal advisory committee that was created by Congress in an effort to accelerate progress in autism spectrum disorder research and services by improving coordination and communication across the Federal government and by working in partnership with the autism community. With the recent reports of increasing prevalence of ASD (CDC, 2009; Kogan et al., 2009), the work of the IACC becomes more urgent and more important than ever. This article will explain the formation of the IACC and its responsibilities, in addition to the committee's recent progress identifying important scientific advances, developing a strategic

Thomas R. Insel, MD

research plan for autism spectrum disorders, and assessing the state of current ASD research funding.

Originally established through the Children's Health Act of 2000, the IACC was reauthorized under the Combating Autism Act (CAA) of 2006 and its mandate expanded to cover all autism spectrum disorders. The committee is composed of officials from many different Federal agencies involved in autism research and services, as well as a person with ASD, parents, advocates and other members of the autism community. Under the CAA, the committee is charged with developing and annually updating a strategic plan for ASD research. The IACC is also responsible for monitoring federal activities related to autism, preparing an annual summary of advances in ASD research for Congress, and making recommendations to the Secretary of Health and Human Services (HHS) and the Director of the National Institutes of Health (NIH) regarding the strategic plan for autism research and federal activities related to autism. As an advisory committee, the IACC does not have its own budget with which to fund research and relies on other agencies to implement the committee's research recommendations. More information about the IACC is available at www.iacc.hhs.gov.

Advances in Autism Research

The pace of ASD research is rapidly accelerating. This includes recent work supporting the accuracy of early diagnosis as well as evidence for the impact of early interventions. A 2009 study found that children who started a comprehensive developmental behavioral intervention before the age of 2 ½ showed substantial improvements in IQ, language skills, adaptive behavior, and autism diagnosis (Dawson, et al., 2009). This was the first randomized, controlled trial to evaluate and demonstrate the effectiveness of a comprehensive behavioral intervention designed specifically for toddlers. It is hoped that this groundbreaking study will open doors to further evaluations of early

see IACC Update on page 40

An Autism Spectrum News Interview with Margaret L. Bauman, MD Director of the Lurie Family Autism Center - LADDERS

By David H. Minot, BA Autism Spectrum News

We are indeed fortunate to have an opportunity to speak with Dr. Bauman about her work in clinical and basic research at the Lurie Family Autism Center/Learning and Developmental Disabilities Evaluation and Rehabilitation Services (LADDERS). In the interview that follows, Dr. Bauman reveals her current and past work as a pediatric neurologist, her thoughts on the increasing prevalence of autism, the role of auto-immune factors in the development of autism, and the direction she would like to see autism research move in the near future. Dr. Bauman leaves parents with a hopeful message that early diagnosis, early treatment and intensive services with high quality, experienced professionals can really turn around many children with autism spectrum disorders and can

Margaret L. Bauman, MD

result in much brighter futures for these children and their families.

Q: How did you first get involved in autism research and clinical treatment?

A: My interest in autism was an accident. When I was a resident I remember thinking that autism was a totally impossible problem. I couldn't understand how you could even begin to think about it. However, during my residency program at the Massachusetts General Hospital (MGH) in Boston, MA, I was privileged to be able to spend 6 months working with Dr. Paul Yakovlev, MD whose long and very productive career involved studies of the human postmortem brain during development, aging and in a number neurological disorders. It was during this time that I learned about the neuroanatomy and neuropathology of the brain and met my eventual research colleague, Dr. Thomas Kemper. While working in this laboratory, Dr. Kemper and I conducted a neuroanatomical study of the brain in Phenylketonuria (PKU), a genetic disorder that is characterized by an inability of the body to utilize the essential amino acid phenylalanine, which was eventually published in 1982.

After leaving Dr. Yakovlev's laboratory and my residency training, I spent much of my time seeing patients with a variety of neurological and developmental disorders, primarily those with learning disabilities and seizure disorders. About a year after Tom and I finished the phenylketonuria project, I felt that I needed to move beyond the clinic setting. By that time, Tom had moved over to Boston University School of Medicine (BUSM). One day, while visiting him in his laboratory, I said, "I need to get out of the clinic, would you mind if I spent some time in your Lab? I don't have any time, I don't have any money, but I need to do something different." I cannot tell you to this day why I said this, I said, "You don't have a case of autism do you?" Happily Tom agreed and suggested that I begin to

see Bauman Interview on page 42

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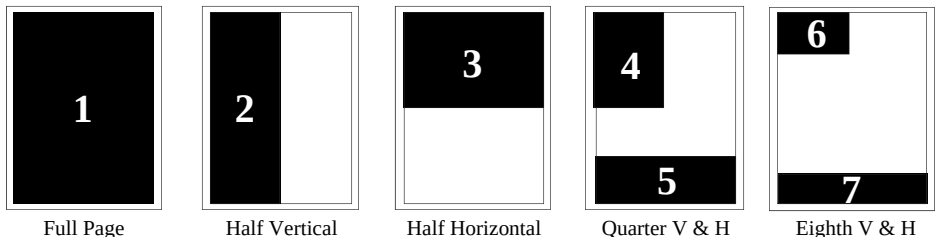

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"Understanding and Accessing Clinical Treatment Services"
Deadline: March 15, 2010

Summer 2010 Issue:
"Helping Families Cope With Stress"
Deadline: June 15, 2010

Fall 2010 Issue:
"Addressing the Growing Needs of Adults"
Deadline: September 15, 2010

Winter 2011 Issue:
"Mental Health Treatments for Autism"
Deadline: December 15, 2010

From The Publisher

The Autism Science Community Embraces Autism Spectrum News

By Ira H. Minot, LMSW
Founder and Executive Director
Mental Health News Education, Inc.

The theme of this issue of *Autism Spectrum News* is "Advances in Autism Science." We are truly inspired by the quality of articles and leaders in the field of autism who have collaborated with us to bring you this exciting issue. Our goal is to bring you the highest quality of science-based information and education in each issue of *Autism Spectrum News*.

We reached out to respected pillars of the autism science community who have devoted their lives to improving the lives of individuals with autism. It is a true testament to the growing reputation of *Autism Spectrum News* that these individuals volunteered time out of their hectic schedules to contribute information about their current research projects, latest data and clinical trials, and advocate the vital need for parents to educate themselves about and utilize scientifically proven interventions for their children.

Our esteemed Editorial Board approves all content for each issue to help ensure that *Autism Spectrum News* contains only clinical treatment best practices and evidence-based information. After previewing this issue's articles, Pat Schissel, LMSW, President of the New York Asperger Syndrome and High Functioning Autism Association (NYAHA) and *Autism Spectrum News* Editorial Board member commented that, "This issue is by far the most important issue of *Autism Spectrum News* published to date. Parents waste untold amounts of time, energy, and money on magic bullets and it is unfortunate that some professionals in the field foster them. One article after another that I have read clearly states the facts and this issue of *Autism Spectrum News* is truly an invaluable resource to the autism community." Publishing the scientifically proven facts is the hallmark of this publication and we are proud to continue our mission of bring strictly evidence-based information and education to the autism community.

In putting together this issue of *Autism Spectrum News*, one main theme has emerged. Many commonly used interventions and treatments are not supported by scientific data to prove their effectiveness as a treatment for autism. Article after article explains the importance of utilizing treatments that are scientifically proven. Treatment methods that are not proven to be evidence-based should be avoided as they can be unsafe, ineffective, costly and a waste of time that could be spent utilizing an approach that has been proven effective.

Often, parents read about or hear from another parent a success story where an intervention has worked for one child and they may feel inclined to try that approach for their own child. The media all too often glamorizes a single positive outcome in the absence of evidence. The "n of 1" story, meaning something that has worked for just one person, must not be perceived as trusted information. For an autism treatment to be considered scientifically proven, there are rigorous requirements that must be met. The articles in this issue of *Autism Spectrum News* will instruct the reader that anecdotal evidence is not the same as scientific evidence, will provide a roadmap of the latest current trends in autism science, and will inform the reader of the vital work so many individuals and organizations are doing to further advocate for and advance evidence-based treatment and interventions for individuals with autism spectrum disorders.

Ira H. Minot, LMSW

Autism Spectrum News is now featuring exclusive interviews with leaders in the autism community. As the theme of this issue is "Advances in Autism Science," it seemed only natural to sit down with Margaret Bauman, MD, a renowned pediatric neurologist and scientist who has devoted her life to understanding how autism affects the brain and to connecting basic science to clinical practice in the field of autism. Dr. Bauman's candid interview reveals her current clinical and research work as well as where she hopes and strives for science to move in the future - towards a better understanding of autism as it first develops, as opposed to merely intervening down the road after a child has been diagnosed. Dr. Bauman concludes her interview with a message of hope that, "It is really thrilling and wonderful how early diagnosis, early treatment and intensive services with good quality people really have turned around so many children."

Our cover story features an update on recent progress of the Interagency Autism Coordinating Committee (IACC), identifying important scientific advances, developing a strategic research plan for autism spectrum disorders, and assessing the state of current ASD research funding. This federal committee is composed of officials from many different federal agencies involved in autism research and services, as well as a person with ASD, parents, advocates and other members of the autism community "With its continued efforts, the IACC is working to enhance and accelerate ASD research that will benefit people with ASD across the lifespan and the communities that support them."

In our front page interview with Dr. Margaret Bauman, she states that she would like to see science move more towards understanding autism before birth. On page 12, Dr. Eric London advocates for the need to "know who will turn out to be autistic much earlier or even in utero, so that we could intervene with very young children and guide the brain development into a more healthy outcome." Dr. London outlines some of the vital work being conducted in autism treatment research at the New York Institute for Basic Research where they are studying the behavioral and cognitive development of babies in the neonatal intensive care unit.

On page 13, Dr. Edward Ritvo introduces a theory for a possible cause of both autism spectrum disorders and schizophrenia. His theory proposes that, "The symptoms of autistic spectrum disorder and schizophrenia express abnormal development of the brain. This abnormal development is caused by abnormal micro-RNA programming. The degree of severity and clinical course of the disorders is determined by the segments of micro-RNA involved and their degree of abnormality."

Dr. Ted Brown, Director of the New York Institute for Basic Research brings us exciting news that science seems to be moving ever closer to finding potential new treatments for fragile X syndrome. On page 14, Dr. Brown states that, "double blind trials are underway at our Institute's fragile X clinic and nine other fragile X clinics in humans with fragile X and also in subjects with ASD using a purified form of the GABAergic drug Baclofen." Also, "It was discovered that a commonly prescribed antibiotic, minocyline, could produce dramatic improvements in brain function and behavior in the mouse model of fragile X."

On page 17, Drs. Sylvie Goldman and Isabelle Rapin of the Albert Einstein College of Medicine, discuss the importance of motor dysfunction in autism spectrum disorders. Drs. Goldman and Rapin explain that, "Systematic study of sensorimotor function in autism is new. The focus of our laboratory and others has been to describe these deficits in children with ASD and other developmental disorders. In studies largely yet to be done, our goal is to understand their brain basis."

Paula Goines and Dr. Judy Van de Water from the MIND Institute at the University of California Davis address the connection between autism and the immune system and the implications maternal autoantibodies on the maternal fetus. On page 19, Goines and Van de Water write that, "Researchers at the University of California, Davis, Johns Hopkins, and the Kennedy Krieger Institute have found that some mothers of children with autism produce autoantibodies that target the developing fetal brain. Children born to mothers with autoimmune diseases like systemic lupus are susceptible to damage mediated by these maternal autoantibodies. The autoantibodies which are found in mothers of children with autism are also passed to the fetus, where they may interfere with brain development and function."

On page 21, Dr. Susan Wilczynski, Executive Director of the National Autism Center, presents the National Standards Project and how it supports evidence-based practice for autism spectrum disorders. "Understanding the scientific literature is not easy given the volume of studies that have been published on the treatment of autism spectrum disorders. To address this challenge, the National Autism Center undertook the National Standards Project, a multi-year effort completed in the fall of 2009. The project is the most comprehensive systematic review of the autism treatment literature specific to children and adolescents with autism spectrum disorders available to date."

In addition to the articles mentioned, there are many others that address the latest advances in autism science by experts in the field of autism that we hope will inform and inspire you. Let me conclude by telling you about our exciting roundup of themes in the upcoming quarterly calendar of *Autism Spectrum News*. Our spring issue theme will be "Understanding and Accessing Clinical Treatment Services." Our deadline for articles and advertising for this important issue is March 15th.

Our calendar continues with our summer issue which will focus on "Helping Families Cope With Stress." Next fall we will take an in-depth look at "Helping Families Cope With Stress" and next winter our theme will be "Mental Health Treatments for Autism."

We would like to invite everyone to participate in these exciting upcoming issues. Our goal is to continue our format of providing evidence-based news, information, education, advocacy, and resources on a variety of topics of importance to the autism community. As a non-profit organization, we ship thousands of free copies of each issue of *Autism Spectrum News* to our growing family of autism and mental health organizations. For those who may not have the opportunity to pick up copies of each issue at our delivery locations, we post each entire issue for free on our website: www.mhnews-autism.org. On our website you can subscribe to receive your own personal hard-copy that will be mailed to your home or office address. You can also order our group subscription and receive 50 copies of each issue for your clients and staff.

We look forward to hearing from you. Please e-mail us at dminot@mhnews.org and tell us what topics are important to you, so that we can address them in future issues of *Autism Spectrum News*.

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Have a Wonderful Winter Season!

AUTISM SPECTRUM NEWS DESK

Stephen E. Freeman and Thomas A. Dern Promoted to Chief Operating Officers of the YAI Network

By YAI/National Institute for People with Disabilities Network

Stephen E. Freeman, a member of the *Autism Spectrum News* Editorial Board, and Thomas A. Dern have been promoted to the position of Chief Operating Officer of the YAI Network.

"We're pleased to promote Stephen and Thomas, two consummate professionals, both of whom have been with the organization for more than three decades and have contributed immeasurably to the growth and quality of the YAI Network," said Dr. Philip H. Levy, Chief Executive Officer and President of the YAI Network.

Both executives are highly respected leaders throughout the Network and the field. They are widely recognized for their commitment to people with developmental and learning disabilities, their families and professionals. They most recently served as Associate Executive Directors of the YAI Network.

Freeman, who has been with the organization for 33 years, currently oversees YAI/National Institute for People with Disabilities' Day Services and Clinical and Family Services departments and the YAI Autism Center, as well as Premier HealthCare, the New York League for Early Learning, and the International Institute for People with Disabilities of Puerto Rico (all of which are members of the YAI Network).

Stephen E. Freeman

Thomas A. Dern

"I'm proud to serve with an organization that has been a pioneer in the development and implementation of groundbreaking services which have had a tremendous impact on the quality of life of people with disabilities and their families," Freeman said. "I look forward to continuing to make our organization stronger and to helping to make this world a better place for individuals with disabilities."

A graduate of Queens College of CUNY, Freeman earned his Master's of Social Work from Hunter College, where he was inducted into the Hall of Fame in 2008.

Dern, who has been with the organization for more than 30 years, oversees more than 100 YAI/National Institute for People with Disabilities' residential programs, as well as YAI's Long Island Services, YAI's Certified Home Health Agency, the Rockland County Association for Learning Disabilities, and the National Institute for People with Disabilities of New Jersey, all members of the YAI Network.

"Thirty years ago many people with disabilities were living in dehumanizing conditions in institutions," said Dern. "Today, these individuals are leading more independent, fulfilling, productive and integrated lives in their communities. It has been a privilege and a pleasure to be part of this social revolution."

A graduate of St. John's University, Dern earned his Master's of Social Work from Hunter College. He is a Fellow of the American Association of Intellectual and Developmental Disabilities. Since 1989, he has served as chairman of the InterAgency Council's of Mental Retardation and

see YAI Promotions on page 17

Autism Speaks Launches Science Ambassador Program

By Autism Speaks

Autism Speaks is pleased to announce the launch of the new Science Ambassador Program. The program is volunteer-based, offering individuals interested in advancing the science mission of Autism Speaks an opportunity to work directly with the science and field staff. Ambassadors are trained to serve as liaisons to help educate the community about Autism Speaks' science programs in order to advance their understanding, participation and support of our efforts to advance autism research. Under the supervision of the science staff, ambassadors will work with their local field staff, their local researchers and members of the community to increase public awareness of current events in science, ongoing clinical trials and Autism Speaks' funded research.

Additionally, through a private, on-line community specifically created for Science Ambassadors, volunteers can interact with the science and field staff of Autism Speaks and ask questions about the current state of the science. The science staff will work with ambassadors to answer questions and provide research updates to help them stay informed of advances in autism research, public and fundraising events as well as provide them with a forum so that they can network among their fellow ambassadors.

For more details about the Science Ambassador Program, please visit us at the Autism Speaks web page: www.autismspeaks.org/science/programs/science_ambassadors.php

If being an Autism Speaks Science Ambassador (SA) is of interest to you, contact your local Autism Speaks field staff leader or visit our web page section "How to become an Autism Speaks Science Ambassador" and email the program director. We will help you get started.

Below are comments from some of our volunteers and why they choose to be an Autism Speaks Science Ambassador.

Betty W. - By being a science ambassador, I get the privilege of helping other families know about the work the research community is doing for autism as well as to help others in the community who will be "touched" by autism better understand it. That is the very thing Autism Speaks is trying to achieve. Find out autism's modus operandi if you will. There are people out there, many of them who are just like I USED to be. Front line teachers, doctors, therapists, coaches, day-care workers, churches, are just a few who will be "touched" by autism. They need to know. I'm pretty sure they want to know, and would be willing to help if they were educated about autism.

I want to be able to help the next set of parents who have an autistic child. To keep them from having to go through what I went through. It doesn't have to be that way. It's already getting better. But it's not completely there yet. Being able to inform as many people as possible about the possibilities available when programs such as the Autism Tissue Program (ATP) (www.autismspeaks.org/atp) receive a precious brain donation is extremely important for the success of autism research. Their faces literally light up when they know there is a way they can help tremendously by donating their brain post-mortem. Most of them are already organ donors, and were not aware there is a need for brain tissue. Then they tell someone. And we know how that works!

Yasmin S. - I am an RN and a mom that has a passion for autism and the science behind it. I want to channel my energy and interest in research and science somewhere. I was so excited to come upon the science ambassador program. I want to be a part of autism anyway I can.

I believe that educating the public and bringing awareness to autism is essential to the success of our children. I believe in giving back to the community, that's why I wanted to volunteer and put my efforts where I can make a difference. I say that because if my pediatrician and the teachers that where around my son where aware of autism he would have been diagnosed much sooner. The best way I can give back to the community is to stay informed of what is going on in the autism community, particularly in science, and share that information.

Melinda E. - My son, Brian, was diagnosed with autism at the age of 2 1/2. He

see Science Ambassador on page 17

Social Skills Interventions: Considering Generalization

By Moira Lewis MS, CCC-SLP
Speech-Language Pathologist
YAI Autism Center

It is well known that people with autism spectrum disorders (ASD) often have difficulties generalizing newly learned skills. Children with autism frequently cannot apply what they have learned in one situation to a similar - though not identical - situation, especially one related to learned social skills.

This has important implications in a therapeutic context.

Parent-professional collaboration and community-based instruction are important ways to improve the generalization of social learning in students with autism. Generalization can be enhanced by incorporating treatment in the classroom and home, such as providing intervention within everyday classroom routines with typical peers, or within everyday routines at home whereby parents are taught to incorporate therapeutic techniques. As it relates to interacting with other children in everyday settings, generalized environments are the "acid test" for mastered social skills.

Research supports a number of social and language intervention models aimed at improving children's social communication skills, across ages and ability levels. On the other hand, there are a number of social skills intervention approaches currently available to professionals and parents that have not been empirically tested, nor do they have data supporting children's achievements or social successes outside the intervention setting. A few of the outlined interventions described here do include components and steps aimed at facilitating the individual's ability to respond across many social situations, beyond the therapy setting.

Social skills often need to be taught explicitly to children with autism by professionals who can provide teaching, reinforcement and replacement behaviors. Traditional social skills strategies (such as discussion and reflection of interactions or board games) may be too subtle of an approach.

Moira Lewis, MS CCC-SLP

Integrating Peers as Models

The use of peer mentors is one example of an effective social skill intervention model that inherently addresses generalization for children with ASD. Peer mediated interventions have been designed and used to promote positive social interactions among preschool and school-aged peers (Strain & Odom, 1986; Odom, McConnell & McEvoy 1992, Goldstein et al., 1997). Within these approaches, peers are systematically trained to respond appropriately to the initiations and communication of children with ASD during the course of their school day. The use of peer mentors allows the teacher or clinician to act as a coach, facilitating play among peers rather than participating in it. The use of peer mentors also facilitates generalization of skills by ensuring that the child's acquired skills are monitored by adults and practiced with peers in an ordinary setting.

Goldstein et al. (1997) describe how the tendencies of typically developing preschoolers to avoid interacting with children with disabilities can be mitigated if they are taught and encouraged to use special interaction strategies. The authors evaluated the effects of a peer intervention model that distributed participation across the school day within short periods of play. Three strategies for being a "good buddy" structure that program. This includes, "Stay with your friend, play with your friend and talk with your friend," so that buddies were taught to "stay-play-talk." The training of "buddy" strategies followed a standard protocol, including discussion, adult modeling, guided practice, feedback and independent demonstration, with a generalization period included. This model did show effectiveness in increasing interactions among typically developing children and those with disabilities, with successful interactions observed within generalization probes.

Social Stories

A social story simplifies and explains social concepts, rules or situations that may be difficult for a child with a disability (Gray, 2000), and are often used as an intervention strategy for children and adults with autism. This strategy can be used to teach a number of social and pragmatic skills, such as joining play with others, taking turns and starting a game. Carol Gray (1995; 2000) outlines essential components to a successful social story: The story should be written in response to the child's personal need; the story should be something the child wants to read on his own (depending upon ability level); the story should be written according to the child's comprehension level (including incorporating pictures); and the story should use terms such as "can," or "could," instead of "will" or "must."

Bellini (2006) states that children with ASD learn best when social stories are used in conjunction with practice, such as role-playing. For example, after reading a social story, the child then practices the skill introduced in the story, such as initiation or "politely interrupting." Immediately after reading a story about joining an activity, the child can practice the skill outlined in the story with the clinician. Then, after reading the story and practicing the skill, the child would be given the opportunity to perform the skill in a second social situation, such as free play in a classroom or playground. Real peers would replace the clinician, who could serve to facilitate or monitor this practice, and then judge performance outside the teaching/therapy setting. Social stories, as a visual and portable tool, can remain available to the child and eventually "faded" to improve practice and support generalization of skills taught.

Including Parents and the Home

Gresham et al. (2001) recommends that social skills training be implemented as frequently as possible and more intensely than what is typical, emphasizing that instruction should be focused and include all environments where the child encounters opportunities to interact. Multiple settings where communication occurs include the home, classroom, therapy room, playground, extracurricular activities and social skills groups. Among those various settings, educational plans can be designed to facilitate transfer of skills, strategies and reinforcement in order to move to the natural environment with the least amount of prompting for effective interactions. Parents are a natural resource and can contribute to a child's effective social practice, with appropriate strategies and training, to prompt and reinforce the skills that are taught.

More than Words, The Hanen Program for Parents of Children with Autism, is designed to help families support the communication and social skills of their children with ASD at home (Sussman, 1999). This program aims to teach caregivers to identify their child's communication strengths, needs and methods to interact. Parents are taught to recognize their child's communication attempts, and how to teach the child to socially communicate in new ways for new reasons. Depending on their child's stage of communication, the parent is given facilitative strategies to reinforce communication opportunities and generate interaction within real routines, such as meal times, games, getting dressed, songs and outings. This particular program was found to be effective in a small group of children, whose caregivers increased their use of spontaneous interaction strategies and their children increased their vocabulary following participation in More Than Words (Girolametto et al., 2007). This program can serve as a means to promote generalization, because additional intensity and frequency is added to an existing program by targeting communication and interaction not only with new partners, but at home as well.

Regardless of the therapy method, involving parents, therapists, educators and peers in a variety of settings provides a more holistic method of intervention, and possibly more effective outcomes and skill performance. As children with ASD develop, it is important for educators, clinicians and parents to apply evidence-based social skill intervention models that both consider the needs of the individual child and also aim to target generalization.

YAI Network's International Conference: April 26-29, 2010 at The Hilton New York

By YAI/National Institute for People with Disabilities Network

The YAI Network's 31st Annual International Conference will take place on April 26-29, 2010 at a new venue, The Hilton New York. The conference, "Decade of Decisions: Moving Forward in Developmental and Learning Disabilities," will have a new format, featuring more extended sessions and full-day workshops from some of the most prominent experts in the field of autism spectrum disorders. Among the world-class presenters are:

- Carol Gray, Director of The Gray Center for Social Learning and Understanding, on social skills development
- Dr. Vincent Carbone, Director of the Carbone Clinic, on methods to increase vocal production in children with autism
- Tom Caffrey, on the verbal behavior approach to teaching children with autism
- Dr. Stephen Shore, author, advocate and educator, with a firsthand perspective on autism spectrum disorders
- Dr. Sima Gerber, Associate Professor of Speech-Language Pathology at Queens College, on language acquisition and intervention for children

The conference will include more than 120 seminars dealing with autism and other topics pertaining to people with developmental disabilities.

To register or for further information, visit yaiconference.org or contact Tina Sobel, Conference Co-Director, at tina.sobel@yai.org or 212-273-6457.

To reserve your room at The Hilton New York and receive the special YAI discount rate of $259, please visit yai.org/conference or call The Hilton at 1-800-HILTONS (1-800- 445-8667) and ask for the YAI Network conference rate.

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The Neurobiology of Sensory-Perceptual Symptoms in Autism

By David Grodberg, MD
Seaver Autism Center for Research and Treatment
Mount Sinai School of Medicine

A significant proportion of people with Autistic Disorder and other pervasive developmental disorders exhibit sensory symptoms, which can include over-responsiveness, under-responsiveness, and paradoxical responses to environmental stimuli. Indeed, autobiographical accounts by people with autism reveal that heightened sensitivities, sensory seeking and high pain thresholds form a crucial part of their experience and cause distress, anxiety, fear and confusion. Sensory symptoms can exist across all modalities and can be categorized into three domains: distal senses (visual and auditory), proximal senses (tactile and olfactory), and internal/regulatory senses (vestibular, proprioceptive, pain). Studies examining rates of sensory symptoms in school-age children with autism report a range from 42% to 88%. A recent study found that scores on the Sensory Profile in young children with autism were significantly higher than in children with other developmental disorders and high scores correlated with stereotyped interests and behaviors. Sensory symptoms thus contribute significantly to the heterogeneity of autism and present to researchers an

David Grodberg, MD

opportunity to further understand the neurobiology and clinical features associated with this specific symptom domain.

Kanner's clinical observations of autistic children from 1943 include sensory-perceptual symptoms and the Diagnostic and Statistical Manual of Mental Disorders (DSM) over the decades has included this symptom domain either in the diagnostic criteria for autism or as an associated feature. However, despite longstanding awareness, relatively little is known about the neurobiology or phenotypic nature of sensory-perceptual symptoms.

One reason sensory-perceptual abnormalities in autism are poorly understood is due to the traditional belief that sensory and perceptual abnormalities each arise from very distinct etiologies. That is, sensory abnormalities were thought to occur somewhere between the level of the sensory receptor and the earliest stages of information processing. Perceptual abnormalities, on the other hand, were thought to be mediated by higher-order brain structures. This dichotomy, which has been reinforced over the decades has shaped many research endeavors and in some ways has proved to be a false lead.

For instance, in the 1960's and 1970's the prominent theories of autism focused on the physiology of sensory responses to various stimuli. Researchers thought that abnormalities existed in the more distal areas of the central nervous system that initially receive and process primary sensory information. According to this view, malfunction would directly lead to sensory-perceptual symptoms and then to the associated impairments in social and communicative functioning. Most physiologic experiments failed to show a robust difference in sensory function between autistic individuals and healthy controls. Furthermore, a popular treatment called Sensory Integration Therapy has shown only mixed or negative results in scientifically rigorous studies.

Sensory-perceptual symptoms of autism were further marginalized in the 1980's and 1990's as the rise of cognitive theories (i.e., central coherence, theory of mind, etc.) focused on a fundamental deficit in higher-order "global processing" of information. Such an impairment would lead an individual to gravitate away from higher order social and communicative functioning and towards a preoccupation with details and stimuli. However, no data has consistently proven the presence of an all-encompassing central, global processing impairment. In 1987, the DSM-IIIR reclassified sensory-perceptual symptoms as no longer being among the symptom criteria but as associated features of the condition.

This study, funded by the Seaver Autism Center and the Mount Sinai School of Medicine's General Clinical Research Center, seeks to measure and categorize sensory-perceptual abnormalities in autism by using functional MRI to study brain activity in response to touch. The neuroanatomy of this fundamental sensory system is well understood and this study seeks to correlate the presence of functional abnormalities in cerebellar-parietal pathways with the presence of sensory-perceptual symptoms on behavioral measures.

Neuroanatomy of Touch

Discriminatory touch pathways enter the spinal cord's posterior column and

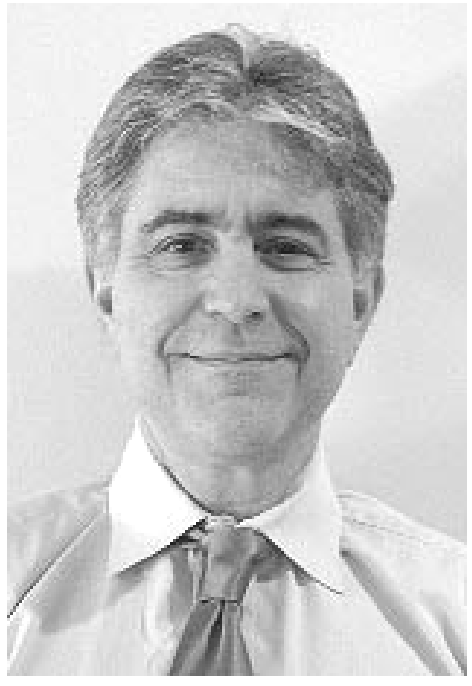
see Neurobiology on page 38

The Very Early Identification of Autism - An Indispensable Goal

By Eric London, MD
Director
Autism Treatment Research at IBR

The clinical presentation which we call "autism" is now widely believed to be a condition caused my multiple factors with a very variable presentation. In the scientific literature it is frequently called "the autisms". I would like to present a case which shows that progress in our understanding of autism will depend on our ability to study the very youngest children, that is the newborn, and with the help of newer technologies, eventually the pre-born.

One of my favorite stories, which illustrates the predicament of the research world, is as follows. A drunk came out of the bar staggering around and realized that he had dropped his house key. He saw a streetlight and got on all fours to look for his key. Just at that time his friend was going into the bar, and he stopped and asked him what he was looking for. He told him and his friend wished him luck. Two hours later his friend left the bar and there was our hero still on all fours in the same place. "What are you doing there for two hours?" his friend asked. "Looking for my key" the drunk man replied. "Well it probably is not there if you haven't found it yet" his friend observed. "Yes I know, but this is the only streetlight around."



Eric London, MD

Autism research has been done mostly on older children and adults, because autism cannot be diagnosed rigorously until the age of 2-3 years. So for us the autism diagnosis is the streetlight. The problem is that by that time we can make the diagnosis, the brain has completed so much development, and in a way that is "autistic." If we could know who will turn out to be autistic much earlier or even in utero, we could intervene with very young children and guide the brain development into a more healthy outcome.

This idea has led many groups to study children at high risk for developing autism. It would be prohibitively expensive to study every child born and see who turns out to be autistic at age 3, but if we can only focus on a subset of children, it is much more realistic. In fact this is what has happened. The most attractive group of high risk children to study is the baby siblings of already diagnosed children. Originally it appeared that there would be a 5-10% rate of autism in the siblings. However, the groups who are doing this work are observing an even higher rate. In addition, many of the children who are not autistic have signs of the "broader phenotype" such as language or social deficits. Much has already been learned about autism through this strategy and there is optimism that much more will come out of these studies.

At the New York State Institute for Basic Research in Developmental Disabilities on Staten Island, we have had a program to study babies who needed to be in the Neonatal Intensive Care Unit. For over a decade we have been following these babies and studying their behavioral and cognitive development. Most of these babies were premature, although some had other problems such as hypoxia or bleeding in the brain. With new techniques available now for saving younger and younger children, we are now facing a new challenge: the developmental problems inherent in the large number of very premature babies who survive. New reports in the past two years coming out of Montreal and Boston have documented that a very large number of very premature babies fail the autism screening tests at 18 months. This does not mean that they will all go on to be diagnosable as autistic, however many of them will. This phenomenon has not been noted in the autism literature primarily because the epidemiologic studies are done on 8 year olds and with the research lag, when we talk about the latest autism numbers it is likely these children were born 10-11 years earlier. It could be that some of the apparent increase in the numbers of autism is coming from children who might have been saved in the neonatal ICU's.

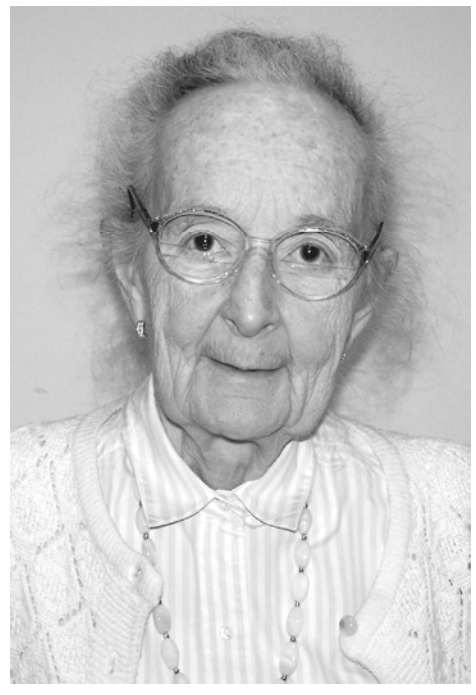
In our research, we have videos of babies from the time of birth and we have identified 33 of these children who later went on to be diagnosed in the autism spectrum. This is out of over 2,000 babies from the NICU. When we compared those who became autistic to other matched babies we found three predictive signs, which were different in the autism children. These finding were: an inability to visually track an object equally to both sides at one month, an asymmetry of arm and leg strength at one month, and a persistent attraction to high

see Early Identification on page 36

Importance of Motor Dysfunction in Autism Spectrum Disorders

By Sylvie Goldman, PhD, Developmental Psychologist and Isabelle Rapin, MD, Child Neurologist Albert Einstein College of Medicine

Sylvie Goldman, PhD



Isabelle Rapin, MD

Experienced clinicians often get their first diagnostic impression from observing their young patients' initial social response, but also from looking at their odd posture or movements as they walk into the office. In his original paper, Kanner noticed several atypical aspects of his patients' motor function such as their paucity of gestures, clumsiness, and, in some, delayed gross motor development. Though sparsely studied, motor impairments in individuals with Autism Spectrum Disorders (ASD) – autism for short – are frequent, with some studies reporting up to 80% of individuals having some type of motor deficit. Some of these, already identifiable during the crawling phase, are coming into focus in follow-up studies of the younger siblings of ASD children. Observations of gait abnormalities suggesting dysfunction of the basal ganglia go back to 1981 (Vilensky, Damasio, & Maurer, 1981). Motor abnormalities may interfere with adaptive functioning like dressing or writing, or the gestures that normally accompany and accent communication to emphasize its intent. With the exception of meaningless repetitive movements and gestures – stereotypies – motor abnormalities are categorized as "associated symptoms" of autism; thus they have not received nearly as much attention as social and language deficits, core criteria for an ASD diagnosis.

The unappreciated complexities of movement and posture make it challenging to define the motor deficits of children with ASD. Even such seemingly simple and overlearned movements as reaching for an object, walking while avoiding an obstacle, drawing, brushing teeth, or riding a bicycle involve complex sequences of motor commands that involve many interconnected parts of the brain. Before and during its execution, movement is inextricably linked to sensory information like vision and feedback from joints and muscles (proprioception, implicit awareness of body posture). In addition it depends on intention, planning (executive function), and attention. There are mirror neurons in the brain that need to be activated for imitation and for many types of conscious and unconscious motor learning to occur.

Motor performance is observable clinically or on videos, and there are now advanced technologies to quantify its many aspects for scientific study, but these are only starting to be used in ASD. Genetic research is seeking reproducible behavioral or other characteristics to help make sense of the findings in genetic studies on chips which regularly reveal involvement of some genes with as yet unknown functions. Well defined motor abnormalities are strong candidates, among many others, to help define genetically meaningful clinical subtypes of ASD. Also, we know more about the brain pathways involved in the control of sensorimotor function than about those that underlie more complex abilities like sociability. These characteristics emphasize the need for advanced studies of sensorimotor function in autism.

Correlations of motor signs with anatomic MRI, especially the recently developed tensor imaging, show pathways between cortex and subcortical brain structures. Functional imaging reveals correlations between particular tasks' activation of specific brain areas. Together they are

see Motor Dysfunction on page 27

Potential New Treatments for Fragile X Syndrome and Autism

By W. Ted Brown, MD, PhD, Director
New York State Institute for Basic Research in Developmental Disabilities

There are exciting new developments occurring in finding potential new treatments for the fragile X syndrome, and by extension for autism. The fragile X syndrome, an X chromosome-linked syndrome and the most commonly inherited condition associated with intellectual deficiency, is considered to be the leading genetic cause of autism and autism spectrum disorders (ASD). Approximately 60% of males diagnosed with fragile X syndrome meet the criteria for autism or PDD-NOS, while among untested children with ASD 2 - 8% test positive for fragile X (Harris et al., 2008). The fragile X syndrome is due to the silencing of the fragile X gene, FMR1, and the lack of production of the fragile X protein, FMRP. This protein modulates the expression of a limited set of other genes that appear to be involved with neuronal plasticity and synaptic connections.

W. Ted Brown, MD, PhD

In a mouse model of fragile X, there is abnormal hyperactivity and seizure susceptibility due to over-activity of the excitatory glutamic acid neuro-transmitter pathway (Bear et al., 2004; Dolen et al., 2007). We and Dr. Frank Kooy's lab in Belgium have also found there is reduced activity of the inhibitory GABA (gamma aminobuteric acid) pathway (El Idrissi et al., 2005; D'Hulst et al., 2006). These abnormalities in the brain of the mouse model of fragile X syndrome offer potential therapeutic targets for the fragile X syndrome. Because of the overlapping aspects of fragile X and autism, they may also be of benefit for at least a subset of subjects with ASD.

Basic research on the mouse model has lead to the discovery that certain drugs that partially block some of the glutamate receptors in the brain produce dramatic improvements in the mice (Yan et al., 2005). Also, drugs that stimulate the inhibitory GABA pathway reduce seizure susceptibility in the mouse (Pacey et al., 2009). Now, double blind trials are underway at our Institute's fragile X clinic and nine other fragile X clinics in humans with fragile X and also in subjects with ASD using a purified form of the GABAergic drug Baclofen (known as STX209 or R-baclofen; see www.clinicaltrials.gov) sponsored by the Seaside Therapeutics Corporation (www.seasidetherapeutics.com). Results of potential benefits from this new drug formulation should be known by later this year. Also, initial phase I human trials are beginning with drugs that partially block the Glutamate receptor (STX107) and if proven safe and effective should lead to comprehensive clinical testing. Another drug that partially blocks glutamate receptors, Fenobam, has undergone a successful open label phase I trial in fragile X subjects as well (Berry-Kravis et al, 2009).

Another potential treatment for fragile X is receiving widespread interest in the fragile X community. It was discovered that a commonly prescribed antibiotic, minocyline, could produce dramatic improvements in brain function and behavior in the mouse model of fragile X (Bilousova et al. 2009). Minocyline appears to inhibit a brain enzyme, MMP9, which is over-expressed in fragile X mice. Controlled clinical trials are just beginning for minocyline supported by FRAXA (www.FRAXA.org) and by the National Fragile X Foundation (www.NFXF.org). The hope is that some of these new targeted therapeutic drugs, if they work for fragile X, may also have important therapeutic benefits for some children with ASD.

A Fragile X Clinical and Research Consortium (FXCRC) was initiated in 2006 by the National Fragile X Foundation (NFXF) to advance clinical practice and facilitate coordinated, collaborative multi-site research on the fragile X syndrome. With support of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) and the Centers for Disease Control and Prevention (CDC), the FXCRC has expanded to include 20 Fragile X Syndrome clinics in the U.S. and one in Canada (For locations see www.NFXF.org). The Institute for Basic Research (IBR), located on Staten Island, NY, is the site of one of the Fragile X clinics and is coordinating the CDC supported project that will speed research into emerging treatments for Fragile X syndrome and bring better care to the more than 100,000 Americans affected by

see Fragile X on page 38

Medications for ASD and the Future of Psychopharmacology of Autism

By Evdokia Anagnostou, MD
Child Neurologist
Bloorview Research Institute

The first fact we need to acknowledge when we talk about medications for autism, is that that there are no pharmacologic treatments that actually treat autism. There is no data to date to suggest that any medications actually teach skills or change the developmental course of the disorder. As such, medications are used to facilitate interventions shown to be efficacious in this population, and decrease the burden of care that is associated with some of the associated symptom domains of autism. In other words, it makes no sense to be prescribing medications for individuals with autism, especially for children, if no psychoeducational interventions are in place.

Having said that, there have been significant advances in the area of psychopharmacology of autism over the past two decades. Large, multisite randomized controlled trials have taken place by NIH-funded networks and we have a better understanding of the positive effects as well as the safety of commonly used medications in children with autism. A main limitation in our pharmacology research has been that until recently, we have had no molecular targets to develop medications for. As such, we looked at symptoms associated with autism

Evdokia Anagnostou, MD

(irritability, hyperactivity, repetitive behaviors) that have similarities with symptoms of other neurodevelopmental/ neuropsychiatric disorders, hypothesized that similar symptoms across disorders may share neurobiology, and then "borrowed" such medications and tested them in children with autism. Although the approach has not always been productive, it has provided for a series of medications that are useful when considering pharmacotherapy for children with autism.

Irritability/Impulsive Aggression - Risperidone is the only medication that has an FDA indication for children with ASD, at the time of this article. There is now data from large randomized controlled trials to document efficacy of risperidone for irritability and impulsive aggression (RUPP 2002, Shea et al 2004). Discontinuation of risperidone in studies resulted in relapse rates between 25% and 62.5% (Troost et al 2005, RUPP 2005). Open label data, small randomized controlled data and larger emerging studies suggest that other atypical neuroleptics may be useful in this population. The main side effect of this class of medications has been weight gain. The reason we are concerned about this is that the mechanism of such weight gain seems to be insulin resistance, and as such, may predispose children to metabolic syndrome. In addition, concerns exist about the potential for developing movement disorders related to an extrapyramidal syndrome (EPS), and the potential of elevated prolactin levels seen with some of these medications to affect bone density.

Repetitive Behaviors - Previous data has suggested that SSRIs may be useful in the treatment of interfering repetitive behaviors. It is important to note, however, that not all repetitive/restrictive behaviors (RRB) that individuals with autism engage in are interfering. Further, some can be used to develop functional skills. Hypotheses were based on data from obsessive compulsive disorder suggesting that newer SSRIs, fluvoxamine and fluoxetine, may effectively treat compulsive behaviors. Hollander et al, (2005) found that fluoxetine maybe useful in children with autism spectrum disorders (ASD) and McDougle et al. (1996) reported that fluvoxamine may be useful in adults with ASD. However, the largest clinical trial published in autism to date, found that citalopram had no effect on repetitive behaviors. Instead, the authors found that citalopram caused significantly more side effects than placebo, including agitation, insomnia and mood lability, as well as GI dysfunction. Hence, the effectiveness of SSRIs for repetitive behaviors is now questioned and studies with other SSRIs are needed before we could determine the usefulness of this class. On the other hand, studies of atypical neuroleptics have shown effectiveness for repetitive behaviors of autism (McDougle et al 2005).

Hyperactivity/Inattention - Currently, the DSM-IV does not allow individuals to be diagnosed with attention deficit hyperactivity disorder (ADHD) if they have a diagnosis of ASD. However, the data suggest that 40-59% of children with ASD

see Medications on page 19

Understanding What is Meant by "Evidence-Based Practice"

**By Cece McCarton, MD,
Mary Jane Weiss, PhD, and
Ivy Feldman, PhD,
The McCarton Foundation**

Identifying effective teaching methods for children with autism is an overwhelming task for many parents and professionals. Autism is a disorder that attracts a great deal of attention, possibly because of its severity. Treatment claims are common, and it is difficult for parents and professionals to evaluate the veracity of the claims.

Furthermore, those who live with children and adults with autism understand the severe impact of the disorder on both the individual and the family, and many wish for a breakthrough that will cure the individual with autism. This understandable desire for a "cure" leaves many families vulnerable and susceptible to the appeal of treatments that are based solely on hearsay, anecdotal evidence, and biased report.

It is a genuine challenge for professionals to navigate the sea of treatment options, to understand the potential utility of new treatments, and to help guide parents in making effective decisions for their children. The task is even more difficult for parents, who often begin the process with little knowledge or training (although many become experts in a short period of time).

Cece McCarton, MD

How the Effectiveness of Treatment is Defined

In recent years, much discussion has taken place in many fields regarding evidence-based treatment. In all human service professions, there has been interest in accountability, efficiency of intervention, and the evaluation of the effectiveness of treatment. Increased emphasis has been placed on the use of empirically supported treatments for psychological disorders, including autism.

It is certainly true that many of the commonly used treatments for children with autism have not been scientifically validated as effective. ABA is, by far, the intervention with the greatest empirical support. The support for ABA is extensive, and meets the criteria that generally are accepted in scientific circles (which will be discussed below).

One should note that interventions that do not have empirical evidence may not be ineffective; rather, it may be that these interventions have not yet been evaluated using the scientific method and should be used with caution. At best, these treatments may be effective. However, at worst, these treatments may be seriously detrimental to the health or well being of the individual with autism. Even benign ineffective treatments may be detrimental if the treatment replaces, reduces the intensity of, or delays access to an evidence -based treatment that could potentially benefit the child (Green, 1996). Considered in this context, it is very important to consider the quality of evidence in choosing an intervention for a particular learner.

It is important for us as clinicians to help consumers to understand the quality and level of evidence that exists for interventions. It is difficult for those who have not been trained in the scientific method or in the evaluation of research findings to understand these differences without explicit training. We will review some broad elements of science and some recommendations that have been made by the scientific and clinical communities.

Science, Pseudoscience, and Antiscience

Science lays the foundation for all evidence-based intervention. To identify therapies that are evidence-based, it is helpful to ensure that the elements of science and the scientific method have been used to demonstrate support for the effectiveness of a given intervention. Science is based in part on: (1) the direct and objective observation of measurable events, (2) a systematic manipulation of conditions, (3) procedures that rule out alternative explanations for results, and (4) replication of the results (Green, 1996).

In contrast, pseudoscience promotes specific phenomena without the use of the scientific method and without providing evidence of efficacy or effectiveness (Green, 1996). Pseudoscience relies heavily on the use of persuasive arguments that are marketed to consumers.

Antiscience describes the body of treatments that reject the use of scientific methods altogether (Green, 1996). In contrast to pseudoscience, antiscience demonstrates a complete disregard for any type

see Understanding on page 25

The Autism Spectrum Rating Scales: Development and Clinical Utility

By Sam Goldstein, PhD, and Jack A. Naglieri, PhD

Sam Goldstein, PhD

Jack A. Naglieri, PhD

Our understanding of Autism Spectrum Disorders (ASD) is complex and continues to evolve as does the methods we use to diagnose the disorder. While the ideal assessment would be to observe impairments resulting from ASD in the natural setting by following a child for several days, this method is cost prohibitive. Rating scales, however, offer an alternative method and have become the gold standard for summarizing the observations of others in natural settings. The development of rating scales requires carefully crafted, nationally standardized methods, which should be accompanied with evidence of reliability and validity. We developed the Autism Spectrum Rating Scales (ASRS, Goldstein & Naglieri, 2009) to measure ASD related behaviors as reported by parents and teachers to meet this need. The ASRS consists of seventy-item long and fifteen-item short forms for young children age 2 to 5 years and older children and adolescents age 6 to 18 years. The ASRS is the only nationally standardized, norm referenced instrument available today.

The development of the ASRS began with an initial conceptualization phase during which the content structure of the rating scale was determined by combining our clinical and research experience with a comprehensive review of current theory and literature on the assessment of ASD as well as the DSM-IV-TR and ICD-10 diagnostic criteria for these disorders. This process was used to generate test items, which were tested in a pilot study and were reviewed by a series of experts in the ASD field. The final scale construction was based on the normative and validity samples comprised of over 4,000 parent and teacher ratings of children age 2 through 18 years. The normative sample includes 2,500 ratings that very closely match the U.S. Census on several important demographic variables. In addition to the normative sample, over 700 ratings of children previously diagnosed with ASD were collected as well as nearly 900 ratings of children with other clinical diagnoses such as Attention Deficit Hyperactivity Disorder, developmental delay, generalized anxiety and mood disorders.

Data from the normative and validity samples were analyzed and the results from a series of factor analyses revealed that the ASD symptoms fit a two dimensional model in early childhood while a three dimensional model best fit the data for the school age and adolescent version. On both the early childhood and school age versions, one factor labeled "Social/ Communication" includes items related to both socialization and communication (e.g., keep a conversation going, understand how someone else felt). The other factor labeled "Unusual Behaviors" includes items related to behavioral rigidity (e.g., insist on doing things the same way each time), stereotype (e.g., flap his/her hands when excited) and overreactions to sensory stimulation (e.g., overreact to common smells). A third factor that only appears on the school age form includes items pertaining to self-regulation and attention (e.g., become distracted), impulsivity and compliance. Results from subsequent factor analyses revealed that this factor structure was replicated across several demographic groups (gender, age, race/ethnicity and clinical status).

Our view of ASD overlaps somewhat with the DSM-IV-TR conceptualization of autism but not exactly because our data strongly demonstrate that socialization, communication and stereotypical behaviors do not form three separate symptom

see Rating Scales on page 41

YAI Promotions from page 7

Developmental Disabilities Residential Committee.

By teaching and lecturing at several colleges, both executives are helping to prepare future generations of social workers.

YAI Network comprises seven independent, not-for-profit, health and human service agencies. The Network serves more than 20,000 people with intellectual, developmental, learning and other disabilities and their families in over 450 programs throughout the New York City metropolitan area, New Jersey, Puerto Rico and the U.S. Virgin Islands. For more than 50 years, the YAI Network has been a national and international leader in service provision, program design, professional education, advocacy, conferences and training.

For more information about the YAI Network or to obtain services, call 1-866-2-YAI-LINK or visit yai.org.

Please Tell Our Advertisers that Provide Treatment and Support Services: "We Learned About Your Organization in Autism Spectrum News"

Science Ambassador from page 7

is now 15. Over the years, I have seen great increases in interest and awareness of autism. Obviously there is much more to be done. My husband and I are both pediatricians (both sub-specialists), and we are still frequently overwhelmed with the day to day disasters no one has answers for. When the science ambassador program first started at the D.C meeting, I jumped at the chance to participate. I talk with my patients' every day, translating medical jargon into plain English. I thought I could help do the same with autism, helping to get more people to understand this horrible disease, and hopefully, getting them to participate in getting to a cure! I am hoping for more involvement as my daughter leaves for college and I have more time to devote to this program.

Allison B. - I became a SA because I had several friends with children who are autistic. Until I met these families, I had never heard of autism, and I had 4 grown children!! I felt unable to do anything for them, as I watched their struggle to reach the child 'within' their child. I wanted to try to spread the word about autism so that we could make life better for these kids and their families. Knowledge is power, as the saying goes, and these families need our power!!! The ATP program was the information source for me, and I used my position in the community to spread the word about autism. I have been accepted by our local group of families as they organized and carried out walks for the past 4 years, and each year I have a table full of information for the public, explaining our programs and educating them in services available. Believe me, many of these attendees educated ME with some of the things they have had to do to obtain services for their child. I have learned to be an advocate for our cause to local politicians, too, and they quickly respond when I send them an email supporting upcoming legislation that will help our families.

I am looking forward to the expansion of this program, and am excited at the possibilities for the future!! With any luck, autism will disappear; but, our affected families will still be out there, looking for information and support, and it is up to us to stand with them. I am proud to be a part of this program, and will continue to teach the public, and will know that the work we did, the speeches we gave, the questions we answered all added to the solution needed to finally understand, and contain, autism in our world.

A. Blenham - Science Ambassadors strive to share knowledge about current research, and assist others to find resources and information. With knowledge, comes power – an educated community can be an influential one. So much has changed since our son was young. We are encouraged by the heightened awareness surrounding autism, and the dedication of those researching its causes. More research is essential, and support from all will be necessary to keep the momentum going. There is so much that has to be done. As a SA, I hope to provide as much support as possible, and to give something back to those who have helped us throughout our son's life, and to make things a bit easier for those beginning, or well along, their own journeys.

The Immune System in Autism Spectrum Disorders

By Paula Goines, BS and
Judy Van de Water, PhD
MIND Institute at UC Davis

Paula Goines, BS

Judy Van de Water, PhD

Recent evidence implicates the immune system in some cases of autism spectrum disorders. Researchers at the University of California, Davis, Johns Hopkins, and the Kennedy Krieger Institute have found that some mothers of children with autism produce autoantibodies that target the developing fetal brain (Braunschweig, Ashwood et al. 2007; Zimmerman, Connors et al. 2007; Croen, Braunschweig et al. 2008). When these maternal autoantibodies are injected into pregnant monkeys or mice, the offspring show behavioral abnormalities that resemble aspects of autism (Martin, Ashwood et al. 2008; Singer, Morris et al. 2009). Subsets of children with autism also have immunological differences from their typically developing peers (Ashwood, Wills et al. 2006; Enstrom, Van de Water et al. 2009). These findings present an exciting opportunity for a deeper understanding of these enigmatic disorders.

Autism and the Immune System

Autism is on the rise, with the latest estimates of 1 in 100 children diagnosed each year. Though autism has received extensive attention, the biological underpinnings of the disorders are not well understood. It is generally accepted that genetics play a large role, though several avenues of research suggest that additional factors are involved. For decades, unique immunological phenomena have been described in people with autism and their family members. Findings include altered maternal immune activity during pregnancy, as well as immunological changes in the child with autism. The role of the immune system in autism has been historically controversial. However, several recent large-scale studies have provided credibility to the connection between autism and immunity. A particular area of interest involves a potential role for antibodies directed towards brain proteins in autism.

Autism and the Maternal Immune System

Some of the most intriguing immune-related findings involve mothers of children with autism. Independent studies have shown that subsets of these women harbor autoantibodies in their bloodstream that react with protein targets in the fetal brain. These autoantibodies are found in about 12-14% of mothers of children with autism. Most importantly, these autoantibodies have never been observed in mothers of typically developing children.

What Are Antibodies and Autoantibodies?

Antibodies are specialized proteins made by the immune system. They work by marking unwanted assailants in the body for destruction and removal. Antibodies do not react with the body itself under normal circumstances. This is important to prevent misdirected and potentially damaging immune responses. However, on occasion the immune system mistakenly produces antibodies that target tissues within the body. This phenomenon is called "autoimmunity," and is observed in diseases like multiple sclerosis, rheumatoid arthritis, and systemic lupus. Antibodies that target self-tissues are known as "autoantibodies." The autoantibodies found in mothers of children with ASD target the developing human brain.

Why do Maternal Antibodies Matter in Pregnancy?

During pregnancy, the developing fetus does not have a functional immune

see Immune System on page 35

Medications from page 15

meet criteria for ADHD (Gadow et al, 2006, Goldstein et al, 2004). Literature examining the effects of stimulants on individuals with ASD who express ADHD like symptoms have suggested that both stimulants (Rupp 2005, Posey 2007) and atomoxetine (Arnold et al 2006) are effective treatments for these symptoms. It is important to note, however, that the effect sizes are smaller and the prevalence of side effects is higher in the studies examining individuals with ASD than in the studies examining individuals with ADHD. Common side effects for both medications include irritability, insomnia, emotional lability, and anorexia. Further, like SSRIs, there is a black box warning about suicidal ideation for atomoxetine. The significance of this for individuals with ASD is not clear. There is also early, small randomized placebo controlled data and open label data on Alpha 2 adrenergic agonists including clonidine and guanfacine. This data suggests that these compounds may play a role in the treatment of hyperactivity and inattention in individuals with ASD (Jaselskis et al 1992, Frankhauser et al 1992, Psey 2004, Scahill et al 2006).

Alternative Medications

Up to 70% of children with ASD are reporting complementary and alternative medicine (CAM) use (Hanson et al 2007). There are several types of CAM treatments that have been reported to be in use for children with autism. Most commonly, these include biological treatments that aim to reduce oxidative stress (e.g. B12, Vitamin C, hyperbaric oxygen treatments), change the GI flora (e.g. probiotics), reduce inflammation (e.g. omega 3 fatty acids), remove heave metals (e.g. chelation), and special diets with unclear biological mechanisms (e.g. GFCF). Other types of CAMs used in this population include Yoga, massage, brushing protocols and chiropractic therapies, as well as energy techniques such as Reiki. Unfortunately there is very little data regarding the efficacy/safety of most of these interventions. Some early data is encouraging and justifies further study of some of these interventions, including omega-3 fatty acids, Vitamin C and possibly GFCF diet. Some, such as massage therapy and brushing protocols have a plausible biological mechanism, but no data exists to make a recommendation either way. Finally a few likely have enough data to discourage their use given their safety profile (e.g. IV chelation) or lack of efficacy in randomized clinical trials (e.g. hyperbaric oxygen treatments). Given the widespread use of such interventions in the parent community, the research community has an obligation to produce well designed studies based on neurobiologically plausible hypotheses to establish both efficacy and safety of such approaches. At the same time, parents should consider that time lost experimenting with unproven and usually costly methods is invaluable as intervention with evidence-based treatments should be started as early as possible.

Where we go From Here

As previously mentioned, we have selected and tested medications based on the fact that they are effective in other disorders that have symptoms similar with common complaints in children with autism. There is now accumulating basic science work from genetics, neuropathology and animal models to suggest a few molecular targets that may be involved in the neurobiology of autism. Examples include the glutamate and GABA systems, neuropeptides such as oxytocin, and immune system dysfunction among others. These can be targeted with both novel traditional/western and alternative compounds. Furthermore, there are multiple complaints children with autism present with to a doctor's office that are likely amenable to medication but have never been a target of proper intervention studies (e.g. anxiety), and randomized controlled trials in such areas are urgent. In addition, as children with autism grow up, we are realizing that we have tested very few compounds in adults with autism. At the time of this article, a PubMed search for clinical trials and autism revealed only 17 publications, including seven that were not related to medications. Given the developmental nature of this disorder, it is important that we start paying attention to research at all developmental stages, including adulthood. At the end of the day, we think that multidisciplinary approaches are beneficial for individuals with autism and therefore such models of care need to be tested. In other words, intervention research needs to mirror the way we practice, which usually means combining psychoeducational and pharmacological interventions.

Dr. Evdokia Anagnostou is a child neurologist who has subspecialized in neurodevelopmental disabilities. She completed medical school at McGill University in 1998 and her residency in child neurology in 2003. She subsequently completed a research fellowship in neurodevelopment disabilities at the Seaver Autism Center in New York. She is currently a Clinician Scientist at the Bloorview Research Institute and an assistant professor at the department of pediatrics at the University of Toronto. Her research program focuses on investigating developmental differences in the brains of children with autism using fMRI, MR spectroscopy, and DTI techniques and on psychopharmacology of autism. She is also the co-editor of the Manual for the Treatment of Autism published by APPI press in 2007.

The Daniel Jordan Fiddle Foundation Produces Free Informational Brochure

Autism, Epilepsy & Seizures: How to Recognize the Signs and Basic First Aid

By Linda Walder Fiddle, Esq.
Founder and Executive Director
The Daniel Jordan Fiddle Foundation

The Daniel Jordan Fiddle Foundation (DJF), a national autism organization with the mission to develop, advocate for, and support programs and services for adolescents and adults with Autism Spectrum Disorders (ASD), has released a free informational brochure entitled *Autism, Epilepsy & Seizures: How To Recognize The Signs and Basic First Aid When You Do.*

The purpose of this enlightening brochure is to offer general information about Autism and Epilepsy as well as about the co-condition of the two. In fact, 30% of people with autism also have epilepsy, so it is essential to know the different types of seizures that might occur and the basic first aid recommended by the Epilepsy Foundation of America. "The autism/epilepsy link has been observed and assumed for many years, but it took this brochure to bring that information to light. Many thanks to the Daniel Jordan Fiddle Foundation for sponsoring and producing this excellent piece of material," said Paul Potito, Acting Director of Autism Family Services of New Jersey and a member of the foundation's Advisory Board.

Linda Walder Fiddle, Esq.

The brochure is available on the DJF website in both online readable and "printable" versions at www.djfiddlefoundation.org. The Autism Society of America, Autism Speaks, Organization for Autism Research, SAARC and POAC have also added the brochure to their websites to help expand the dissemination of this important information.

This public service endeavor is geared especially to the autism and epilepsy communities but, importantly, to the population at large to educate them on what to do in a seizure emergency. This DJF-spearheaded project is a collaborative effort of Dr. Ruth Nass, a specialist in pediatric behavioral neurology, who is also a member of The Daniel Jordan Fiddle Foundation Advisory Board and The New York Child Study Center, The Epilepsy Foundation of New Jersey and Autism Family Services of New Jersey.

"This brochure will increase awareness about epilepsy and thus enhance the ability of families with autistic patients of all ages to identify the symptoms and seek appropriate treatment. Treating epilepsy appropriately improves the lives of those of have it and can even be life saving," said Dr. Nass.

"We are offering this brochure free of charge nationwide because the need to create more awareness about the co-condition is necessary since the public has little, if any, basic information about it," says Linda Walder Fiddle, Executive Director of The Daniel Jordan Fiddle Foundation. She adds, "The brochure includes a fold-out chart that can easily be displayed in all community settings, and is being offered to families, schools, colleges, community centers, restaurants, fire and police stations, EMS providers… anyone who might be a first-responder that could make a life-saving difference."

Dr. Ruth Nass states, "It is our goal to create broader awareness within the community about this co-condition; however, we would always advise that individuals and families discuss their questions and concerns with their own physician. This brochure is an excellent starting point to begin the discussion."

Dr. Nass is a Professor of Child Neurology and Child and Adolescent Psychiatry at New York University School of Medicine and a nationally recognized pediatric behavioral neurologist. She offers diagnosis and support to children and young adults with autism, ADD, and learning disabilities, as well as migraines and seizures.

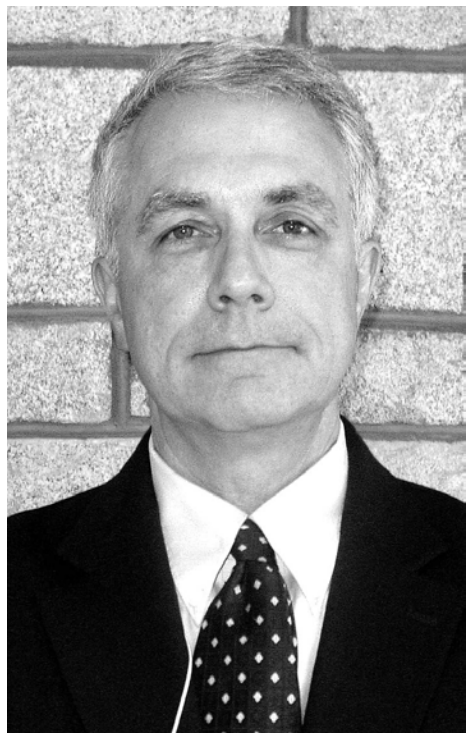
The new brochure fits squarely within The Daniel Jordan Fiddle Foundation's mission to develop and support programs, services and information that benefit adolescents and adults with Autism Spectrum Disorder. Adolescence is one of the two most prevalent times that epilepsy arises in individuals with ASD (the other time is infancy).

Relationship Development Intervention: A Review of Its Effectiveness

By Thomas Zane, PhD, BCBA, Director
Center for Applied Behavior Analysis at The Sage Colleges

The theme of this issue of *Autism Spectrum News* is "Advances in Autism Science." One facet of autism science is the adherence to "evidenced-based practice" (EBP); a requirement that those who work with persons with autism – teachers, psychologists, speech therapists, etc. – use strategies and tactics that have been "experimentally" tested, thoroughly researched, and found to have an empirically-demonstrated improvement in some aspect of the autism condition. Most of the major organizations that promote the treatment of autism support this requirement (e.g., Association for Science in Autism; The Autism Society; American Academy of Pediatrics).

The importance of using evidenced-based practice is supreme. Autism treatment has been termed a "fad magnet (e.g., Jacobson, Foxx, & Mulick, 2005) due to the numerous treatments that are used that have no empirical support of their effectiveness (e.g., Facilitated Communication). Service providers are required to use treatments that have substantial evidence of effectiveness so that there is a strong likelihood of improving language, skills, and behaviors of persons with autism. Treatments for which there is little



Thomas Zane, PhD, BCBA

or no evidence of effectiveness will likely have little to no effect on the person being served, resulting in a waste of time, money, and emotional investment (Zane, Davis, & Rosswurm, 2009).

What constitutes "evidence" of effectiveness? Many professional organizations (e.g., American Psychological Association, United States Department of Education, Coalition for Evidenced-Based Policy, and the Council for Exceptional Children) have published sets of criteria that establishes levels or goals that must be reached to consider a treatment as having evidence of effectiveness. Some of these criteria include well-established scientific principles, such as reliable and valid measurement of a dependent variable; clear identification of the independent variable or treatment; use of a commonly accepted research design (such as the traditional experimental-control group design, or within-subject designs such as reversals or multiple baselines), and careful screening and selection of subjects.

Morris (2009) described Relationship Development Intervention (RDI) as a treatment for autism developed by Dr. Steven Gutstein from Texas. According to Gutstein, RDI has a focus of increasing social awareness through the use of dynamic intelligence (Morris, 2009). RDI methods are employed by the parents of the children in RDI therapy, since the general goal of the treatment is more natural and complete interactions among family members. The developer, Gutstein, calls RDI a "cognitive-developmental" parent training program. The program attempts to impact "experience sharing" and inflexibility in thinking (e.g., Gutstein, 2001). Morris and others (e.g., Gutstein & Sheely, 2002) have outlined the types of methods and goals built into RDI, including dynamic analysis, flexible problem solving, and resilience. As of September, 2009, there are currently over 200 certified RDI therapists (http://www.rdiconnect.com/pages/Find-a-Consultant.aspx). This number has steadily increased over the past several years, suggesting an increasing popularity of this treatment.

However, an important question is whether or not RDI can presently be considered an empirically validated treatment, one that meets the standards for treatments that have proven effective in improving some aspect of autism. Thus, a literature review was conducted using the keywords "Relationship Development Intervention," Gutstein," "RDI," and "social development." Any published article found related to RDI was assessed as whether or not it met the criterion of a "research" study, such as a test of whether or not RDI intervention caused the change in a group of participants, or possibly a comparison of RDI to other interventions in autism or education.

This search found only one published article that attempted to evaluate the effectiveness of RDI (Gutstein, Burgess, & Montfort, 2007). The purpose of this study was to determine whether children who participated in RDI treatment improved in selected measures related to autism. The authors reviewed the files of

see Effectiveness on page 36

How the National Standards Project Supports Evidence-Based Practice for Autism Spectrum Disorders

By Susan M. Wilczynski, PhD, BCBA
Executive Director
National Autism Center

Parents, educators, and other professionals serving individuals on the autism spectrum are often overwhelmed by the myriad of treatment options available to them. The process of treatment selection is greatly improved when these decision-makers are aware of the strength of scientific evidence supporting the treatments they might consider. Understanding the scientific literature is not easy given the volume of studies that have been published on the treatment of Autism Spectrum Disorders (ASD). To address this challenge, the National Autism Center undertook the National Standards Project, a multi-year effort completed in the fall of 2009. The project is the most comprehensive systematic review of the autism treatment literature specific to children and adolescents with ASD available to date.

The National Standards Project resulted in two reports that describe the strength of scientific evidence supporting a large number of educational or behavioral treatments that target the core or associated features of ASD. [Free downloads of the *Findings and Conclusions Report* of the National Standards Project (short report) and the National Standards Report (extended technical report) are available via the National Autism Center's website at www.nationalautismcenter.org]. The remainder of this article describes the methodology, major outcomes, and implications of these reports for parents, educators, and service providers.

Susan M. Wilczynski, PhD, BCBA

Method

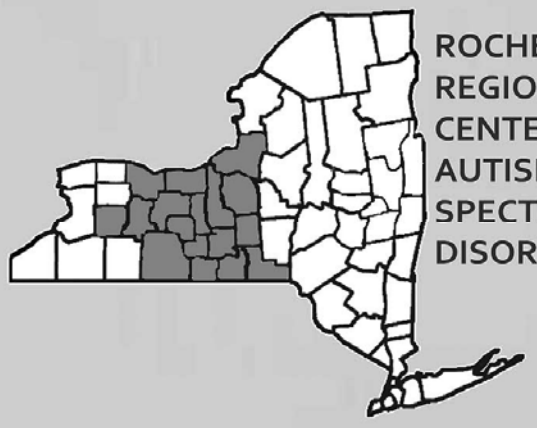
A full description of the methodology used for the National Standards Project is beyond the scope of this article; readers are encouraged to review the National Standards Report for a comprehensive description of the methodology. A brief synopsis is offered here.

Forty-five autism experts from across the country provided input to the National Standards Project. They developed a model for evaluating the scientific literature. Once the initial model was developed, over 7,000 abstracts were identified based on computer and hand searches. These abstracts were then compared against the criteria developed for inclusion or exclusion from the review. This process yielded 775 studies. Each of the 775 studies were examined on five dimensions. Specifically, the (a) quality of the research design, (b) dependent measure, (c) treatment fidelity, (d) participant ascertainment, and (e) generalization were assessed. Scores for each of these dimensions were combined and resulted in the Scientific Merit Rating Scale (SMRS) score. The SMRS score reflects the extent to which we can be confident that the data for a given study can be meaningfully interpreted. Treatment Effects Ratings were also assigned to each article. Articles were evaluated in terms of treatment outcomes and categorized as (a) beneficial, (b) unknown (could not be accurately interpreted), (c) ineffective, or (d) adverse.

After each article was assigned an SMRS score and a Treatment Effects Rating, the results were combined for each of the 38 treatment categories. Decisions about the strength of evidence supporting a treatment were made based on the quality, quantity, and consistency of research findings. Treatments were classified as "Established Treatments" if a sufficient number of studies showed that a treatment produced beneficial treatment outcomes. Treatments were classified as "Emerging Treatments" if one or more studies suggested that they produced beneficial outcomes, but more high quality studies would need to be published before scholars could confidently state that the treatments were effective. Treatments were classified as "Unestablished Treatments" if no studies were published to support them or if published studies received poor ratings. Lastly, although no treatments fell into this category, a fourth category was developed for treatments that had clear evidence they were ineffective or harmful for young individuals with ASD.

In addition to information about overall strength of evidence for treatments, information about the extent to which

see National Standards on page 34



ROCHESTER REGIONAL CENTER FOR AUTISM SPECTRUM DISORDERS

The Rochester Regional Center for Autism Spectrum Disorders (RRCASD)

is excited to announce the

2010 Autism Spectrum Disorder Regional Conference Series...

Save the Date!

Registration for all conferences opens March 2nd

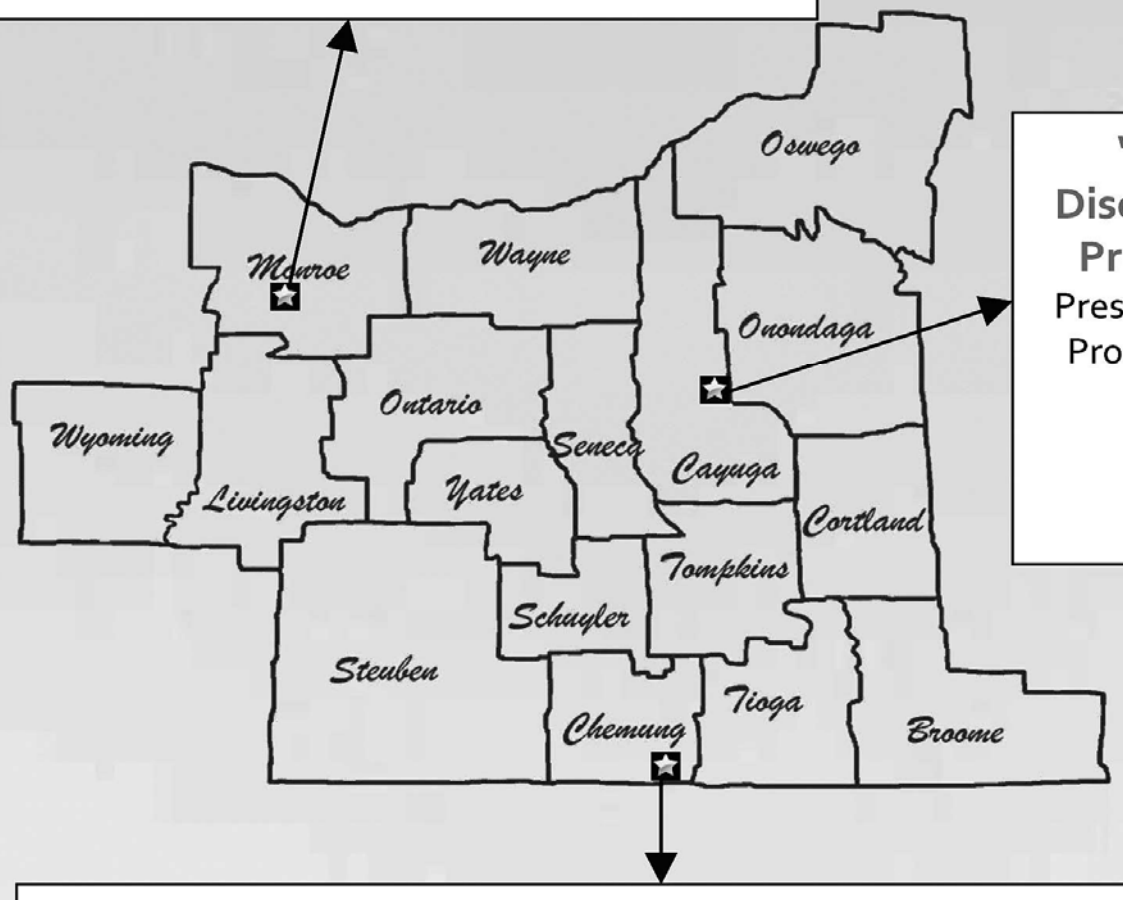
"Mental Health Disorders in Individuals with Autism Spectrum Disorders: Issues and Considerations for Assessment and Intervention"

Presented by Vincent Pandolfi, Ph.D. Assistant Professor, Rochester Institute of Technology

RIT Inn and Conference Center, Rochester, NY

Wednesday, April 21st 2010

9:00a.m.-12:00p.m.



"Adults with an Autism Spectrum Disorder: Characteristics, Diagnosis and Program and Service Considerations"

Presented by Caroline I. Magyar, Ph.D. Associate Professor of Pediatrics, University of Rochester Medical Center

Holiday Inn, Auburn, NY

Wednesday, May 5th 2010

9:00a.m.-12:00p.m.

Light refreshments will be served

Registration opens March 2nd, 2010

"Autism and Transition: Preparing for Life After High School"

Presented by Christine R. Peterson, Ph.D., Assistant Professor of School Psychology, University of Wisconsin

Holiday Inn, Elmira, NY

Wednesday, April 28th 2010

9:00a.m.-12:00p.m.

For more information on speakers and topics, please visit RRCASD at:

www.urmc.rochester.edu/childrens-hospital/autism

Advancing the Evidence-Base in Autism Assessment

By Caroline I. Magyar, PhD, Vincent Pandolfi, PhD, and Charles A. Dill, PhD

Autism spectrum disorder (ASD) refers to a group of complex neurodevelopmental disorders that share a core set of clinical symptoms that includes impairments in *socialization*, abnormal *language* development, and a *restricted* repertoire of behaviors and interests (APA, 2000). Affected individuals may also present with a wide range of other features and co-morbid conditions including emotional and behavioral disorders (EBD; e.g., see DeBruin et al, 2006). In addition, ASD may be prevalent in certain other developmental disabilities such as Down syndrome (see Reilly, 2009 for a review). Wide variability in symptom profiles, rate of development, and level of functioning is observed across affected individuals and even within the same individuals over time.

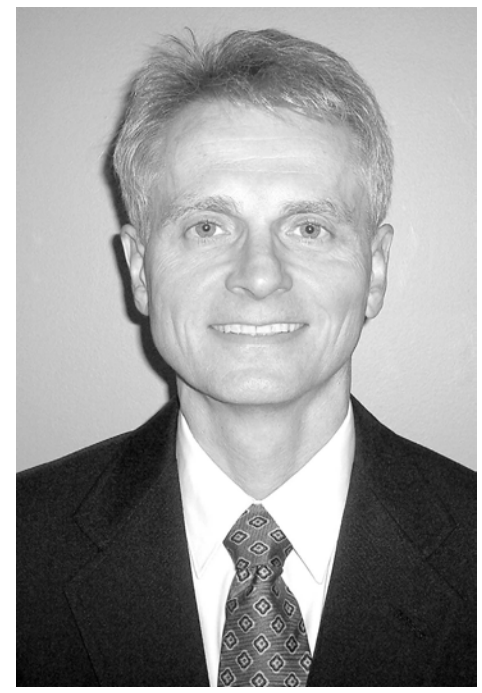
This wide heterogeneity in clinical features can challenge clinicians to accurately identify an ASD and/or co-occurring conditions so that appropriate treatment can be provided in a timely manner. This situation is made more difficult because autism and autism spectrum disorders are behaviorally defined syndromes and there is not yet a biological marker for early detection and monitoring of changes in symptoms over time. The complex symptom profiles of individuals with an ASD therefore require clinicians and researchers alike to be knowledgeable in selecting appropriate assessment instruments for a wide variety of purposes. These include screening and diagnosis, subject selection and characterization for research protocols, clinical progress monitoring, and measurement of outcomes in treatment research.

Although several ASD screening measures are commercially available, they vary greatly with respect to test development procedures and extent to which their psychometric properties have been evaluated. Most measures require more research to fully evaluate their psychometric adequacy, particularly as it relates to their usefulness in the assessment of subgroups within the ASD population (e.g., youth with autism and a co-occurring EBD and/or co-occurring intellectual disability, etc.). This gap in evidence-based assessment is recognized by the Interagency Autism Coordinating Committee (2009) and is listed as a priority area for autism research funding.

To advance our understanding of the psychometric adequacy of several common measures in autism spectrum assessment, a series of studies is being conducted by investigators at the University of Rochester, Rochester Institute of Technology, and Hofstra University. Findings from these studies will contribute to the evidence-based assessment literature, which can advance practitioner and researcher knowledge in the selection of psychometrically sound measures for their clinical and research purposes. Below is a brief summary of some recently completed studies and some that are in progress.

Caroline I. Magyar, PhD

Vincent Pandolfi, PhD



Charles A. Dill, PhD

Screening Measures for Autism and Autism Spectrum Disorders

Magyar & Pandolfi (2007) investigated the factor structure of the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1988), an early autism screening measure that predates the current DSM-IV conceptual model. This was the third independent study of the constructs underlying the CARS. Magyar & Pandolfi (2007) identified correlated Social-Communication, Social Interaction, Stereotypies and Sensory Abnormalities, and Emotional Regulation factors. These constructs represent core and associated features of autism that are conceptually consistent with DSM-IV. These results differed somewhat from two previous construct validity studies (DiLalla & Rogers, 1994; Stella et al., 1999). However, all three studies indicated that the CARS measured constructs consistent with DSM-IV core symptoms and associated features of autism. Differences in the specific results appeared related to differences in administration procedures used, the settings, and sample characteristics. Although its development predates the DSM-IV, and many newer measures are available, the CARS' psychometric properties, conceptual relevance, and flexible administration procedures support its continued use as an autism screening measure.

In another study, Pandolfi, Magyar, & Dill (in press) examined the construct validity of the Gilliam Autism Rating Scale-2nd Edition (GARS-2; Gilliam, 2006). The GARS-2 includes three *conceptually* derived subscales that contribute to the norm-referenced Autism Index, which indicates the probability that a person has autism. The subscales include Stereotyped Behaviors, Communication, and Social Interaction. However, no studies have evaluated the measure's factor structure and therefore, exploratory and confirmatory factor analyses of the standardization sample data were used to *empirically* identify factors underlying the GARS-2. Results did not support the conceptually-derived three subscale structure. In fact, four factors were identified and labeled: *stereotyped/repetitive behavior*, *stereotyped/idiosyncratic language*, *word use problems*, and *social impairment*. The results indicated that the conceptually-derived GARS-2 subscales and Autism Index should not be used for screening. Additional scale development is necessary to determine the future contribution of the GARS-2 in autism screening.

Several other studies are currently underway examining the reliability, construct, and discriminant validity of two other widely used screening measures: the Social Communication Questionnaire (Rutter, Bailey, & Lord, et al., 2003) and the Pervasive Developmental Disorders in Mental Retardation Scale (Kraijer & de Bildt, 2005). Data were collected from children with Down syndrome (DS) and children with DS and co-occurring ASD.

Measures for Evaluating Co-Occurring Symptoms or Disorders

Children and youth with an ASD often present with co-occurring emotional and behavioral disorders (EBD), however, developmental characteristics associated with the ASD such as language and cognitive impairment, poor insight, and problems with accurately reporting changes in thinking, behavior, and mood may make it difficult to identify co-occurring EBD that require specific treatment. Third party report, therefore, is an essential component of a multimethod assessment of children and youth with an ASD. However, EBD screening measures need to be validated specifically for the ASD population. As was the case for the ASD measures described above, evaluating the internal structure (e.g., number and nature of the constructs underlying the scale, scale reliability) and convergent/discriminant validity of EBD measures are necessary to inform clinical and research protocols and practice. This information will help us understand what the instrument measures, how well it identifies those individuals with a co-occurring EBD, how well it discriminates between various clinical and non-clinical subgroups, and its utility for clinical progress monitoring.

Pandolfi, Magyar & Dill examined the factor structure of the Child Behavior Checklist 1.5-5 (CBCL; Achenbach & Rescorla, 2000) and the Child Behavior Checklist 6-18 (CBCL; Achenbach & Rescorla, 2001). These are both widely used and well researched measures for EBD. The scales are constructed similarly in that they contain several norm-referenced scales derived through factor analysis of data from the general pediatric population. Each measures emotional and behavioral syndromes that have also been observed in the ASD population, such as anxiety, depression, aggressive behavior, and attention problems.

In these studies, confirmatory factor analysis of archival data evaluated the adequacy of the CBCL 1.5-5 and 6-18 factor models in well-characterized samples of preschoolers (18 months to 5 years; *N*=128) and school-age youth (6 to 18 years; *N*=122) with an ASD. Psychometric results from both the CBCL 1.5 to 5 (Pandolfi, Magyar, & Dill, 2009) and CBCL 6-18 (Pandolfi, Magyar, & Dill, in preparation) supported the factorial validity of each measure. Preliminary analyses indicated that the CBCL 6-18 can discriminate those with an ASD from those with an ASD and a co-occurring EBD. Discriminant analyses are still required for the CBCL 1.5-5. Although more validity studies are needed, these results suggest that practitioners can use these measures to screen for EBDs in children and youth with ASD in conjunction with other clinical data.

Summary

Given the variability in clinical symptom profiles between individuals with an ASD and within the same person over time, the clinical and research communities will require a variety of reliable and valid measures from which to choose. Most of the ASD measures that are commercially available require additional comprehensive psychometric evaluations, such as the ones described here, in

see Autism Assessment on page 41

University of Albany Conducts Research Aimed at Improving the Lives of Children and Families Affected by Autism

By Lindsay A. Washington, MA, Melissa Rinaldi, PhD, and Kristin V. Christodulu, PhD
Center for Autism and Related Disabilities, University of Albany

The Center for Autism and Related Disabilities at the University at Albany (CARD Albany) is a university - affiliated resource center that brings research and practice together in community settings. CARD Albany provides evidence-based training and support to families and professionals, and through ongoing research, contributes knowledge to the field of autism spectrum disorders (ASD). In keeping with our mission statement, our research has addressed a number of areas relevant to children with ASD, including sleep, sibling issues, challenging behavior, feeding, social skills, and peer acceptance.

CARD Albany's director, Dr. Kristin Christodulu, has conducted research investigating behavioral interventions for sleep disturbances in children with autism spectrum disorders (Christodulu & Durand, 2004; Durand & Christodulu, 2004). Results of these investigations suggest that interventions that promote positive bedtime routines (including activities such as taking a bath and reading a story) and implement sleep restriction (reducing the

Lindsay A. Washington, MA

number of hours the child slept while maintaining a consistent bedtime and wake-up time) resulted in improvements in the child's sleep patterns and overall quality of life. Specifically, the behavioral interventions used in the studies resulted in elimination of bedtime disturbances, reductions in nighttime awakenings and the time it took to put the child to bed, and improvements in the parent satisfaction with the child's bedtime behavior.

Over the past few years, CARD researchers investigated the effectiveness of a frequently used support program for siblings of children with ASD, *Sibshops* (Meyer & Vadasy, 1994). In the *Sibshop* program, siblings of children with autism attend monthly group meetings with other siblings. These meetings include high energy games, discussion, and information. CARD held a number of *Sibshops* and collected information from both parents and siblings prior to and following the programs. Initial results of the study did not suggest improvements in social skills or decreases in problem behaviors for the siblings of children with an ASD that completed the *Sibshop* program. However, the findings indicated that these workshops may produce positive changes in the sibling relationship, such as an increased understanding of their sibling's disability and a willingness to discuss this information with others. In a follow-up study, researchers at CARD examined the inclusion of a parent component to the traditional sibling support group model. Results from this follow-up study also found positive changes in the sibling relationship following attendance of these events, as well as increases in the siblings' knowledge of ASD and overall decreases in family stress levels.

CARD Albany has also collaborated with the University at South Florida on a project that evaluated two approaches to parent education, both of which have been shown to be effective in improving children's behavior. Parents who participated in this study attended eight sessions with a trained therapist and learned to deal with their children's behavior more positively and effectively. Results from both sites indicated that participating parents reported reductions in their children's challenging behavior. Although CARD Albany is no longer recruiting families, investigators at South Florida continue to work with parents on this project. In addition, Dr. Melissa Rinaldi, a researcher for the Positive Family Intervention Project, examined parent and therapist perceived barriers-to-treatment at the conclusion of study participation. Results indicated significant relationships between parental scores on depression items and child behavior outcomes across parent education conditions. In addition, therapist reports of stressors and obstacles to treatment were related to session attendance. Results also support the use of parent training programs targeting both child behaviors and parental perceptions to improve child behavior and family outcomes.

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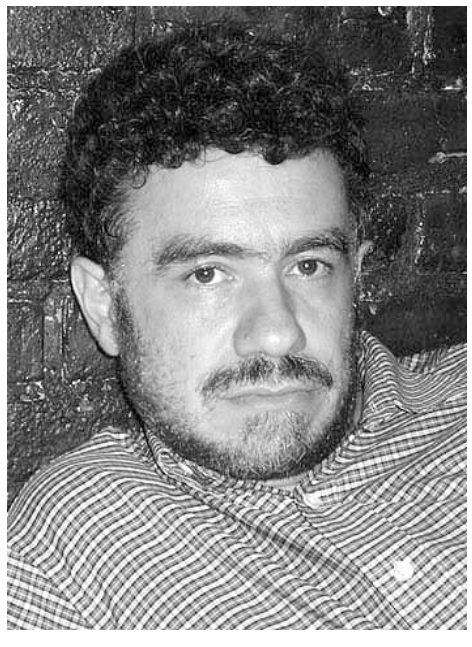
National Meeting Devoted to Improving the Lives of Adults

The Perspective of an Adult on the Spectrum after Attending

By Karl Wittig, PE
Facilitator of NYC GRASP

On Friday, November 13, 2009, I had the opportunity to participate in an event that will hopefully improve the lives of adults on the autism spectrum throughout the U.S. (and, at the same time, refute the superstition that this date is somehow unlucky!). This was the day when Advancing Futures for Adults with Autism (AFAA) held the first-ever national town meeting whose entire agenda was devoted to issues facing adults with autism. Such an initiative was long overdue, given that literally 100% of autistic children grow up to become autistic adults, and that many public services for individuals with autism end around age 21 in most if not all states.

AFAA is a national consortium of autism organizations, including the Organization for Autism Research (OAR), dedicated to the goal of advancing a national agenda and influencing public policy on issues that affect adults on the autism spectrum. It began with a think tank, in January 2009, to develop strategies for addressing these issues and focused on the areas of housing, employment, and community life. The town meeting, which was attended by more than 1,000 people, dealt with these same issues. The meeting took place in Chicago and at 15 other locations throughout the U.S., including Long Island, all connected by a teleconferencing system and satellite network. The Asperger Syndrome and High Functioning Autism Associate of New York (AHANY) co-sponsored the meeting at the Four Points Sheraton in Plainview, NY and was responsible for the invitation and subsidizing of several individuals on the spectrum (including myself). Each location hosted a gathering of autism professionals and advocates, community and business leaders, family members, as well as a significant representation of individuals on the spectrum. An electronic poll of all attendees revealed a figure of 7%, which may well be unprecedented for a gathering of this nature (even if we could still do better!).



Karl Wittig, PE

The meeting itself was organized, at each location, into groups of several people seated at a table with its own facilitator from America Speaks, the organization that arranged the facilities and resources for the event. A number of prospective issues in each of the main areas of focus were presented; participants then discussed these issues and voted on their respective priorities using wireless keypads and an electronic system that recorded, tabulated, and presented combined results from all of the locations. Each participant was given equal opportunity to express their views, and the result was a full day of spirited, lively, and productive discussions.

As an individual on the spectrum, I was able to discuss many of the ASD-related issues that affected me throughout much of my life and that I have become especially concerned about since my diagnosis in 2000, particularly those concerning public awareness, accommodations, transportation, employment, and inclusion in the community. Although I have been involved with the Asperger Syndrome community for all of this time in a number of capacities, such as attending and speaking at conferences, addressing various groups and organizations, attending and facilitating the New York City GRASP support group, and serving on the boards of GRASP, this was my first participation in something that actually has the potential to directly influence public policy. The final phase of this effort will be an autism congress in 2010 that incorporates results of the town meeting to recommend new public policies for improving the lives of adults on the autism spectrum. We can all only hope that it succeeds in its mission, and that the promise of the AFAA initiative is fulfilled.

Karl Wittig, PE, a retired electronics engineer who worked in research and development for over 28 years, was diagnosed with Asperger Syndrome at the age of 44. He currently facilitates the New York City support group and serves on the Board of Directors of GRASP.

This article will be published in AHA's Winter 2010 issue of On The Spectrum to be delivered January 2010.

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of data. Interventions supported by anti-science are often based on belief, and the demand for scientific proof of effectiveness may seem inconsequential or even be deemed inappropriate.

A major distinction between science and pseudoscience or antiscience is the former's commitment to ensuring that confounding variables are not responsible for the apparent effectiveness of the intervention. There is a strong desire to demonstrate that the effects were created by the treatment, and not by any other factor. Science makes use of comparative research, in which the treatment in question is compared to other treatments or to lack of treatment to ensure that other variables—such as the passage of time or significant events in the environment—are not responsible for the observed effect on the targeted phenomena. Scientific research is well controlled to ensure that the treatment variables are responsible for change (Green, 1996; Cooper, Heron, & Heward, 2006). In contrast, pseudoscience approaches are often non-comparative, relying only on indirect reports, anecdotal information, or pre-post measures.

The Definition of Empirically Supported Treatments

With the increased focus on and need for evidence-based treatments among the population of children with psychological disorders, Division 12 of the American Psychological Association assembled the Task Force on Promotion and Dissemination of Psychological Procedures to develop guidelines by which a treatment could be identified as an "empirically supported treatment." These guidelines helped the professional community to understand the different levels of evidence for interventions. Lonigan, Elbert, and Johnson (1998) reported on these guidelines, citing criteria for both "well-established interventions" and "probably efficacious treatments." Well-established interventions for childhood disorders are supported by a body of evidence comprised of at least two well-conducted group design studies implemented by at least two different investigators that indicate that the treatment is either more effective than placebo or an alternative treatment, or is equivalent to previously established treatments.

Another acceptable form of empirical support comes from single-subject research designs (used by many researchers within the field of behavior analysis) to measure the effects of treatment on individuals. Each single-subject design is constructed to ensure that the results of the treatment are not due to external, or confounding, variables (Cooper et al., 2006). Within applied behavior analysis—and especially in the field of autism—researchers utilize single-subject design to examine the effects of treatment at an individual level. Lonigan et al. (1998) acknowledge that many treatments for children are supported by single-subject design research. The authors note that a body of evidence that includes more than nine single-case design studies that use good experimental design, utilize treatment manuals, and clearly specify sample characteristics may constitute well-established evidence.

Probably efficacious treatments are supported by bodies of evidence in which either (1) two studies indicate that the studied treatment is more effective than a no-treatment control group, (2) two group -design studies that meet the criteria mentioned above for well-established interventions but are conducted by the same investigator offer support for the treatment, or (3) a series of 3 or more single-subject design studies that fit the criteria described above support the effectiveness of the treatment (Lonigan, Elbert, & Johnson, 1998).

The criteria for well-established treatments and probably efficacious treatments, as described by Lonigan et al. (1998), are lofty. There are also criteria for empirically supported treatments, which involve comprehensive programs of intervention. While many focal treatments that target specific skill deficits within the population of learners with autism (e.g., motor deficits, communication deficits, social deficits) meet the criteria for well established and probably efficacious treatments, no comprehensive treatment program—a program that seeks to improve the overall functioning of individuals with autism—currently meets criteria for an empirically supported treatment as per Lonigan et al.'s definition (Rogers, 1998).

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The Sibling Experience

By Lorraine Donlon
Author, The Other Kid

Navigating the waters of parenthood has always presented a complex mix of joys, challenges, frustrations and intense love. When a special needs child is added to the equation, the typical family dynamics can become more intense and complicated.

Parenting a child with any serious illness, injury or disability is a life altering experience. Dealing with your own worries and fears can have a profound impact on your marriage and the typically developing kids in the family. Have you ever wondered how to talk about your exceptional child with your other children? Are you concerned about the emotional impact on everyone in your family?

I am an elementary school teacher and the elder sibling to 2 autistic sisters. Back when I was growing up in the 1960s, not much thought was given to understanding the specific emotions that siblings may experience: anger, shame, fear, sadness, guilt, loneliness, frustration or embarrassment. Today, we acknowledge the importance of age appropriate information, explanations, and opportunities to openly express all emotions. But where do you start and what do you say? Loving communication has to start when kids are first noticing differences and are curious about the special needs of their brother or sister. The dialogue must start early so there is a starting point for future communication. Siblings need to be reassured that all their feelings are normal, valid and open for discussion.

My own journey began while researching services for my sisters in preparation for becoming their guardian in the future. As luck would have it, I met Dr. Jane Perr, a New York psychiatrist and advocate for the special needs population. Contemplating the role of siblings led to the creation of a workbook entitled: The Other Kid – A Draw It Out Guidebook for Kids Dealing With a Special Needs Sibling. Children are invited to read, write and draw directly into this book. Gentle prompts guide you through a thoughtful and supportive conversation, allowing kids to express all their wonders and worries in a safe way. The book is appropriate for ages 5 -12 and has been recommended for use in home, hospital and clinic settings. Ronald McDonald House in NYC has incorporated The Other Kid workbook into their program to support the siblings of kids receiving treatment for cancer. The Spanish version, El Otro Nino, is used as a resource to help Spanish speaking children voice their feelings. Please visit www.theotherkid.com for more details.

After receiving a copy of the workbook, my friend and neighbor Marsha Luftig, a social worker, psychotherapist and the mother of a special needs daughter, began offering workshops for parents and the siblings of special needs kids in NYC and Long Island. Parents have expressed gratitude for a nonthreatening way to lovingly connect with their children and create an atmosphere of communication.

Although this project initially began as a way to help myself sort through my own experiences, The Other Kid workbook is now used as a resource in the US, Canada, England, Wales, Scotland and Ireland by parents, sibling support group leaders, child life specialists, and social workers. The positive side of being "the other kid" is the opportunity to develop empathy, tolerance, insight and loyalty. You also meet the most incredible people coping with challenging situations with grace, humor and love. This workbook is my way to "pay it forward."

The ABC's of Medicaid and SSI Eligibility for People with Disabilities

By Raymond J. Falcon, Jr., Esq.
Falcon & Singer PC

Persons with severe disabilities will find it hard, perhaps impossible, to earn a living, or even perform such basic activities of daily living as eating and drinking, bathing, dressing, walking and grooming without assistance. Moreover, the nature and scope of the disabilities may very well cause the persons with special needs to require a tremendous amount of medical care, possibly even long term custodial care in a skilled nursing facility or group home at some point.

Medical and long term care costs have been growing dramatically over the years. In the greater New York City area, the cost of a long term care facility can top $10,000.00 per month. The cost of such medical and long term care can be devastating. A recent study performed by Harvard researchers indicted that roughly one-half of all bankruptcy cases filed in 2001 were attributable to medical expenses.

There are three basic ways these expenses can be covered: you can pay privately if you have the means; you can obtain health insurance coverage or long term care insurance, if it is available; or you can seek the government's assistance. This article addresses one of the governmental assistance programs - Medicaid.

Raymond J. Falcon, Jr., Esq.

Since Medicaid rules may vary from state to state, this article will cover some of the general principles; however, you should look to your state rules regarding specific entitlement criteria for Medicaid. For those who are internet-savvy, most states have state-specific Medicaid information on their Health Department or similar websites.

Medicaid provides health care and long term care coverage for certain groups of people who have very low income and limited assets. Medicaid is a joint program of the federal and state governments. Funding for Medicaid is shared by the federal and state governments; however, Medicaid is administered by the state. In most states, persons who receive Supplemental Security Income (SSI) automatically receive Medicaid. In addition, persons who are blind, disabled or over 65 may qualify for Medicaid directly if they meet the financial tests, even though they do not receive SSI.

For persons with disabilities, there are three criteria that must be met in order to qualify for SSI or Medicaid without SSI (Medicaid-Only programs): disability; asset test; and income test. For SSI, these tests are set out in federal laws and regulations. For Medicaid, federal rules also set out financial criteria; however, for Medicaid-only programs, states are allowed to modify the basic income and asset tests to make them more lenient than the federal rules. You should contact your state Medicaid agency to get the specific income and asset limits in effect in your area.

Disability Test

Most programs for persons with disabilities use the Social Security definition of disability. A person under 18 is "disabled" if the person has a medically determinable physical or mental impairment which results in marked and severe functional limitations and can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months. If the person is over 18, the test changes somewhat: an individual age 18 and older is "disabled" if the medically determinable physical or mental impairment prevents the person from engaging in any "substantial gainful activity" and can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months. Generally speaking, "substantial gainful activity" is measured by the ability to earn an income. For 2009, the Social Security "Substantial Gainful Activity" income limit for a person with disabilities is $980.00 per month.

Asset Test

In order to qualify for SSI and Medicaid in states where Medicaid is automatic for persons on SSI, as well as in most states that provide Medicaid-only coverage to persons who are not on SSI, a person cannot have more than $2,000.00 in countable assets. Countable assets include bank accounts, stocks, bonds, and other investments, including most retirement assets if they can be withdrawn, as well as real estate. There are some assets that are

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starting to advance our understanding of some of the underlying brain bases of autism. Sadly, imaging in young anxious children with ASD is difficult unless they are sedated, which may be acceptable for ruling out a serious or treatable brain disease, but is not for research. Progress is being made toward shortening the procedure and making it more suitable for such children, rather than limiting it to the cooperative older children and adults with ASD who are the main subjects of current research.

Clinically-Defined Subtypes of Motor Findings in Children with Autism Spectrum Disorders

There are two main categories of movement, *fine* and *gross*, each of which engages sensory as well as motor brain networks. We emphasize that some individuals on the autism spectrum have no sensorimotor deficit, in fact that some are gifted, for example exhibiting extraordinary dexterity for spinning small tops, twirling strings, flicking a tiny piece of paper between their fingers, or swiftly and dexterously taking mechanical toys apart. Others show great agility at climbing on furniture or walking on edges while incapable of hopping on demand. We also emphasize that deficiency in one skill does not predict that others will also be deficient. The reasons for these puzzling differences remain explained.

Most purposeful movements require a lengthy apprenticeship (learning, praxis). Some of the deficits of fine motor abilities are impaired imitation and coordination (dyspraxia), writing (graphomotor deficits), gestures, and oro-motor control (speech articulation, feeding). Gross motor deficits involve the many aspects of gait and posture, including negotiating the physical environment. A recent clinical review of ASD children (Ming, Brimacombe, & Wagner, 2007) reports hypotonia in 51%, motor apraxia in 34% of the younger group, and intermittent toe-walking in 19%. Our laboratory found similar results in a prospective controlled study being prepared for publication.

Rogers and colleagues (Rogers, Hepburn, Stackhouse, & Wehner, 2003) found that imitation in children with ASD (mean age 34 months) was strongly correlated with joint attention and severity of autistic symptoms. The investigators suggested that difficulty imitating gestures may have more to do with generating or using internal sensory representations of movements than with understanding the meaning of gestures, because the children had more trouble copying postures and oral movements than manipulating objects.

Dyspraxia, often referred to as clumsiness, consists of difficulty learning a motor task despite the lack of demonstrable sensorimotor deficit. Clumsiness may be inappropriate as impaired gestures in ASD are not due to poor motor coordination. A comparison of children's errors imitating movements, gesturing to command, and using tools suggests a generalized praxis deficit rather than a specific imitation deficit (Mostofsky et al., 2006). The investigators confirmed that on average children with ASD have poorer handwriting than age and IQ matched controls and that it involves letter formation specifically (Fuentes, Mostofsky, & Bastian, 2009), although large and sloppy handwriting might also reflect poor motivation or attention to the task.

We have devoted considerable effort to examining in detail video recorded motor stereotypies, defined as apparently purposeless repetitive movements. These often disrupting and stigmatizing behaviors may evolve into more serious self-injury or become maladaptive ways of avoiding tasks or social interactions. Based on the study of over 500 videotaped standardized play sessions, we have characterized and categorized motor stereotypies and examined their outcome in children with autism and other developmental disorders (Goldman et al., 2009). At preschool, stereotypies are linked to autism, as opposed to other developmental disorders, but by schoolage compromised nonverbal intelligence plays a crucial role in their persistence. We are currently evaluating whether there are particular stereotypies sufficiently characteristic of autism to serve as warning signals of the diagnosis and looking for brain correlates of stereotypies on MRIs.

Assessment of Motor Deficits

Clinical evaluation of motor function is a task for neurologists, developmental pediatricians, and physical and occupational therapists who may ponder whether

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Interventions for Individuals on the Autism Spectrum and How Best to Evaluate Their Effectiveness

By Robert H. LaRue, PhD BCBA-D and Amy Hansford, BA
Rutgers University Douglass Developmental Disabilities Center

Autism is a complex disorder characterized by significant deficits in social reciprocity and communicative ability as well as the presence of repetitive behavior/restricted interests. Given the heterogeneous nature of autism, many interventions have emerged with disputed claims of effectiveness. Applied Behavior Analysis (ABA), sensory integration, specialized diets (e.g., gluten-casein free diets), pharmacological interventions (e.g., Risperdal), and mercury detoxification procedures are among the most commonly used interventions with learners on the autism spectrum. However, many of these treatments persist in the absence of scientific data supporting their use. This absence of data is particularly problematic for parents and practitioners who are trying to provide the best possible intervention for their learners with autism. The prospect of selecting an appropriate treatment for autism can be overwhelming for anyone with the vast amount of conflicting information available. In fact, it is estimated that three quarters of parents will enlist an alternative treatment method

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Amy Hansford, BA

as part of their child's intervention (Hanson et al., 2007).

Most experts agree that the best first line of treatment is an intensive, coordinated program of special education and behavior management. Developmentally appropriate intervention programs generally include a language-based curriculum, systematic intervention to improve communication and social skills and a structured plan to address maladaptive behavior. Behavioral intervention strategies, such as ABA, have the most empirical support for their use. A considerable amount of recent research has validated the use of these approaches to treatment (e.g., Dawson et al., 2010). In addition, ABA has been endorsed by the U.S. Surgeon General (1999), National Institutes of Health (NIH) and the National Standards Report published by the National Autism Center (2009).

Non-behavioral treatments can generally be divided into two main categories: biological and non-biological interventions. Biological interventions include treatments such as Hyperbaric Oxygen Therapy (HbOT), vitamin therapy, secretin therapy, chelation, specialized diets (e.g., gluten-casein free diets, Feingold diet) and psychotropic medication. With the exception of psychotropic medication research, sound empirical evidence supporting the effectiveness of these interventions for learners with autism is sparse. Several studies have shown that certain psychotropic medications (e.g., Risperdal) can decrease aberrant behavior commonly associated with autism (e.g., impulsivity, aggression). While psychotropic medications can be effective for decreasing maladaptive behavior, parents and practitioners must be vigilant while monitoring for side effects. A significant

see Evaluate on page 38

How Do I Explain My Decision to Use Science-Based Treatments for Autism When Friends and Relatives Often Insist I Try Something New?

By David Celiberti, PhD, BCBA-D and Pamela F. Colosimo, PhD
Association for Science in Autism Treatment

When friends or acquaintances hear about our experiences with autism, quite often the first thing that person asks is, "What is your opinion of vaccines?" Then, in many cases, that person asks if we have heard of or read anything about Jenny McCarthy and how she cured her son's autism. The vaccine debate is an issue that lingers on, despite numerous scientific studies that don't find any evidence to support a link between vaccines and autism. As citizens, we respect any individual's right to their own opinion, but as scientists, we believe that objective data and evidence should guide treatment options for all diseases and disorders, and autism is no exception. It is simply a matter of fact that theories, hypotheses and individual experiences do not provide adequate information to guide treatment decisions.

Sadly, the controversies surrounding vaccines have detracted attention from the most important of conversations: How do we effectively help children who are already diagnosed with autism? Although ABA therapy is the treatment for autism that has the most empirical support, we are rarely ever asked our opinion of this therapy, or if it is effective.

Every few weeks or so, some "new" treatment or "repackaging" of a known treatment will gain the attention of consumers. In an ideal world, all treatment providers would make a commitment to science and evidence-based practices, and the media would make a commitment to responsible journalism. Until these ideals become reality, those who do understand science-based treatments should do what they can to inform and educate autism parents about the benefits of scientifically validated treatment and the use of data to guide decision-making when assessing autism treatments.

Given the large numbers of television programs, newspaper articles, and websites putting forth "miracle cures" and "breakthroughs", it is not surprising that parents frequently receive advice and suggestions from extended family members, neighbors, and co-workers, particularly after a news item is broadcasted, printed, or otherwise disseminated. Many of these individuals have the best intentions and are eager to share what they believe is "cutting edge" information about autism. In other cases, the advice can be provided in a manner that comes across as critical of what you are choosing to do or not do for your child (i.e., there may be the implication that you may not be doing enough as a parent to help your child).

If the information is offered by a more casual acquaintance, it may be best to simply thank him or her for their interest and concern and move on; however, such a strategy may not fare as well with individuals with whom you have a closer relationship. In these cases, you might consider sharing the following:

- There are dozens of "miracle cures" and "breakthroughs" for autism that manage to receive widespread media attention, even if they have not been proven effective;
- It is important to be critical of all available information, regardless of the source and to recognize that not all information on the internet is reliable and accurate;
- There is a large body of scientific research published in peer-reviewed journals that supports the choices that you have made;
- There are numerous task forces (listed at the end) that have looked closely and objectively at the available research and have determined that the vast majority of autism treatments lack scientific support;
- Autism treatment is a multi-million dollar industry and many treatment proponents rely heavily on sensationalism and extraordinary claims to "sell" their products;
- Interventions that are actually shown to be the most effective often get the least amount of media attention; and
- For most other medical conditions, a provider that disregards proven intervention and uses a fringe treatment may actually be sued for malpractice (you may even consider drawing an analogy to a medical condition of particular interest to the person providing the advice).

Of course, you may also consider addressing this matter proactively. This would involve explaining your choices and commitment to science-based treatment to more significant family members and friends on your terms and at your convenience. It may helpful to view this discussion as a series of tiny conversations. You may even consider sharing links to websites such as asatonline.org, which will help your family members and friends separate the wheat from the chaff.

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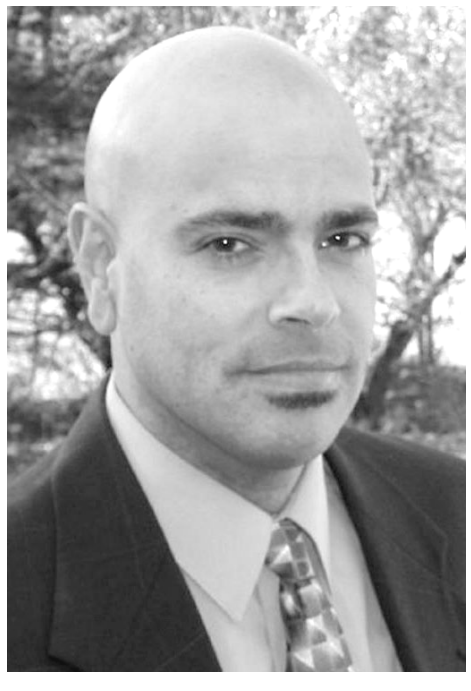
A Review of "The Complete Guide to Autism Treatments"

A Parent's Handbook - Make Sure Your Child Gets What Works

By David Celiberti, PhD, BCBA-D
President, Association for Science in Autism Treatment

The array of treatments for autism is indeed quite diverse, and taken together can be absolutely overwhelming to parents of newly diagnosed children. Consumer advocates who think that exposure to many diverse treatment options is a good thing are likely not considering the agonizing decisions parents must make about how best to help their child with autism, or the second-guessing and guilt that may come from worrying that one is not doing enough, or the extraordinary financial burdens that come from paying for numerous treatments out of pocket. Individuals with autism deserve a clearer path to effective intervention.

Thankfully, there is a resource available to help parents and other consumers develop the skills needed to differentiate science from pseudoscience. Dr. Sabrina K. Freeman is a prolific writer who has published numerous works related to autism and its treatment. Her latest book, The Complete Guide to Autism Treatments, may indeed be her most important contribution to parents of children with autism, as well as to those professionals who work with this clinical population. It



David Celiberti, PhD, BCBA-D

is also noteworthy that Dr. Freeman is the parent of a 21 year-old daughter with autism, and holds a PhD in Sociology from Stanford University, where she specialized in small group research. As will be detailed below, Dr. Freeman shares her perspectives as a mom, which further contributes to the authenticity of this book, and may appeal to parents who may be more amenable to the cautionary words of one who walks in their shoes.

The book is comprehensive, thoroughly researched, and well organized. Throughout, Dr. Freeman communicates a critically important message: *Individuals with autism deserve access to science-based treatment; their time, their potential, and the overall resources of their families should not be wasted*. The Complete Guide to Autism Treatments is divided into two primary sections. Section I is organized around topics related to the various treatments for autism, of which there are several dozen. Section II highlights basic concepts about science, hypothesis testing, and research methodology. Section I begins with a review of behavior-analytic treatments for autism across home and school settings, as well as within the area of early intervention. The various offshoots of applied behavior analysis are also summarized and evaluated (e.g., intensive behavioral treatments, pivotal response training, positive behavior support, verbal behavior therapy, and fluency training). Then there is a fairly comprehensive subsection related to the myriad of non-behavioral treatments, including those that occur in school, as well as those that are child-initiated or parent-facilitated. These subsections are followed by biomedical therapies, speech and language therapies, and ultimately a final section for miscellaneous therapies not better categorized in the above subsections. Each of these subsections is divided, and in some cases divided further, in an effort to capture the more frequently -touted treatments for autism.

Each of these treatment subsections is organized around responses to a series of 8-9 questions. These questions are applied to each treatment discussed:

(1) *What is ____?* - Dr. Freeman defines the treatment and describes its rationale, theoretical underpinnings, and hypotheses about autism's etiology and treatment.

(2) *What evidence do the practitioners have that this really works?* - Dr. Freeman summarizes and evaluates peer-reviewed research and other possible sources of support (e.g., anecdotal evidence) and reports the results of database searches.

(3) *What does this therapy actually look like?* - Dr. Freeman describes, often in great detail, the actual procedures associated with the treatment including side effects and/or adverse effects. This information is essential, as many parents may know little about the therapies to which they are subjecting their children.

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Please Tell Our Advertisers that Provide Treatment and Support Services:

"We Learned About Your Organization in Autism Spectrum News"

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David Celiberti, PhD, BCBA-D and Pamela F. Colosimo, PhD are both board members of the Association for Science in Autism Treatment (ASAT).

Some Helpful Resources

Interventions for Autism Spectrum Disorders: State of the evidence. (A collaboration of the Maine Department of Health and Human Services & the Maine Department of Education) - www.muskie.usm.maine.edu/

Report of the MADSEC Autism Task Force (2000) - www.madsec.org/LinkClick.aspx?fileticket=YmikqkW4tFk%3d&tabid=81

New York State Department of Health Clinical Practice Guideline for Autism and Pervasive Developmental Disorders - www.health.state.ny.us/community/infants_children/early_intervention/disorders/autism/

National Professional Development Center's Evidence-Based Practices for Children and Youth with Autism Spectrum Disorders (ASD) - www.fpg.unc.edu/~autismPDC/resources/resources_public_ebp.cfm

Association for Science in Autism Treatment - www.asatonline.org

Science in Autism Treatment, ASAT's free e-newsletter - www.asatonline.org/signup

Robin's Voice

A Resilient Mom's Commentary on Autism

Children with Autism are People Too

By Robin Morris
Freelance Writer

There is great controversy about the efficacy of gluten or casein free diets for children with autism. According to Dr. Samar H. Ibrahim of the Mayo Clinic "There is actually no trial that has proven so far that a gluten-free and casein-free diet improves autism," she said. "The diets are not easy to follow and can sometimes cause nutritional deficiencies."

There is a plethora of parents who insist that the absence of gluten and casein in their children' diets have made the difference improving language and behaviors. Anecdotal stories remain firm.

Whether or not dairy or wheat increases the symptoms of autism have yet to be proven by scientific data. However, (and this is a huge caveat) when children with autism are in pain, and cannot articulate that torture, gastrointestinal issues must be investigated.

Nearly 20 years ago I had the privilege of hearing pediatric neurologist Dr. Margaret Bauman, lecture on autism. She has devoted her life's work to this complex disorder, including research on the pathology of the autistic brain. Her message revolved around symptoms and diagnosis. Given that our son was a toddler at the time, I dreamed of new vistas that we'd reach on our journey.

Last year, equipped with the seasoning of time, I attended another lecture by Dr. Bauman. My cynical self begged the question, what's new in the

Robin H. Morris

arena of autism? Oddly, I was not surprised to learn that the only solid evidence for improvement is that of early intervention, one that we fortunately utilized 20 years ago. We did the best we could at the time, employing speech, occupational, and physical therapies and they continue to be key tools for intervention. Perhaps my Cinderella dream envisioned Dr. Bauman announcing a new inoculation (pardon the pun) to eradicate autism, while it melted away from our son, like magic. Bippety Boppety Boo. Okay, I can dream, can't I?

What Dr. Bauman did share was a very important piece of information for families of autism. She spoke of her efforts to involve all areas of medicine in the intervention of autism. Dr. Bauman recognized the essential fact that many children who suffer from autism also are in physical pain, for a myriad of reasons. The frustrating component for doctors and parents is that sometimes the child cannot express what hurts. Even if the child is verbal, being in touch with articulation of pain is not as clear.

Dr. Bauman illustrated this concern, while describing a scenario of a 12 year old child erupting in 133 bouts of aggression and tantrums in a 24 hour period. His mother locked herself in the bathroom and called Dr. Bauman (on her cell-- what a devoted doctor) Dr. Bauman advised the mother to get to an emergency room; there had to be a physical reason for the behavior. The mother insisted on traveling the hour to Harvard, by ambulance, and fortunately the psychiatrist on duty was willing to examine the boy. (Apparently it is a rare venture for psychiatrists to touch patients, they just talk to them.) Lo and behold, the boy had bilateral ear infections and following treatment, his aggressions diminished to 1 every 3 days.

Another situation took place on the West coast, where a mother was at a loss to help her son with autism. The local pediatricians were unsuccessful, and frankly many physicians are not willing to delve into the medicine, while dealing with the behavioral issues that are part and parcel to autism. The mother spoke with Dr. Bauman about her son's distress. Instinctively, Dr. Bauman advised her to see a gastroenterologist. The mother flew with her son the 1,000 miles from West to East coast, and her son was diagnosed with severe esophagitis. It is described by the Cleveland Clinic as "an inflammation of the lining of the esophagus, the tube that connects the throat to the stomach. If left untreated, this condition can become very uncomfortable, causing difficulty in swallowing and ulcers or scarring of the esophagus." This is an ulcerative, painful condition. The prospect of that pain with no threshold for understanding is horrifying.

I am reminded of a variety TV show in the late 70's titled Kids Are People Too. The catchy phrase gave children a rite of passage that their thoughts and ideas mattered. Whether it was guest athletes giving advice or the "Dear Alex and Annie" segment, the appeal was about listening to kids. Dr. Bauman's message to me was that doctors should recognize that autistic kids are people too. They should not be distinguished differently in any way. Sometimes, their behaviors have a physical origin, or catalyst.

Margaret Bauman has engaged the efforts of gastroenterologists, urologists, neurologists and endocrinologists to the same end; respecting her patients, respecting autism. What a refreshing notion!

Robin Hausman Morris is a freelance writer and can be reached at RobinHausmanMorris@gmail.com. Robin is a parent examiner for Examiner.com - www.examiner.com/x-3565-Hartford-Parenting-Examiner.

Judging Vaccines and Diagnosis - Autism Takes the Hit

By Robin Morris
Freelance Writer

Truth in advertising is hardly a novel approach. The mantra for Syms discount stores: "An Educated Consumer is Our Best Customer" rings provocative. Everyone wants a bargain, but do we gamble with our health in the process? Does a diagnostic label bring us to our knees?

How so, does the public manage to skew scientific research or concrete data in favor of speculation? What bias alters the classification system admitting or denying diagnoses into a spectrum disorder?

Michael Specter's new book *Denialism*, as reviewed in the NYTimes tackles the recent segue from science. The term "denialism," used by Mr. Specter as an all-purpose, pop-sci buzzword, is defined by him as what happens "when an entire segment of society, often struggling with the trauma of change, turns away from reality in favor of a more comfortable lie." Regarding the link between vaccines and autism, he ridicules Robert F. Kennedy Jr. (accused of writing an anti-vaccine article "knit together by an almost unimaginable series of misconceptions").

Simon Baron-Cohen thoughtfully argues the dangers in eliminating Aspergers Syndrome from the spectrum of autism. The Short Life of a Diagnosis explains in careful detail that the "Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychiatric Association, is the bible of diagnosis in psychiatry, and is used not just by doctors around the world but also by health insurers." The implication of diagnosis far exceeds the paper it is written on; what happens to the individuals who have already been diagnosed? What is their future regarding supports and services?

Dr. Baron-Cohen reminds us that the psychiatric manual is decided by a group of doctors who consider symptoms and behaviors, not biology. This is a significant point of fact. Adding and removing qualifications for diagnoses are part of the nomenclature, but it is not without caution and caveat.

"We don't yet know if Asperger syndrome is genetically identical or distinct from classic autism, but surely it makes scientific sense to wait until these two subgroups have been thoroughly tested before lumping them together in the diagnostic manual. I am the first to agree with the concept of an autistic spectrum, but there may be important differences between subgroups that the psychiatric association should not blur too hastily."

Ultimately, the importance of science should prevail. It is an unbearable responsibility for parents and families to make decisions based on hearsay. Whom, where and when to trust should be more comfortable choices for the "educated consumer."

Hopefully, research and hard evidence will make the difference.

The New York Times book review of Michael Specter's "Denialism" quoted in this article can be found online at www.nytimes.com/2009/11/29/books/review/Sanghavi-t.html.

Understanding from page 25

As Rogers points out, treatment for many childhood disorders can be disseminated over a short period of time, but comprehensive treatments for children with autism are much more time and labor -intensive. The author notes that the study of a comprehensive treatment for autism requires the implementation of a treatment delivered for 20 to 30 hours per week for at least 24 months to a minimum of 25 children. The pre- and post-treatment assessments and delivery of treatment would require countless hours and personnel, and the use of control groups and random assignment creates both ethical and practical difficulties (Rogers, 1998).

The procedures for distinguishing empirically supported treatments for childhood disorders (Lonigan et al., 1998) limit the identification of such evidenced-based practices for autism treatment. Therefore, other guidelines have been developed specifically for individuals with autism to increase the utilization of effective treatment and to limit the dissemination of ineffective or unsupported treatments. These guidelines supplement the lists of well-established and probably efficacious treatments that have been identified.

Guidelines

The National Research Council (2001) identified both comprehensive and focal interventions for individuals with autism supported by scientific evidence. In the committee's report, research in support of various treatments for individuals with autism was evaluated based on strength in each of three areas: internal validity, external validity, and generalization. For instance, a study was ranked highly if it compared the proposed treatment to an alternative treatment or placebo in which evaluators were blind to the hypotheses of the study. In addition, the participants in the study would have been assigned to conditions randomly, samples would have been well defined, and the sample size would have been large enough to allow for comparison. The effects of the study, to achieve the highest rating in generalization, would have been documented in at least one natural setting outside of the treatment setting, and a measure of social validity must have been included.

In addition to national guidelines, individual state governments have published guidelines for identifying best practices for working with individuals with autism. For example, the New York Early Intervention Program published a comprehensive resource of evidence-based practice recommendations for working with children with autism and developmental disorders between the ages of 0 and 3 years (New York State Department of Health, Early Intervention Program, 1999). Guidelines such as those published by the New York State Department of Health and the National Research Committee offer wonderful resources to parents and professionals seeking informed criteria for evidence based practice.

Brief Note on ABA Treatments

The treatment of autism spectrum disorders continues to receive a great deal of attention in professional circles, in the media, and in the culture at large. Applied Behavior Analysis has been extensively documented as effective in addressing the deficits associated with autism. It is prominently referenced in all of the guidelines and designations of evidence-based practice (both at the broad level and at the level of specific ABA instructional approaches). No other treatment approach comes close to ABA in empirical validation or strength of scientific evidence.

ABA comprehensively addresses the diverse profiles and characteristics encountered in learners with ASDs. ABA has an impressive body of evidence documenting its effectiveness. While there are some applications and extensions of ABA treatment that have not been fully explicated for this population, it is a highly effective and efficient treatment for autism spectrum disorders. It stands in stark contrast to all other treatments for autism, both in terms of the evidence that exists and in terms of its commitment to accruing more evidence to inform clinical practice.

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References

Cooper, J. O., Heron, T. E., & Heward, W. L. (2006). *Applied behavior analysis.* Upper Saddle River, NJ: Merrill Prentice Hall.

Green, G. (1996). Evaluating claims about treatments for autism. In C. Maurice, G. Green, & S.C. Luce (Eds.) *Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals.* Austin, TX: Pro-Ed.

Lonigan, C. J., Elbert, J. C., Johnson, S. B. (1998). Empirically supported psychosocial interventions for children: An overview. *Journal of Clinical Child Psychology, 27(2),* 138-145.

National Research Council (2001). *Educating children with autism.* Washington, D.C.: National Academy Press.

New York State Department of Health Early Intervention Program (1999). *Clinical practice guideline: The guideline technical report for autism/pervasive developmental disorders, assessment and intervention for young children (age 0-3 years).* Albany, NY: Author

S. J. (1998). Empirically supported comprehensive treatments for young children with autism. *Journal of Clinical Child Psychology, 27(2),* 168-179.

Handbook Review from page 29

4) *What else do I think?* - Dr. Freeman speaks to broader issues that bear relevance when judging the merits of the particular intervention.

(5) *Would I try it on my child?* - Here Dr. Freeman offers a more personal take on the treatment: a take that is honest and at times, blunt. Even if readers disagree with Dr. Freeman's stance, they will appreciate the candor and thoughtfulness of her position as a fellow parent.

(6) *What kind of study would I like researchers to do?* - Dr. Freeman argues that it is not sufficient that treatment proponents simply churn out publishable research, but rather that they design research that carefully addresses questions pertinent to that particular treatment. These may include, but not be limited to, better definition of the independent variable, use of tighter research designs, selection of more appropriate dependent variables, and a clearer demonstration of the relationship between the manipulation of the independent variable and the dependent variables.

(7) *Who else recommends for or against ____ as a method for the treatment of autism?* - Dr. Freeman highlights recommendations from professional-membership organizations, from state and federal government entities, and from other organizations such as Quackwatch. These recommendations should be an important factor in decision making and I applaud Dr. Freeman for reporting them throughout her book.

(8) *So you're still on the horns of a dilemma?* - Dr. Freeman provides further information for those still struggling with their decision for any number of reasons.

(9) *What's the bottom line?* - Dr. Freeman offers a "bottom line." Essentially, based on the scientific research to date, she clearly states when there is either no evidence, not enough evidence, or sufficient evidence to conclude that a particular intervention is effective.

Section II, titled "How do we know what works and what doesn't?" focuses on the scientific method, hypothesis testing, and research methodology. At times, the content may seem somewhat dense, but that speaks more to the complex nature of scientific inquiry than to Dr. Freeman's writing style. These more technical sections are preceded by a number of caveats empowering parents to question the "experts" whom they will undoubtedly encounter over the course of their child's treatment. There is considerable attention paid to the components of research, data interpretation, and analysis of a study, as well as descriptions of many all-too-common red flags in autism treatment. Section II ends with 57 pages of references!

This book has many notable strengths. The format of nine recurring questions within Section I provides a predictable framework for the reader. In fact, Dr. Freeman's careful analysis of the state of the research underlying specific ABA treatments is offered in the same spirit and with the same diligence as the non-behavior analytic treatments. This is critically important, given that the abundance of research in ABA may mistakenly give some the impression that all that falls under the umbrella of ABA is well supported empirically.

Proponents of the various treatments would benefit from careful consideration of the suggestions offered in the "What kind of study would I like researchers to do?" section. Far too often, a single study is put forth as validation of an entire treatment and all of its theoretical and conceptual underpinnings. The reader will find that Dr. Freeman has individualized her recommendations based on each treatment's existing research history. Execution of these research agendas may enable a number of treatments to live up to their promises.

Perhaps of greatest significance is that that the author is writing from the dual perspectives of professional and parent. When speaking as a parent, her commitment to science is unwavering and, appropriately so; she is unapologetic in honestly sharing her perspectives as an informed mother. This is greatly needed at a time when many individuals fear being perceived as close-minded or unwilling to recognize the contributions of other disciplines. Her professional perspective only adds further credence to her stance regarding treatment options.

There are wonderful insights throughout the book which will make this resource useful to those who will tend to read this book a few sections at a time. For instance, there is a very interesting discussion at the beginning of the book about participation in research with the caveat that precious time and resources should never be wasted on low-quality research, for not all research is created equally.

There are a few minor concerns. Many readers may have benefitted from an introduction to some of the content in Section II at the very beginning of the book. To her credit, Dr. Freeman makes the suggestion to review this content first. I suspect this introduction would have laid a foundation for readers to synthesize the tremendous amount of information in Section I. Organizationally, I believe that the judicious use of tables and charts would have facilitated comparisons across treatments.

In summary, I believe The Complete Guide to Autism Treatments is a much needed contribution to the field of autism. The diligence and comprehensiveness of the various treatment reviews make this book an important "go-to" resource for parents and professionals alike. Undoubtedly this is a resource that the reader can expect to pick up time and time again.

David Celiberti, PhD, BCBA-D is President of the Association for Science in Autism Treatment.

You've Been Told Your Child Needs Social Skills... Now What?

By Stacey Kanin, MS, CCC-SLP
Fay J. Lindner Center for Autism

This article will provide answers to some important questions parents may have after learning that their child would benefit from social skills group therapy.

Why are social skills groups important?

Social skills groups provide children with the opportunity to meet others and form relationships. Direct teaching of social skills will allow your child to gain valuable skills that they fail to detect just from observing their environment. Social skills groups will allow your child to practice skills in a safe and comfortable environment. Developing a child's social repertoire will facilitate their future success with regard to education, career, and relationships where appropriate social abilities are imperative.

Many facilities advertise "social skills" groups so how do I narrow down the choices?

Some facilities provide information about their groups on their websites. However, it is always best to call a facility and speak with the facilitator or director of the group. Although "social skills" may appear in the name or description of

Stacey Kanin, MS, CCC-SLP

a group, it may not be the most appropriate placement for your child. Here are some questions to ask when speaking with a facility:

What are the age, language, and cognitive levels of the group members?

Although group members do not need to be matched precisely by age, language, or cognitive level, severe differences between members can make it difficult for sessions to run smoothly. Comfort level and motivation to participate often increase when members feel similar to those around them. It is more important that members be matched by the aforementioned areas and not solely on diagnosis as diagnoses do not typically provide enough information about a child's overall ability level.

What is the skill-set of the facilitator?

It is important that the facilitator has a good understanding of autism spectrum disorders (ASDs) and the strengths and challenges of these diagnoses. If a facilitator is new at running groups, find out if they will be supervised. Many times, student clinicians may be facilitating groups but are directly supervised by licensed clinicians who have had experience running groups. Social skill facilitators can include: speech language pathologists, psychologists, and social workers

How is eligibility determined?

Some facilities may schedule a meeting with you/your child. These meetings are highly recommended as they allow the facilitator to directly interact with your child. It also gives you the opportunity to ask more questions, get to know the facilitator, and see how your child responds to him/her.

How do you determine the skills that are targeted in the group?

Goal formation will vary from group to group. Some facilities will work directly with the parents and the members to determine the group objectives. Other facilities may have pre-determined goals. The most important factor is that the goals being targeted are appropriate for your child. Also be aware that some groups may focus on one particular goal while others will target numerous goals throughout the series.

Are there peer mentors involved in the group?

Typically developing peers are ideal models for the development of social skills in children with ASDs. Peers can provide the group with opportunities to practice social skills and serve as role-models. Before joining a group peers should participate in a peer mentor training to provide them with tools for understanding ASDs. This training will also teach how to interpret the groups' behaviors and the appropriate ways to cue members.

What should I expect to occur during an actual group session?

Current research has provided information in regards to best practices to

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National Standards from page 21

favorable outcomes were reported based on specific treatment targets (e.g., communication, interpersonal, problem behaviors, etc.), ages, and diagnostic groups was also included in the National Standards Report.

Major Findings

Eleven treatments were identified as "Established Treatments." These treatments are: Antecedent Package, Behavioral Package, Comprehensive Behavioral Treatment for Young Children, Joint Attention Intervention, Modeling, Naturalistic Teaching Strategies, Peer Training Package, Pivotal Response Treatment, Schedules, Self-management, and Story-based Intervention package. Each of these treatments is defined in the National Standards Report. An even more detailed description of these treatments can be found in the National Autism Center's newly published manual, *Evidence-Based Practice and Autism in the Schools*, which can also be found on the Center's website. The vast majority of treatments in the "Established Treatments" category came exclusively or primarily out of the behavioral literature. However, a growing number of well-controlled treatment research is being conducted by scholars in other fields of study such as speech-language pathology and special education; all of these approaches appear more influenced by developmental considerations.

Most of the treatments reviewed in the National Standards Project (22 out of 38) fell into the "Emerging Treatments" category. Five treatments fell into the "Unestablished Treatments" category; two of these treatments (Facilitated Communication and gluten- and casein-free diet) are accompanied by cautionary statements.

Implications

The National Standards Report may impact practice and treatment selection in several ways. Parents, educators, and other professionals serving individuals with ASD now have easy access to information that identifies the level of research support available for the treatments they are considering. This should make the selection of treatments easier for many of these decision-makers. It is important to note that the Report emphasizes that treatment selection should be based not *only* on research findings, but on other essential factors as well. For example, professional judgment and data-based clinical decision-making, the values and preferences of families, and the capacity to accurately implement treatments should all influence the selection and/or the ongoing use of treatments.

Often, decision-makers want to know more than whether a treatment has been shown to be effective for individuals on the autism spectrum – they also want to know if there is evidence to show that the treatment can result in a favorable outcome for a specific goal. To meet this need, the National Standards Report includes information about treatment targets, age, and diagnostic groups. Table 8 in the Report provides an overview of this detailed analysis for each of the "Established Treatments."

Although it is important to know which treatments currently have evidence of effectiveness, it is just as important to know which treatments require more rigorous scientific investigation. The National Standards Report can be used to promote more high quality research for treatments for which greater quality, quantity, or consistency of research findings are required.

Finally, the National Standards Report may prove useful to individuals trying to secure appropriate services for their clients, students, or children on the autism spectrum. It may prove easier to obtain these services when organizations responsible for paying for them understand that there are, indeed, treatments that have been established as effective.

About the National Autism Center

The National Autism Center is dedicated to serving children and adolescents with Autism Spectrum Disorders (ASD) by providing reliable information, promoting best practices, and offering comprehensive resources for families, practitioners, and communities.

An advocate for evidence-based treatment approaches, the National Autism Center identifies effective programming and shares practical information with families about how to respond to the challenges they face. The Center also conducts applied research and develops training and service models for practitioners. Finally, the Center works to shape public policy concerning ASD and its treatment through the development and dissemination of national standards of practice.

References

National Autism Center. (2009). *Findings and conclusions of the National Standards Project: Addressing the need for evidence-based practice guidelines for autism spectrum disorders*. Randolph, MA: National Autism Center.

National Autism Center. (2009). *National Standards Report: National Standards Project - Addressing the need for evidence-based practice guidelines for autism spectrum disorders*. Randolph, MA: National Autism Center.

Wilczynski, S. M. & Pollack, E. G. (2009). *Evidence-based Practice and Autism in the Schools.* Randolph, MA: National Autism Center

Motor Dysfunction from page 27

they are seeing transient immaturity or evidence of a neurologically-based disorder. Worse, they are frequently unable to tell whether a child with ASD "couldn't or wouldn't do" a task like drawing a circle, throwing a ball, or hopping (Mandelbaum et al., 2006). Was it lack of cooperation, attention, imitation, or understanding of the commands that was at fault? Making naturalistic observations of the child during play or of spontaneous movements in other settings may help resolve the issue.

Standardized motor batteries are essential for research but do not explain the causes of failures. The Peabody Developmental Gross Motor Scale is most widely used for preschool children. Denckla's timed tests of simple repetitive movements, the Physical and Neurological Examination for Subtle Signs (PANESS) (Denckla, 1974), apply to schoolage children and adolescents. These tests quantify motor deficits but are not specific markers for autism. Comparing preschool with autism and other developmental disorders, we determined that, in general, the neurologist's clinical examination revealed that higher IQ rather than diagnosis determined better sensorimotor skills, except for stereotypies which were more prevalent in the autism group. Yet an attempt was made to differentiate high functioning autism from Asperger syndrome, a currently highly controversial issue, on the basis of quantitative kinematic analysis of targeted hand use (Rinehart et al., 2006). That study suggested that slower movements might characterize Asperger syndrome. Obviously, motor characteristics are but one potential screening approach for making this type of distinction.

Conclusion

Systematic study of sensorimotor function in autism is new. The focus of our laboratory and others has been to describe these deficits in children with ASD and other developmental disorders. In studies largely yet to be done, our goal is to understand their brain basis.

The main treatment for motor impairments in ASD is physical and occupational therapy, from which the majority of children clearly benefit. But we lack evidence on exactly what and how these therapies help and which child is most likely to benefit. Many studies have been published, but many had weaknesses. Some studies were short term, some enrolled single subjects or small groups, groups were not always well defined and homogeneous, and few used standardized measures to assess progress. Rare studies compared effectiveness among interventions in ASD compared to other developmental disorders, and few had sufficient power to evaluate the size of reported improvements and their effects on adaptive daily function.

The cost-effectiveness of all these expensive time-consuming interventions begs for more detailed assessment. More rigorous research on sensorimotor function in autism and better understanding of its neurologic basis are sorely needed. Various treatments are made available to children on the basis of diagnostic label rather than an analysis of the specificity of deficits to be remediated. The common goal of all professionals who care for individuals with ASD is to develop innovative, more effective, and less demanding and costly treatments than those currently available.

Reference List

Denckla, M. B. (1974). Development of motor co-ordination in normal children. *Developmental Medicine and Child Neurology, 16,* 729-741.

Fuentes, C. T., Mostofsky, S. H., & Bastian, A. J. (2009). Children with autism show specific handwriting impairments. *Neurology, 73,* 1532-1537.

Goldman, S., Wang, C., Salgado, M. W., Greene, P. E., Kim, M., & Rapin, I. (2009). Motor stereotypies in children with autism and other developmental disorders. *Developmental Medicine and Child Neurology, 51,* 30-38.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2,* 217-250.

Mandelbaum, D. E., Stevens, M., Rosenberg, E., Wiznitzer, M., Steinschneider, M., Filipek, P. et al. (2006). Sensorimotor performance in school-age children with autism, developmental language disorder, or low IQ. *Developmental Medicine and Child Neurology, 48,* 33-39.

Ming, X., Brimacombe, M., & Wagner, G. C. (2007). Prevalence of motor impairment in autism spectrum disorders. *Brain and Development*.

Mostofsky, S. H., Dubey, P., Jerath, V. K., Jansiewicz, E. M., Goldberg, M. C., & Denckla, M. B. (2006). Developmental dyspraxia is not limited to imitation in children with autism spectrum disorders. *Journal of the International Neuropsychological Society, 12,* 314-326.

Rapin, I. (1996). Preschool Children with Inadequate Communication. Developmental language disorder, autism, low IQ. Rapin, I. Clinics in developmental medicine[No 139]. London, Mac Keith.

Rinehart, N. J., Bellgrove, M. A., Tonge, B. J., Brereton, A. V., Howells-Rankin, D., & Bradshaw, J. L. (2006). An Examination of Movement Kinematics in Young People with High-functioning Autism and Asperger's Disorder: Further Evidence for a Motor Planning Deficit. *Journal of Autism and Developmental Disorders, 36,* 757-767.

Rogers, S. J., Hepburn, S. L., Stackhouse, T., & Wehner, E. (2003). Imitation performance in toddlers with autism and those with other developmental disorders. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 44,* 763-781.

Vilensky, J. A., Damasio, A. R., & Maurer, R. G. (1981). Gait disturbances in patients with autistic behavior: a preliminary study. *Archives of Neurology, 38,* 646-649.

Support Group For Families of Adults with Asperger's Syndrome and High Functioning Autism

The focus of the support group is to assist families in understanding the complex issues related to their adult child impaired with Asperger's Syndrome or High Functioning Autism. At many of our meetings, we have speakers address various topics of importance related to these syndromes.

For further information contact the facilitators:

Bonnie Kaplan - Parenttalk@gmail.com
Judith Omidvaran - Judyomid@aol.com

Socialization and Life Skills Group For Asperger's Syndrome and High Functioning Autistic Adults

Focused on:

Employment & Vocational Issues
College Coaching & Supports
Socialization
Self-Advocacy
Dating & Relationships

On the second Sunday of every month there will be an outing.

For further information contact the facilitators:

Patricia Rowan, LMSW - (914) 736-7898 - Patrowan@bestweb.net
Susan Cortilet, MS, LMHC - (845) 406-8730 - Susan.cortilet@gmail.com

Meeting Dates:

2010 - 1/24, 2/21, 3/14, 4/25, 5/23, 6/13

New Location:

Westchester Arc
The Gleeson-Israel Gateway Center
265 Saw Mill River Road (Route 9A)
Hawthorne, NY 10532

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teaching children with ASDs. Some techniques to be implemented include:

- Direct teaching of skills. Skills should be broken down then modeled and taught piece by piece using different modalities (writing, pictures, movies, etc.)
- Role-playing
- Videotaping for feedback and self-correction
- Take home assignments to allow for generalization and maintenance of skills

What are some topics that can be covered?

Topics will vary based on the purpose of the group and the group members. Some areas that may be targeted based on an ASD diagnosis include:

- Perspective taking: Understanding that others have thoughts, feelings, and experiences that are different from your own and modifying your actions based on this information
- Nonverbal communication including facial expressions, eye-gaze, and body language
- Higher-level language including making inferences, figurative language (idioms), humor, etc.

This article was first published in the Spring 2009 issue of AHA's "On The Spectrum."

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system. The maternal immune system is therefore responsible for protecting the child in addition to the mother. To accomplish this, antibodies produced by the mother's immune system are passed across the placenta into fetal circulation. These maternal antibodies protect the child during gestation and for months after birth, until the child's own immune system matures. If the mother has autoantibodies in her circulation during pregnancy, the fetus will receive them as well. Children born to mothers with autoimmune diseases like systemic lupus are susceptible to damage mediated by these maternal autoantibodies. The autoantibodies which are found in mothers of children with autism are also passed to the fetus, where they may interfere with brain development and function.

Animal Models: Demonstrating the Pathogenic Significance of Autoantibodies

Animal models have been used to explore the developmental consequences of in-utero exposure to the autoantibodies found in mothers of children with autism. It is difficult to model autism behaviors in animals; though monkeys and mice demonstrate numerous observable forms of anxiety, learning impediments, and social difficulties that can be likened to autism. Antibodies were obtained from mothers of children with autism and injected into pregnant Rhesus monkeys and mice. For comparison, antibodies from mothers of typically developing children were injected into separate groups of pregnant animals. The results of these studies have been fascinating. Monkeys exposed in utero to antibodies from mothers of children with autism behaved very differently from the control animals. They showed unique repetitive behaviors which overwhelmed their desire to interact with their mothers during testing. Mice also behaved differently when exposed to these antibodies during fetal development.

Remaining Questions and Future Directions

There are several questions that remain unanswered. First, the precise targets of these maternal autoantibodies in the fetal brain are not fully characterized. Determining the nature of the target proteins will allow for a better understanding of their significance in autism. Second, it is unclear how the maternal autoantibodies impact fetal development. They may initiate damaging immune reactions in the brain of the developing child, or interfere with important developmental and functional processes. Further research is needed to delineate their exact mode of action. Third, it is unclear whether these autoantibodies will lead to treatment options. In children born to mothers with conditions like myasthenia gravis and systemic lupus, immune-mediated damage can be ameliorated by various pre and post-natal interventions including plasmaphoresis. The findings among mothers of children with autism are too preliminary to know if similar options would be beneficial. Regardless of future treatment options, these antibodies may serve as a valuable biomarker of autism susceptibility in mothers. A newly formed company, Pediatric Bioscience, now offers a test for these maternal autoantibodies commercially.

In addition to our work on maternal autoantibodies, we have a strong interest in the immune function of children with autism and, in particular, their response to immune challenge. These studies are still in their infancy, though preliminary data suggests that there are immunological differences in subgroups of children with autism. We are also working on the development of a device that will enable us to measure immune function in infants using a very small blood sample. This may help us determine which children may have difficulties with future immune challenges. Continued research will surely lead to a greater understanding of ASD, and may provide options for early interventions and therapy.

Dr. Judy Van de Water, PhD has been involved in researching the immunobiology of autism spectrum disorders for 10 years. She is with the Department of Internal Medicine and works in collaboration with the MIND (Medical Investigation of Neurodevelopmental Diseases) institute at the University of California, Davis. Paula Goines is a PhD candidate in Immunology, and has been working with Dr. Van de Water since 2005 to delineate the connection between autism and immunity.

References

Ashwood, P., S. Wills, et al. (2006). "The immune response in autism: a new frontier for autism research." J Leukoc Biol **80**(1): 1-15.

Braunschweig, D., P. Ashwood, et al. (2007). "Autism: Maternally derived antibodies specific for fetal brain proteins." Neurotoxicology.

Croen, L. A., D. Braunschweig, et al. (2008). "Maternal mid-pregnancy autoantibodies to fetal brain protein: the early markers for autism study." Biol Psychiatry **64**(7): 583-588.

Enstrom, A. M., J. A. Van de Water, et al. (2009). "Autoimmunity in autism." Curr Opin Investig Drugs **10**(5): 463-473.

Martin, L. A., P. Ashwood, et al. (2008). "Stereotypies and hyperactivity in rhesus monkeys exposed to IgG from mothers of children with autism." Brain Behav Immun.

Singer, H. S., C. Morris, et al. (2009). "Prenatal exposure to antibodies from mothers of children with autism produces neurobehavioral alterations: A pregnant dam mouse model." J Neuroimmunol **211** (1-2): 39-48.

Zimmerman, A. W., S. L. Connors, et al. (2007). "Maternal antibrain antibodies in autism." Brain Behav Immun **21** (3): 351-357.

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16 children who ranged in ages between 20 -96 months, representing various diagnoses of autism (e.g., Asperger, Pervasive Development Disorder – Not Otherwise Specified (PDD-NOS), and Autism). These children had been receiving treatment based on the RDI model for at least 30 months. The authors attempted to measure three variables to assess whether or not the children improved due to the RDI intervention: (1) a subset of 13 items from the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, Dilavore, & Risi, 2002) and the Autism Diagnostic Interview-Revised (ADI-R); (2) the results of a "flexibility interview", developed by Gutstein, et al., in which parents used a self-report Liekert scale to rate the degree to which they thought their children exhibited "rigidity" in their behavioral adaptation and thinking; and (3) educational placement of the participants, which involved parents and teachers subjectively reporting the type of school placement in which the children resided (ranging from mainstreaming with no special education services to full-time placement with special education support).

Gustein and colleagues collected data on these measurements prior to and following the children's participation in RDI for an average of 18 months. Following treatment, Gutstein, et al. reported: (a) improvement in ADOS diagnosis, (b) improvement in "age appropriate flexibility" to routines, and (c) more children participating in less restrictive, more mainstreamed educational placements. The authors concluded that RDI was a "promising program for remediating critical experience-sharing difficulties…" of children with autism (p. 409). They hypothesized that the RDI treatment was causally related to the positive changes in the children; that is, that RDI appeared to be responsible for the improvement.

For a treatment to be considered within the category of EBP, there is general agreement that there must exist "multiple" research studies, done by a variety of researchers, that show that treatment to be effective (e.g., Chambless, Baker, Baucom, Beutler, Calhoun, Crits-Christoph, et al., 1998). With only one study published on testing whether RDI results in any improvement in participants with autism, it seems that RDI does not pass this initial criterion. Furthermore, it is unclear whether or not the positive conclusions made by Gutstein and colleagues concerning RDI in this current study are actually warranted. In other words, the methodological rigor of the Gutstein, et al. (2007) study was examined to determine whether the research design met minimal criteria for quality and, thus, believability of the authors' conclusions.

Upon careful examination of the design and methodology of the Gutstein, et al. (2007) study, it seems as if there are methodological problems with this study that prevent confidence in the conclusions offered by the authors. For example, the research design used in this study involved one group of participants, with measurements taken prior to and after the RDI intervention. This type of design is a "one group pretest-postest design" (e.g., Fraenkel & Wallen, 2009; Gay, Mills, & Airasian, 2009). It is important to note that this type of design is universally considered "weak" in that it does not control for threats to internal validity. This research design offers unconvincing evidence that the treatment was the sole reason for changes in the dependent measures (e.g., Fraenkel & Wallen 2009). Thus, there is an assumption that the participants in the Gutstein, et al. study could have improved on the measures due to reasons unrelated to RDI (such as maturation).

There are two other issues related to the research design that prevents clearly assuming that RDI was responsible for improvement in the participants. First, an important criterion for a well-designed study is proof of treatment implementation (i.e., procedural integrity; Gresham, Beebe-Frankenberger, & MacMillan, 1999). Gutstein and colleagues not only failed to provide detailed information about what exactly the RDI treatment protocols were that were employed, but they failed to provide any check on whether or not the treatment providers actually implemented the RDI strategies as Gustein, et al. intended. Thus, this study fails to meet this particular research quality criterion. A second essential criterion for "believability" of research is that of measurement reliability (e.g, Gay, et al. 2009). Specifically, researchers are required to provide evidence to support the belief that the dependent variables measured in the study were measured reliably. This is often accomplished by having a second independent observer measure the participants at the same time (and then comparing results), or by demonstrating that standardized instruments have predetermined reliability and validity. In the current RDI study, of the four dependent variables, the authors mentioned that inter-rater reliability was obtained (successfully) with one measure (ADOS), and that the ADI-R developers reported satisfactory reliability. However, the other two dependent variables (flexibility and educational placement) had no reliability measurements reported. In addition, since only a subset of items of the ADOS and ADI-R were measured, the validity of these two assessments was compromised, since the initial strong validity of these assessment tools is based on the tests in their totality.

Conclusion

Due to the weak research methodology used by Gutstein, et al. (2007), the lack of fundamental research methodology, and the existence of only one formal assessment of the effectiveness of this autism treatment, RDI at this time should not be considered to be a treatment that has evidence of effectiveness. There is no existing research base for concluding that RDI has been proven to be effective. Thus, like with other fad therapies and treatments that have no valid effectiveness data, care providers should carefully consider whether RDI is appropriate to use. Researchers must begin to do well-designed research studies attempting to simply determine if RDI is causally related to any improvement of any measure related to autism. Hopefully such studies will be done to determine if RDI is effective. However, until that time, treatment providers and other caregivers would be advised to consider using other treatments that have a proven record of effectiveness (e.g., applied behavior analysis).

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References

Fraenkel, J. R., & Wallen, N. E. (2009). *How to design and evaluate research in education, Seventh Edition.* New York: McGraw-Hill.

Gay, L. R., Mills, G. E., & Airasian, P. (2009). *Educational research: Competencies for analysis and applications, Ninth Edition.* Upper Saddle River, NJ: Pearson

Gresham, F. M., Beebe-Frankenberger, M. E., & MacMllan, D. L. (1999). A selective review of treatments for children with autism: Description and methodological considerations. *School Psychology Review, 28* (4), 559-575.

Gutstein, S. (2001). *Solving the relationship puzzle.* Arlington, TX: Future Horizons.

Gutstein, S., & Sheely, R. (2002). *Relationship development intervention with young children: Social and emotional development activities for asperger syndrome, autism, PDD, and NLD.* London: Jessica Kingsley.

Jacobson, J. W., Foxx, R. M., & Mulick, J. A. (2005). *Controversial therapies for developmental disabilities: Fad, fashion, and science in professional practice.* Mahwah, NJ: Lawrence Erlbaum Associates.

Lord, C., Rutter, M., Dilavore, P., & Risi, S. (2002). *Autism Diagnostic Observation Schedule.* Los Angeles, CA: Western Psychological Services.

Morris, R. (2009). Relationship development intervention. *Autism Spectrum News,* Fall 2009.

Zane, T., Davis, C., & Rosswurm, M. (2009). The cost of fad treatments in autism. *Journal of Early and Intensive Behavior Intervention, 5*(2), 44-51.

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frequency stimulation at four months. If these findings hold up they will represent the earliest predictors that we have of autism or at least the earliest markers we have for high risk children to become autistic.

Although this seems attractive there are still many qualifying factors to consider. One major issue is whether the NICU babies who become autistic are "the same" as other types of autism. In reality this is also true for the baby siblings. There may be many "autisms" and they may not have the same early signs although this remains to be seen. Up until now the baby sibling studies have not looked at children this young and we do not have this type of data.

The other type of early marker that would be very valuable would come from the biology of the child. Biosamples such as the placenta, cord blood, the mother's blood, etc. might yield markers. However, the studies to look at these samples and correlate them with the development of the child have not been done. Our goal in NY State is to focus on "birth cohorts" and look for the early signs of autism or other developmental disabilities. We are hoping to set up many sites and study the issues around pregnancy (such as medical risk, stress, etc.), the environmental influences, and the signs which might be observable in early infancy. In fact there are more types of high risk children and capturing all of them would give us a much better handle on what causes autism as well as the natural course of the disease.

The reason for doing all of this, ultimately, is to reduce the burden of the disease and to improve the lives of those affected children and their families as much as possible. In order to accomplish this there would need to be a treatment component along with these studies. Instituting very early intervention would be of the utmost importance and would have the greatest possibility of having a significant effect on the outcome for a given child. The first two years is one of dramatic development of the brain and it is possible that, through various means (educational, environmental and pharmacologic), we can influence the outcome.

This leads to another scientific question which is in need of answer. How much of the "autism" is present before birth and how much of it occurs in the first two years of life? This is not an easy question to study. We do know from brain tissue research that many of the brain changes noted in autism are findings which could only be explained by in utero changes, some of which occurring as early as the first trimester. This does not however rule out that there are further developmental changes which continue along with the brain development of the child. For example, suppose a child brain at the age of 2-3 months has a problem which prevents that child from processing or modulating sensory information. The child may then "learn" not to focus on speech sounds. It may be that there was nothing inherently wrong with the language parts of the brain, but due to the other problems, the language centers never fully kick in and do their function. Child development studies for many decades have documented that various problems with nurturing such as the Romanian orphans during the Ceausescu regime developed a syndrome very similar to autism. It is likely that these children do not share the biologic underpinning of the autism cases we have here in America and so there is something about severe deprivation early in life that leads to autism symptoms. A question to be posed is whether a biologic lesion is causing a self imposed isolation in the child leading to the syndrome which we call autism. This and other similar questions can begin to be investigated if we move the age down at which we start studying autism. With the support of the advocacy community, the state agencies, and the voluntary sector there is no reason why these goals cannot be achieved.

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Current CARD Albany research continues to incorporate parents and family members into effective interventions for challenging behavior, including behaviors that can be disruptive to mealtime. It is well established that children with autism exhibit greater food selectivity and disruptive mealtime behaviors than typically developing children. If not addressed, these problems have the potential to negatively impact both the child and family. A growing body of research suggests that food selectivity among children with developmental disabilities can be treated via behaviorally-based intervention strategies. Suzanne Milnes, a senior graduate student at CARD Albany, is the principal investigator of the Mealtime Intervention Project, which will examine whether an in-home, parent-implemented, behavioral treatment package is effective in increasing food acceptance and decreasing mealtime behavior problems in children with autism. Participants will be between the ages of 3 to 10 years, have a confirmed diagnosis of autism, and need to exhibit disruptive mealtime behaviors in addition to at least one of the following mealtime difficulties: refusal to eat foods from one or more food groups; refusal to accept most novel foods offered; a diet consisting of a limited number of food items (i.e., less than 20); or a diet resulting in a vitamin/nutrient deficiency as judged by the child's pediatrician and or nutritionist. The intervention will incorporate five target foods and utilize several antecedent and positive reinforcement procedures. Importantly, parents will be trained in how to implement the treatment package. Mealtimes will be videotaped for data analysis purposes and research assistants will code the tapes for the number of bites accepted of the target food and problem behaviors.

Another current focus of research at CARD Albany is the development of social skills in naturalistic settings. Early efforts to improve social skills in children with autism typically involved adult-directed approaches, which are well-established and have robust empirical support (Odom et al., 2003; Rogers, 2000). However, the current focus has shifted to address the ecology of children's social interactions in natural settings and social interactions with peers (Rogers, 2000). Peers are both a developmentally appropriate stimuli for young children and exist in educational settings, which are a natural context. These factors make peers an ideal population to incorporate into social interventions for children with ASD.

Given the research supporting peer-mediated approaches and a need to incorporate interventions into naturalistic settings, Lindsay Washington, a CARD Albany senior graduate student, is currently investigating the effectiveness of a classroom-wide peer modeling program for 1st and 2nd grade students with ASD. Our program utilizes a "buddy system" in which children spend a short period of time each day playing with one other classroom peer. Thus far we have worked with two different children on the spectrum and the peers in their respective classrooms. Prior to program implementation, a focus team convenes to identify three specific social skills goals for the child with ASD. CARD Albany staff then develops brief trainings based on these identified goals and presents them to the participating classroom. Buddies are rotated systematically so that the child with ASD is able to play with every other peer in the classroom. Every buddy session is videotaped and coded to assess for changes in the identified social skills. Results from our first two classrooms indicate improvements in relatively simple social skills (e.g., acknowledging the end of the play session and making eye contact) but also highlight the need for more intensive interventions for more complex social skills. Analysis of the relationship between buddy activity and number of verbal utterances revealed that the target children produced the most comments during activities that required taking turns with their buddies. This observation is consistent with research conducted by Dewey, Lord, and Magill (1988), which indicated that rule-governed games facilitated the most complex social interactions, were the most fun, and kept the children most involved with their peer. It appears that careful selection of play materials and inclusion of rule-governed games may increase the likelihood of communicative gestures between peers. The program has been very well received by both teachers and participating children. CARD Albany is in the process of setting up our third classroom and data collection will begin in spring 2010.

Additional research that CARD Albany will conduct in spring 2010 includes examining how typically developing peers perceive children with ASD. Thus far, investigators have focused more on peer attitudes towards children with physical disabilities. However, as more and more children with ASD enter inclusive classrooms, additional research regarding how they will be received by peers seems particularly relevant. A better understanding of peer perceptions could help us develop more effective interventions to promote social acceptance and hopefully foster friendships. Although robust findings suggest that young children with autism struggle with social interaction and often have difficulty forming and maintaining friendships, this research will try to gather more information from the perspective of peers. Within the area of peer attitudes towards children with ASD, Campbell and colleagues have conducted several studies with older elementary and middle-school children. In order to extend this research to younger children, CARD Albany will investigate whether typically developing children from first grade classrooms express rejecting attitudes towards a hypothetical peer who displays behaviors indicative of autism. Results will hopefully guide CARD staff in developing appropriate interventions that may focus on disability awareness or promoting acceptance.

Finally, researchers at CARD Albany will be collaborating with an investigator at Brown University to examine listeners' perceptions of cries from infants later diagnosed with autism. Findings from this study will hopefully contribute to the growing literature related to early markers of ASD.

As CARD Albany continues to expand its research programs, our fundamental goal remains the same – to help further the understanding of how to assist children with ASD obtain greater quality of life.

Lindsay A. Washington, MA, is a Senior Graduate Student, Melissa Rinaldi, PhD, is Research Coordinator, and Kristin V. Christodulu, PhD, is Director of Center for Autism and Related Disabilities at the University of Albany.

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concern is that individuals with autism are often less able to communicate potential adverse side effects to caregivers. In addition, it is important to monitor (and distinguish between) positive clinical effects and sedative effects. Other biological interventions require more thorough scientific investigation to determine if and with whom they are effective before widespread adoption by the field.

Non-biological interventions include treatments such as Sensory Integration Therapy (SIT), Facilitated Communication and Craniosacral Therapy. While these interventions may often appear to be scientifically-based, there is little to no sound research to support their use. In addition, some of these interventions are marketed to look like behavioral treatments, but lack substantial evidence. Other interventions even have evidence to contraindicate their use in clinical populations (e.g., facilitated communication).

While behavioral intervention is a good, empirically-supported starting point, it does not necessarily preclude the use of "alternative" interventions. Rejecting other types of intervention without understanding and evaluating them is problematic for several reasons. First, the *absence* of supporting evidence is not the same as evidence *against* an intervention. One of the main problems with the new and emerging treatments for autism is that limited research has been done to either validate or invalidate these interventions. The primary burden of validation/ invalidation of these treatments should fall upon the shoulders of practitioners in the field using these interventions and to some extent, the scientific communities in general. Complicating this further is the fact that scientific journals do not typically publish negative research findings. In other words, research indicating that particular treatments are not effective may not be accepted for publication because of a journal's bias to only print positive findings/results. Another complicating factor is the individual variability of response to different treatments for autism. As mentioned previously, autism is a complex disorder with a variety of different etiologies that may affect response to treatment. It is often the case that strategies that work well for one individual do not translate well to other individuals. Practitioners should approach the intervention process with an objective mind. Rather than dismissing alternative approaches to intervention, practitioners should take to opportunity to study these interventions and systematically eliminate components/ interventions that are not effective.

In addition to educating themselves about alternative interventions, practitioners and parents should critically evaluate the effectiveness of the intervention process. It is often the case that people do not use systematic designs to assess the effectiveness of alternative treatments. Implementing treatments in a reversal (ABAB) design or multi-element designs can provide valuable information regarding the efficacy of treatments.

In addition, a variety of behavioral measurement procedures, such as observational data coding, preference and reinforcer assessments, and functional analyses, can be viable ways to evaluate the effects of these interventions. Using behavioral measures for the purpose of evaluation can allow for testing some of these alternative interventions to determine if there is a clinically significant benefit. Such procedures could allow parents and practitioners to determine the effectiveness of interventions and discontinue components or interventions that are ineffective.

Alternative therapies are going to be part of the autism treatment landscape for the years to come. It is the responsibility of both parents and practitioners to become informed consumers of autism services. It is important to critically review the validity of proposed treatments, read the literature (peer-reviewed articles rather than testimonials or anecdotal reports) and look for scientific evidence of benefit, potential health risk, and financial or time cost of all treatments. While the temptation to "leave no stone unturned" may seem appealing, wasting precious time with ineffective interventions may prevent learners from maximizing their potential.

In summary, there exists a wide variety of behavioral and non-behavioral interventions for learners on the autism spectrum. Some of these interventions have garnered empirical support (i.e., ABA, some psychotropic medications) while many have not be studied thoroughly enough to validate the effectiveness for their use. Unfortunately, many treatments that are ineffective persist because they often promise miraculous results and/or are easy to use. The best solution is for parents and practitioners to educate themselves regarding these alternative therapies and critically evaluate the effectiveness of these interventions. In doing this, parents and practitioners can ensure the best possible intervention for their learners, prevent time, money and resources from being wasted and can ultimately help others through the process by sharing their findings with others.

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ascend as primary sensory neurons, and synapse in a brain structure called the medulla. Secondary sensory neurons then ascend in a bundle called the medial lemniscus, and synapse in another brain structure called the thalamus. Information is then sent to the somatosensory cortex where it reaches awareness.

The inferior olivary nucleus, which resides in the medulla, receives information from an offshoot of the above pathway. This nucleus sends information via climbing fibers into the cerebellum and each synapses onto several Purkinje cells. The inferior olivary nucleus also receives input termed "efference copy," which is a copy, or representation of motor innervations, sent down from motor planning areas. This information is also relayed to the cerebellum via climbing fiber input.

The cerebellum, which is involved in predicting the sensory consequences of motor actions, uses the climbing fiber input as a comparator between predicted and actual sensory stimuli. When actual sensory input via the afferent nerves matches the predicted sensory input from top-down efference copy, the cerebellum attenuates the somatosensory response. Neurophysiological data show that active (predicted) touch is "gated" in primary somatosensory cortex of rats and monkeys compared to passive and external (unpredicted) touch of an identical tactile stimulus. This attenuation presumably protects the organism from an overload of sensory input during motor activity and also explains the clinical phenomenon that people cannot tickle themselves.

Functional Imaging and Touch

A group of researchers in England used fMRI to study such brain activity in healthy adults in response to self-produced and externally produced tactile stimuli and found that the secondary somatosensory cortex (S2) becomes less active when responding to a self-produced tactile stimulus and more active in response to an identical, but externally produced tactile stimulus. This pattern of response reflects the brain's capacity to predict and attenuate the sensory consequences of self-produced motor actions. The same authors conducted a PET study, also in healthy adults, which demonstrates that the cerebellum is involved in such sensory predictions: right lateral cerebellar cortex activity attenuates as the delay between movement of the right hand and the subsequent touch of the left palm decreased (via a robotic interface). The shorter the delay, the less of a discrepancy between actual sensory input and "predicted" efference copy leading to more gating of the somatosensory response.

Our study uses fMRI to measure neural activity in response to self-produced tactile stimuli in autistic adolescents and healthy controls. As outlined above, such stimuli are known to produce attenuation in the cerebellum and secondary somatosensory cortex in healthy adults. This attenuation reflects the capacity to predict the sensory consequences of self-produced motor actions. We have piloted a functional MRI protocol that examines brain activity in response to self-produced tactile stimulation. This preliminary data suggests that some autistic subjects may have impairment in the capacity to predict and then attenuate sensory consequences of self-produced movement. We are actively recruiting adolescents for this study. Participants will receive a free diagnostic evaluation including a psychiatric evaluation, ADOS and ADI-R, the opportunity for a free genetic evaluation, and reimbursement for their time.

Parents who are interested in finding out more can call the Seaver Autism Center at (212) 241-2826 or contact the author: david.grodberg@mssm.edu.

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the condition. In addition to IBR, collaborators in the project consist of the NFXF; the Association of University Centers on Disabilities (AUCD), and the Data Coordinating Center at Columbia University.

W. Ted Brown, MD, PhD, is the Director of the New York State Office of Mental Retardation and Developmental Disabilities' Institute for Basic Research and its George A. Jervis Clinic located on Staten Island, New York.

References

Bear, M.F., Huber, K.M., & Warren, S.T. (2004). The mGluR theory of fragile X mental retardation. *Trends in Neuroscience*, 27, 370-377.

Berry-Kravis, E., Hessl, D., Coffey, S., Hervey, C., Schneider, A., Yuhas, J., Hutchison, J., Snape, M., Tranfaglia, M., Nguyen, D.V., & Hagerman, R. (2009). A pilot open label, single dose trial of fenobam in adults with fragile X syndrome. *Journal of Medical Genetics*, 46, 266-271.

Bilousova, T.V., Dansie, L., Ngo, M., Aye, J., Charles, J.R., Ethell, D.W., & Ethell, I.M. (2009). Minocycline promotes dendritic spine maturation and improves behavioural performance in the fragile X mouse model. *Journal of Medical Genetics*. 46, 94-102.

Dölen, G., Osterweil, E., Rao, B.S., Smith, G.B., Auerbach, B.D., Chattarji, S., & Bear, M.F. (2007). Correction of fragile X syndrome in mice. *Neuron*, 56, 955-962.

D'Hulst, C., De Geest, N., Reeve, S.P., Van Dam, D., De Deyn, P.P., Hassan, B.A., & Kooy, R.F. (2006). Decreased expression of the GABAA receptor in fragile X syndrome. *Brain Research*, 1121, 238-245.

El Idrissi, A., Ding, X., Scalia, J., Trenkner, E., Brown, W.T., & Dobkin, C. (2005). Decreased GABA(A) receptor expression in the seizure-prone fragile X mouse. *Neuroscience Letters*, 377, 141-146.

Harris, S.W., Hessl, D., Goodlin-Jones, B., Ferranti, J., Bacalman, S., Barbato, I., Tassone, F., Hagerman, P.J., Herman, H., & Hagerman, R.J. (2008). Autism profiles of males with fragile X syndrome. *American Journal of Mental Retardation*, 113, 427-438.

Pacey, L.K., Heximer, S.P., & Hampson, D.R. (2009). Increased GABA(B) receptor-mediated signaling reduces the susceptibility of fragile X knockout mice to audiogenic seizures. *Molecular Pharmacology*. 76, 18-24.

Yan, Q.J., Rammal, M., Tranfaglia, M., & Bauchwitz, R.P. (2005), Suppression of two major Fragile X Syndrome mouse model phenotypes by the mGluR5 antagonist MPEP. *Neuropharmacology*, 49, 1053-1066.

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intervention strategies, providing critical information to support parents in making informed choices about interventions.

On the forefront of genetics research, recent advances give increasing support to the idea that ASD is a disorder affecting the junctions between brain cells, called synapses, which transmit electrochemical signals from one cell to one another. Researchers have identified common genetic variations (Weiss et al. 2009, Wang et al. 2009), changes in chromosomal structure in specific genomic regions (Marshall et al., 2008; Kumar et al., 2008; Weiss et al., 2008), and rare mutations in several different genes all associated with synaptic connectivity (Alarçon et al., 2008; Bakkaloglu et al., 2008) that appear to play a role in ASD. This converging evidence indicates that abnormalities of the synapse may contribute to core symptoms of ASD.

Scientific advances in understanding ASD may also provide the first step in discovering effective drug therapies for autism and related developmental disorders, for which there are few existing pharmacological treatment options. Genetic syndromes that involve autism, such as Fragile X, Rett syndrome, and tuberous sclerosis, have each provided new candidates for treatment based on extraordinary findings in mice engineered to have the mutation that causes the disease in humans. As one example, scientists found that the drug rapamycin, an immunosuppressant drug normally used to prevent organ rejection after transplant, reduces neurological symptoms in mice with a genetic mutation that causes tuberous sclerosis complex (TSC), a rare genetic disorder that often co -occurs with mental retardation, epilepsy, and autism (Ehninger et al. 2008). Researchers were able to reverse learning and memory deficits in adult mice carrying the TSC mutation, suggesting that cognitive deficits resulting from TSC are caused by reversible changes in brain function rather than permanent damage to the developing brain. While Fragile X, Rett, and TSC are not common disorders, these recent results in mice have fueled the hope that many of the symptoms of ASD could also be reversible with an appropriately targeted treatment, even in adulthood.

Each year the IACC prepares a report called the IACC Summary of Advances in ASD Research that identifies important advances in ASD research. The 2007 and 2008 IACC Summary of Advances reports are available at www.iacc.hhs.gov/summary-advances.

IACC Strategic Plan for ASD Research

In January 2009, the IACC issued the first federal strategic plan for ASD research, developed through an extensive process engaging a wide range of federal agencies and public stakeholders. During this process, the IACC convened scientists and clinicians to participate in four workshops to identify research opportunities, as well as expert workgroups to recommend research objectives for the plan. The committee also sought much public input on ASD research priorities through means such as town hall meetings and Requests for Information.

The 2009 plan is organized around six important questions for people with ASD and their families related to diagnosis, the biology of autism, risk factors, treatments and interventions, services and supports, and questions about issues faced by adolescents, adults, and seniors with autism and their families. Each question is followed by a brief discussion of what is currently known and what more is needed through research. The plan lays out a broad set of research objectives, including several objectives that address biomedical aspects of ASD, as well as objectives that address services research issues.

The 2009 IACC Strategic Plan for ASD Research can be viewed at www.iacc.hhs.gov/reports.

Fortuitously, the 2009 strategic plan was released just before the passage of the American Recovery and Reinvestment Act (ARRA) in March 2009, which included funds to advance biomedical research. NIH used a portion of its ARRA funds to jumpstart implementation of objectives laid out in the IACC Strategic Plan. In spring 2009, NIH issued a Request for Applications (RFA) on the heterogeneity of ASD, a theme taken from the plan, to solicit research proposals for potential funding under ARRA.

In September 2009, NIH awarded more than 50 autism research grants, totaling more than $65 million. ASD projects to be funded over the next two years under ARRA include research on rapid screening instruments, identifying at-risk children, identifying biomarkers for early diagnosis, studying epigenomics to understand how environmental risk factors may interact with the genome to cause ASD, researching services for individuals in urban areas, and understanding autism in the second half of life. Importantly, other ARRA funds, outside of the heterogeneity RFA, will also support new autism research, with the total expected to surpass $90M from the stimulus package. Along with increased commitments to autism research in the regular NIH budget, as President Obama said in a recent speech at NIH, this is the "largest ever infusion of funds into autism research." With these new funds, scientists "will have the opportunity to study genetic and environmental factors of a disease that now touches more than 1 in 150 children, What we learn will hopefully lead to greater understanding, early interventions, and more effective treatments to allow these children to live their lives and achieve their fullest potential."

Updating the IACC Strategic Plan for 2010

Currently, the IACC is in the process of updating the strategic plan for 2010, as required by the CAA. To understand the ASD research funding landscape, the IACC conducted the first comprehensive accounting of all public and private research for ASD. Information from 19 Federal and private funders of ASD research was collected and analyzed to determine how investments corresponded to the research objectives in the 2009 strategic plan. Based on this analysis, more than $222 million dollars went to ASD research in 2008, with 65% of the funds coming from the federal government [Figure 1]. All of the six "question" areas of the strategic plan were covered, with risk factor and treatment research garnering 37% and 24% of the total funding, respectively [Figure 2].

Future progress fulfilling the objectives of the strategic plan will be tracked using the yearly portfolio analysis.

The portfolio analysis and public responses to a Request for Information and a town hall meeting were used as resources during the IACC Scientific Workshop convened on September 30 and October 1, 2009 in Bethesda, MD. Prominent autism researchers, clinicians, and personal stakeholders (including people with ASD) were selected by the committee to provide input on individual chapters of the plan, identifying research gaps and opportunities, and prioritizing the research objectives. Themes that were reiterated throughout the workshop, such as the need to include a focus on nonverbal individuals with ASD and to increase emphasis on adults with ASD, have been taken into account during the plan updating process.

To date, the IACC has succeeding in putting an initial framework in place for ASD research with its strategic plan and has provided the first comprehensive overview of the funding landscape. In the coming year, the committee will update the strategic plan, release a new summary of recent scientific advances, and conduct another portfolio analysis of research funding. With its continued efforts, the IACC is working to enhance and accelerate ASD research that will benefit people with ASD across the lifespan and the communities that support them.

References

Alarçon M, et al. Linkage, association, and gene-expression analyses identify CNTNAP2 as an autism-susceptibility gene. *Am J Hum Genet.* 2008 Jan;82(1):150-9.

Bakkaloglu B, et al.. Molecular cytogenetic analysis and resequencing of contactin associated protein-like 2 in autism spectrum disorders. *Am J Hum Genet.* 2008 Jan;82(1):165-73.

Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders--autism and developmental disabilities monitoring network, 14 sites, United States, 2002.

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators. *MMWR Surveill Summ*. 2007 Feb 9; 56(1):12-28.

Dawson G, et al. Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model. *Pediatrics*. Epub 2009 Nov 30.

Ehninger, D., et al. (2008). "Reversal of learning deficits in a Tsc2+/- mouse model of tuberous sclerosis." *Nat Med* 14 (8): 843-8. Epub 2008 June 24.

Kogan MD, Blumberg SJ, Schieve LA, Boyle CA, Perrin JM, Ghandour RM, Singh GK, Strickland BB, Trevathan E, & van Dyck PC. Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics*. 2009 Nov; 124(5):1395-403.

Wang K,et al. Common genetic variants on 5p14.1 associate with autism spectrum disorders. Nature. 2009 May 28; 459(7246):528-33.

Weiss LA, et. al. A genome-wide linkage and association scan reveals novel loci for autism. Nature. 2009 Oct 8; 461(7265):802-8.

Weiss LA,et al. Association between microdeletion and microduplication at 16p11.2 and autism. *N Engl J Med*. 2008 Feb 14; 358(7):667-75.

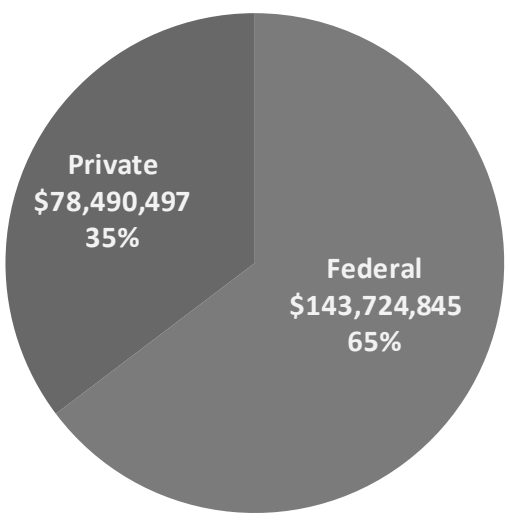

Figure 1. 2008 ASD research funding by type of agency/ organization: public vs. private [Total = $222,215,342].

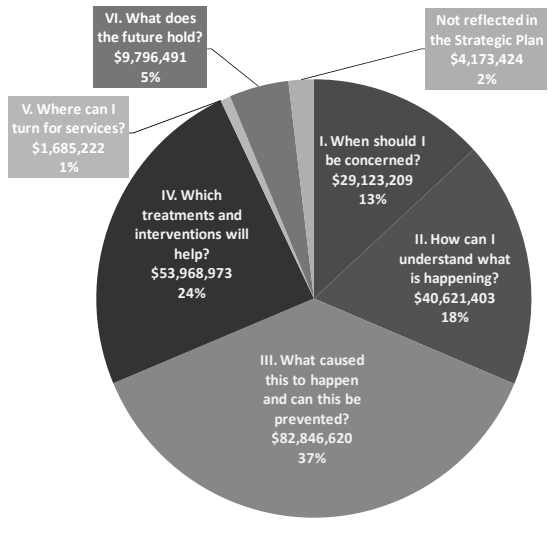

Figure 2. 2008 ASD research funding by IACC Strategic Plan question [Total = $222,215,342].

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clusters. Social and Communication form one factor, Unusual Behavior a second and Self Regulation forms a third. This structure is, however, consistent with more recent conceptualizations by autism researchers such as Gillberg (1990), and is supported by a number of recent studies (Gotham, et al., 2007, 2008). Similarly, the new Autism Diagnostic Observation Schedule (ADOS) algorithm combines social and communication symptoms into a single domain and restrictive and repetitive behaviors as a second domain. It is likely that large scale samples like those used for the ASRS and the ADOS will have an influence on the future structure of the DSM-IV diagnostic criteria for ASD. Results from the school age version of the ASRS further extends the conceptualization of ASD by finding that self -regulatory behaviors are also key characteristics for this population. We augmented these empirically derived scales with treatment scales based on an analysis of the content of the items in order to assist in the planning and monitoring of interventions (Peer Socialization, Adult Socialization, Social/Emotional Reciprocity, Atypical Language, Stereotype, Behavioral Rigidity, Sensory Sensitivity and Attention).

The ASRS Manual also includes a number of important validity findings. For example, the mean scores of groups of children described as a general population, ASD, ADHD and other clinical samples show an important pattern. For both parent and teacher raters, children diagnosed with ASD earned very high scores on all scales. The ASRS Total standard score was over 70 for both raters, indicating that the children earned on average a total score that is more than two standard deviations above the general population mean. The ASD sample also earned scores that were very different from the other clinical groups whose scores were similar to the general population in many ways. A striking finding, however, was that for both parent and teacher ratings on the school age form, children with ASD and ADHD earned almost identical scores on both the Self-regulation and Attention scales. These findings suggest that children with ASD and/or ADHD demonstrate similar levels of self-regulatory and attention problems, consistent with recent research (Goldstein and Schwebach, 2004; Aisling, et al., 2009). The ASRS, however, still differentiates between ASD and ADHD because in addition to elevated Self-regulation scores those with ASD also demonstrated very high scores on the Social/Communication and Unusual Behavior scales. Overall, these results indicate that scores on the ASRS can accurately distinguish not only ASD groups from the general population but also differentiate between ASD and other clinical groups.

A fifteen-item ASRS short form was also developed to meet the need for a brief but effective tool for screening children for ASD related behaviors. Items were selected to maximize the ability of the short form to differentiate children with an ASD from those in the general population. The short form has strong reliability (alpha was > .90 across all forms and rater types) which is similar to results found on the full length ASRS. When comparing Short Form ratings of children in the general population to ratings of children with an ASD or another clinical disorder, ratings of the ASD group earned the highest scores with mean values more than two standard deviations above the mean for this group.

The quality of rating scales used in clinical and educational practice impacts the quality of the information provided. Reliable and valid tools lead to reliable and valid clinical and educational decisions. In the field of ASD, the ASRS provides the first norm referenced, well-standardized assessment that has reliability and validity information in the test Manual to complement the evaluation and diagnostic process for ASD. The data that has been summarized here and which is more extensively presented in the Manual suggests that the ASRS is a valuable tool to guide clinical diagnosis and educational eligibility decisions as well as designing treatment programs and monitoring progress. This instrument will also find wide use in research contexts and for screening purposes in large populations of at risk children.

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References

Aisling, M. A., Anney, R. J. L., O'Regan, M., Chen, W., Butler, L., Fitzgerald, M., et al. (2009). Autism symptoms in Attention-Deficit/Hyperactivity Disorder: A familial trait which correlates with Conduct, Oppositional Defiant, Language and Motor Disorders. *Journal of Autism and Developmental Disorders, 39,* 197-209.

Gillberg, C. (1990). Autism and pervasive developmental disorders. *Journal of Child Psychology and Psychiatry,* 31, 99-119.

Goldstein, S., & Naglieri, J. A. (2009). Autism Spectrum Rating Scale. North Tonawanda, New York: Multi Health Systems

Goldstein, S., Naglieri, J. A. and Ozonoff, S. (2009). Assessment of Autism Spectrum Disorders. New York: Guilford Press

Goldstein, S., & Schwebach, A., (2004). The comorbidity of Pervasive Developmental Disorder and Attention Deficit Hyperactivity Disorder: results of a retrospective chart review. *Journal of autism and Developmental Disorders, 34,* 329-339.

Gotham, K., Risi, S., Dawson, G., Tiger-Flusberg, H., Joseph, R., Coarter, A., et al. (2008). A replication of the Autism Diagnostic Observation Schedule (ADOS) Revised Algorithms. *Journal of the American Academy of Child and Adolescent Psychiatry, 47,* 642-651.

Gotham, K., Risi, S., Pickles, A., & Lord, C. (2007). The Autism Diagnostic Observation Schedule: Revised algorithms for improved diagnostic validity. *Journal of Autism and Developmental Disorders, 37,* 613-627.

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order to advance our understanding of the extent to which a measure can be considered evidence-based. The clinical use of psychometrically sound instruments can assist in the well-being of individuals affected with ASD. In addition, such instruments are needed to further our understanding of the nature of the autism spectrum disorder(s). Multidimensional scales may prove to be invaluable in research on autism subtypes. Future work (e.g., taxometric research) utilizing psychometrically sound measures can be used to examine individual variation within the autism spectrum and investigate whether we can distinguish between differences in type of ASD and differences in degree of ASD. Such work has implications for research on cause, risk factors, course, and treatment.

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References

Achenbach, T.M. & Rescorla, L.A. (2000). *Manual for the ASEBA Preschool Forms & Profiles*. Burlington, VT: University of Vermont, Research Center for Children, Youth, and Families.

Achenbach, T.M. & Rescorla, L.A. (2001). *Manual for the ASEBA School-Age Forms & Profiles*. Burlington, VT: University of Vermont, Research Center for Children, Youth, and Families.

American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders: Fourth Edition Text Revision*. Arlington, VA: Author.

DeBruin, E.I., Ferdinand, R.F., Meester, S., deNijs, P.F.A., & Verheij, F. (2006) High rates of psychiatric co-morbidity in PDD-NOS. *Journal of Autism and Developmental Disorders, 37,* 877-886.

DiLalla, D.L. & Rogers, S.J. (1994). Domains of the Childhood Autism Rating Scale: Relevance for diagnosis and treatment. *Journal of Autism and Developmental Disorders, 24(2),* 115-128.

Gilliam, J.E. (2006). *Gilliam Autism Rating Scale: Second Edition.* Austin, TX: Pro-Ed.

Interagency Autism Coordinating Committee (2009). *The Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder Research (August 15, 2008).* http://www.nimh.nih.gov/research-funding/scientific meetings/recurring-meetings/iacc/strategic-plan/index.shtml.

Kraijer, D. & de Bildt, A. (2005). The PDD-MRS: An instrument for identification of autism spectrum disorders in persons with mental retardation. *Journal of Autism and Developmental Disorders, 35 (4),* 499-513.

Magyar, C.I. & Pandolfi, V. (2007). Factor structure evaluation of the Childhood Autism Rating Scale. *Journal of Autism and Developmental Disorders, 37,* 1787-1794. doi: 10.1007/s10803-006-0313-9.

Pandolfi, V., Magyar, C.I., & Dill, C.A. (2009). Confirmatory factor analysis of the Child Behavior Checklist 1.5-5 in a sample of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39,* 986-995. doi: 10.1007/s10803-009-0716-5.

Pandolfi, V., Magyar, C.I., & Dill, C.A. (in press). Constructs assessed by the GARS-2: Factor analysis of data from the standardization sample. *Journal of Autism and Developmental Disorders.*

Pandolfi, V., Magyar, C.I., & Dill, C.A. (in preparation). Confirmatory factor analysis of the Child Behavior Checklist 6 -18 in a sample of youth with autism spectrum disorders.

Stella, J., Mundy, P., & Tuchman, R. (1999). Social and nonsocial factors in the Childhood Autism Rating Scale. *Journal of Autism and Developmental Disorders, 29(4),* 307-317.

Rutter, M., Bailey, A., Lord, C. et al. (2003). *Social Communication Questionnaire*. Los Angeles: Western Psychological Services.

Reilly, C. (2009). Autism spectrum disorders in Down syndrome: A review. *Research in Autism Spectrum Disorders, 4,* 829-839. doi: 10.1016/j.rasd.2009.01.012.

Schopler, E., Reichler, R.J., & Renner, B.R. (1988). *The Childhood Autism Rating Scale (CARS).* Los Angeles: Western Psychological Services.

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work on the postmortem brain obtained from a young man with autism who had died by accidental drowning. This case had been available for study for five years and had remained uninvestigated. That was the summer of 1983. So I started to analyze the stained sections of this case using a comparison microscope – essentially two microscopes put side-by-side and connected by a bridge, thus allowing the evaluation of two separate brain sections, side-by-side. Using this microscope, we were able to look at identical sections of an age and sex-matched control case and the autism brain. It quickly became very clear that there were some distinct anatomical abnormalities in the autistic brain. The results of our study of this autism brain were subsequently reported at the meeting of the American Academy of Neurology in the spring of 1984. This was the first detailed report of brain abnormalities in the autistic brain. We received many letters from parents and families of autistic individuals that basically said, "Thank you for proving that this isn't the result of bad parenting." Up to that point, Bruno Bettelheim's "refrigerator mother" theory was still a widespread belief and suggested that autistic behaviors stemmed from the emotional frigidity of the children's mothers.

Following this initial study, we were told that we should seek funding from the NIH to continue our investigations of the autistic brain. We tried to submit some grants to the National Institute of Health but they weren't interested. At that time, there were very few postmortem autism brains available for study and it cost approximately $6,000 to embed, section and stain just one brain. I then met Mrs. Nancy Lurie Marks, the person who has recently given a substantial gift to support and expand the current LADDERS/MGH program. Mrs. Marks was the first person who funded our neuroanatomic research and was the person who really helped me to get started in my research career, a career path that I continue to enjoy to the present time. Our techniques have changed with the advancement in technology but we continue to seek a better understanding of the neurobiology of the autistic brain and its impact on behavior, cognition, language and social interaction.

Early in my clinical career, I was particularly interested in working with children with learning disabilities. In 1981, I was recruited by the Youville Hospital in Cambridge, MA to lead their then fairly small outpatient children's rehabilitation clinic. Over time, the program grew and eventually was moved out of the main hospital into their school of nursing. The program continued to grow and began to include children with learning disabilities and other developmental disorders. Following the publication of our basic science research relating to studies of the autistic brain, the referrals of children with autism and related disorders began to increase and eventually became the majority of patients seen at LADDERS. Although the program is largely known because of its work with children, adolescents and adults with autism, LADDERS continues to see patients of all ages with a wide variety of learning, neurological and developmental disorders.

Q: What are your thoughts on the dramatic rate of increase of autism spectrum disorders?

A: There are a number of opinions as to why there appears to be a dramatic increase in children diagnosed with autism and the truth is that no one really knows for sure. Back in the 70s and 80s, the terms "Asperger's syndrome" and "Pervasive Developmental Disorder" were not available or used. At that time, most of the children labeled as "autistic" were those who would sit in a corner, rock back and forth, demonstrate poor eye contact and arms flapping and were non-verbal. LADDERS sees approximately 4,000 patient visits annually. It is an extremely rare day that we see such a child anymore. Where did those children go? We could hypothesize that we are identifying children at risk much earlier and providing them with intensive interventions, thus essentially avoiding or eliminating the previously characteristic severe behaviors in the majority of autistic children. Alternatively, we could hypothesize that "autism" as we once knew it, has really declined in prevalence. What we once called the kind of child who came to most of us in the office now, is hard to define in retrospect. Some may have simply been called "mentally retarded." Others may have been considered to have had "Childhood Schizophrenia," a term which is rarely, if ever, used now.

It should also be recalled that, until the middle to late 80s, the cause of "autism" was blamed on poor mothering or the "refrigerator mother," a term coined by Bruno Bettleheim. Thus, if a child was labeled "autistic" it was assumed that it was his mother's fault. Understandably, giving a child this diagnosis was difficult at best and often resulted in the institutionalization of that child. School and home-based programs as we now know them did not exist. Happily, since that time, research has shown us that autism is a neurodevelopmental disorder and much of the data suggests that it begins before birth. Further, clinical research has helped to develop clinical measures and observational tools that allow us to fairly accurately diagnose children at risk for autism as early as 14 months of age. Newer tools are in the process of development that, if perfected, may allow us to identify high risk children as early as 6 months of age. There are now numerous studies which have shown the significant benefits of intensive early intervention programs for ASD children and the improved developmental outcomes when such services are provided. Currently, a child carrying an ASD diagnosis is eligible, in most states in the United States, for intensive intervention services. With the knowledge that these services exist and can be provided and that, if provided, outcomes are likely to improve, it is substantially less difficult to make and provide an ASD diagnosis to a child than it was 25-30 years ago.

Potentially further escalating the numbers has been the inclusion of Asperger's Syndrome among the Pervasive Developmental Disorders. Formerly, some of these people were considered very bright but socially "quirky." I think we are also recognizing that there is a genetic component to the autism spectrum disorders and we are very cognizant that younger siblings of autistic children may be at high risk. Screening measures are now being recommended for all children at 12-14 months of age.

There is still the issue as to whether or not there might be a role for environmental factors as a contributor to the escalating numbers. This remains a largely unanswered question to date. Happily, some very good research is in progress to address this question. If environmental factors are important, we need to define which ones and to determine if some children/families may be a higher risk than others with regard to the effects of exposure to certain environmental substances.

Q: Do auto-immune factors play a role in the development of autism?

A: This is a very interesting and potentially important area of investigation in autism. Research into the possible role of immune factors is relatively new and can best be described as a "work in progress." Several research groups are working to advance our knowledge in this area. The M.I.N.D. Institute at UC Davis in Sacramento, California has been looking at antibodies and autoantibodies in mothers having ASD children. Another group at Johns Hopkins in Baltimore, Maryland has been looking at postmortem brain tissue and the role of "inflammation" and the immune system in the etiology of autism. Both of these groups, as well as others, are looking at the role of prenatal immune factors and their potential effect on brain development. Anatomical studies of the postmortem brain, including our own, strongly suggest that ASD has its onset before birth. The fact that symptoms do not immediately become evident at birth probably reflects the fact that the brain circuitry that is disordered in autism is not fully operational and functional at birth and only comes "on line" over time, as the result of the developmental process in the brain. It is certainly possible that a subset of ASD persons may develop the syndrome as the result of immune factors and their impact on brain development, but no definitive answers are as yet available.

Q: Where would you like to see research develop from where we are now?

A: Most of us who are involved in either clinical or basic science, as it relates to autism and regardless of our area of expertise or the technology that we are using, are looking at the end-product of events that probably began before birth. Thus, cranial imaging, neurophysiological measures using EEG or MEG, genetic research on ASD subjects and their families, language, cognitive, behavioral or motor assessments, as well as neurochemical and neuroanatomical studies of postmortem brain, are all looking at the "down-stream effect" of events that were probably set in motion very early in life. While these studies are extremely valuable with regard to what they can tell us about correlations between neurobiology and function, for the most part they tell us very little about how the ASD process might have begun. This is where I would like to see future research devote more of its efforts. Some research groups are beginning to look for potential early biomarkers, through studies of maternal blood during pregnancy, and from placental and umbilical cord blood obtained from the high risk child (usually an autism sibling) at birth. It will be interesting to see where some of these investigations begin to take us.

Q: Is there still a lot that science needs to find out about what is happening as the brain is developing in utero?

A: Yes, there is much that we still don't know, and that fact that ASD appears to be heterogeneous in its causes and its clinical presentation, makes the challenge of understanding the autistic brain all the greater. I believe that we are making progress as we begin to better define and look at subsets of ASD persons clinically. However, it must be said that, while we lack a good deal of knowledge about the autistic brain, we know almost nothing about other organ systems in this disorder. As we begin to look at the ASD population more broadly, it is becoming clear that multiple organ systems appear to be involved, at least in a significant subset of ASD persons. In recent years, for example, abnormalities of the gastrointestinal tract in ASD have captured the interest of more researchers. Most of the neurotransmitters present in the brain are also present in the gut. In fact, Serotonin, a neurotransmitter long of interest in autism, is generated in the gut. In addition, there is now some evidence, based on some research from Vanderbilt University Medical Center, that the MET gene may be a marker for the presence of gastrointestinal disorders in ASD persons. There is also some evidence that a subset of ASD children may also have Mitochondrial disorders which would suggest that the children so affected would of necessity, be genetically different and distinct from those without a Mitochondrial dysfunction. Other medical avenues that may be important in the overall health of the ASD person as well as expanding our understanding of the biology of the disorder include hormonal factors, the role of allergies, sleep disturbances, and obstructive airways due to enlarged tonsils and adenoids to name a few. By looking more closely at these and other organ systems, it is possible that we might learn more about the neurobiology of ASD as a whole, and this may help us further clinically phenotype groups of ASD persons into more cohesive subgroups for study. In addition, many of the disorders of these other organ systems are treatable. By dealing with these medical issues, those affected will feel better from a health perspective, and as a result, are likely to do better in their programs and therapies.

Q: What are you currently working on in your own research?

A: I am involved in both clinical research and basic science research. Our basic research over the past 25 years has been devoted to the study of the postmortem autistic brain. Currently, we are collaborating with a group in Rome, Italy on a study related to the potential effect of estrogen as a neuroprotective substance. Our colleagues in Rome have an animal model in which the Purkinje cells of the cerebellum in their female rats appear to be preserved while those in the males are markedly decreased in number. Purkinje cells are the brain's primary inhibitory neurons. In most of the human autistic brains studied to date, there has been a marked decrease in the number of these Purkinje cells. At this time, it is not known whether they never arrived to their

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final destination in the brain during development or whether something happened to them after they arrived at their final location in the cerebellum. Thus, given the sex differences in the rodent model, the question being asked is, "Is estrogen neuro-protective?" If it is, even partially, might this explain why there are more males than females affected with ASD? Our role in this project is to the study the Purkinje cell populations of both male and female postmortem ASD brain and age and sex-matched controls and to compare our results with that observed in the animal model.

We are also working with colleagues at Duke University who are interested in auditory gaiting. This study has to do with auditory sensitivities, symptoms which are often observed in ASD. The Duke researchers have created an animal model in which auditory gaiting is impaired and then have tried to correct it through the use of medications. Our role is to examine the rodent brains from these animals, both treated and untreated, to determine what microscopic structural abnormalities might exist to explain the behavioral findings. The ultimate goal is to try to define therapies that might help ASD persons and others who may have significant auditory sensitivities.

Additional studies include collaborations with Dr. Gene Blatt, one of our colleagues at Boston University School of Medicine, in which we are looking at the anterior cingulum, cerbellum and language areas in the postmortem autistic brain in comparison with controls.

On the clinical side, we have a baby siblings project in conjunction with the Kennedy Krieger Institute in Baltimore, MD. In these studies, we are assessing younger siblings of children with autism. We are in the second stage of this project. The first stage was to evaluate these autism siblings from ages 6 months - 3 years. We are now looking at the same group of children at ages 4 - 8 years to evaluate development outcomes over time.

We are also involved with colleagues at Vanderbilt University Medical Center with regard to the gastrointestinal tract and the role of the MET gene. We are also part of the Boston Autism Consortium, a group involving all of the major teaching hospitals in the Boston area, in a project devoted to the genetic analysis of ASD children and their families. In addition, we are involved in a number of projects under the auspices of the Autism Treatment Network (ATN), a group of academic centers in the United States and Canada, dedicated to the investigation of medical disorders which may be co-morbid in autism.

Q: Has any recent research made a causal relationship that some cases of autism are manifestations of early onset bipolar disorder?

A: There was an early study conducted by G. Robert DeLong, MD, then at Duke University, in which there appeared to be a connection between the presence of family members with bipolar disorder and depression and the prevalence of ASD children in these same families. This is a pattern that continues to be observed in some of our families and may reflect a genetic risk factor in these families. More research in this area is needed before any direct conclusions can be made.

Since 1996, we have convened an annual group of closed door "Think Tanks" in which researchers from differing backgrounds and expertise come together to discuss their respective studies. It is an unusual opportunity to hear from others outside of one's own area of interest and to see how differing pieces of the research puzzle may begin to fit together into a whole. The group usually consists of representatives from 15-20 labs from the United States and Canada. It is our hope that each will learn from the other and that collaborations will develop to benefit the field as a whole.

Q: Did anything interesting come out of this year's annual meeting?

A: We heard more about the studies related to immune factors. We also learned more about the estrogen work from the group in Rome and about the potential role of Mitochondrial disorders in ASD. We heard about the studies from the Johns Hopkins group relative to their findings and probable significance of the presence of inflammatory abnormalities in the autistic brain and more about the role of Gamma Amino Butyric Acid (GABA), the brain's primary inhibitory neurotransmitter. My belief is that we, as research scientists and clinicians can no longer work in our respective silos. That approach isn't working. We need to learn what others are doing and increase our interdisciplinary collaborations in order to begin to solve the puzzle of autism. That is what this meeting is all about and I am pleased to be able to report that many collaborations have been developed as a result of these gatherings and several important papers have been published as a result. I hope there will be many more.

Q: Do you think the solution to the puzzle of autism is near or may we not find the key for many years?

A: Over the past 20-25 years, the field has grown enormously, thanks to greater awareness and more research funding. However, we still have a very long way to go. As mentioned previously, autism is a behaviorally defined syndrome that probably results from multiple different causes. Because of the marked clinical variability among those with the disorder, we need to do a much better job defining our study populations into specifically characterized subgroups. We need to begin to include medically defined subtypes in the description of our study populations - for example those with and without gastrointestinal disorders, those with or without sleep disturbances and so on. Are we including males or females (there is some thought that females with ASD may be biologically different than males with ASD), what age groups should be included and why, and are siblings really "controls?" In short, we need to be more precise when describing our study populations, and descriptors should go beyond language, behavior, and cognition which is primarily what has been described up to this point.

Q: What hopeful message would you like to leave for parents?

A: I think that the emphasis on early identification has made an extremely important difference in how we evaluate and treat children with autism and what our outcome expectations are. The idea that we recognize that younger siblings are at risk, that the field has recognized that, even if you are not a younger autism sibling, if you have some of these early risk signs, a diagnosis can be made and intensive services implemented. There is growing evidence that early identification and intervention can have a very positive effect on developmental outcomes. Unfortunately, good outcomes are not uniform across the spectrum but it is far better than we have been able to achieve in the past. I think that this has been the biggest change over the last few years and I would anticipate continued gains in this area as we learn more about effective interventions in the future. There is a growing subset of children now, who by ages 5, 6 and 7 years, appear to have left their diagnosis behind. Dr. Deborah Fein, PhD, Neuropsychologist at the University of Connecticut recently spoke at our recent "Current Trends in Autism" conference (Natick, Massachusetts) and is currently conducting a study that involves the evaluation of the children who appear to no longer meet the criteria for autism. What is different about those children and why did they succeed whereas others have not? We have more ASD children going on to college, growing up and getting married, and it has been really fun to watch this happen. On the more discouraging side, we still have a small subset of ASD children who, no matter what we do or how much intervention has been provided, simply don't make effective progress. What is it that is holding these children back? These are the children who really bother me. I worry that there must be some other disorder that is complicating their clinical picture or getting in the way of progress that we are missing and haven't figured out yet. If I have one thing that keeps me up at night, this is probably it.

The hopeful story is that early diagnosis, early treatment and intensive services with high quality, experienced professionals, can really turn around many autistic children and can result in much brighter futures for these children and their families. I think this is just really thrilling and wonderful.

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not counted, including the person's primary residence, an automobile of limited value, clothing and personal property, and some other assets that are specifically exempted by law. Some states have increased the permissible asset limit beyond $2,000.00 for Medicaid-only programs, so check with your local state Medicaid agency.

Income Test

Income limits and the calculation of income for purposes of the income test are very complex. Following are some general guidelines. For SSI purposes in 2009, if a person only had earned income (such as salary from a job) and received more than $1,433.00 per month in earned income, the person would lose SSI. If the person only had unearned income (interest, dividends) and received more than $694.00 per month in unearned income, the person would lose SSI (an explanation of the calculation for a person having both earned and unearned income is beyond the scope of this article). If the person was in a state where Medicaid was automatically given to SSI recipients, the person would lose Medicaid as well.

Important to remember: since the financial tests for state Medicaid-only programs may be more lenient, you should check with your local state Medicaid agency with respect to income limits for Medicaid-only programs. A person with disabilities may qualify for Medicaid-only even if the person does not qualify for SSI.

Often, a person with disabilities may meet the asset test, but make a bit too much income to qualify for state Medicaid-only programs. In order to avoid loss of coverage simply because the income is too high, some states have another type of program, sometimes referred to as "Medically-needy" or "Medicaid Spend-down" programs. These programs usually have the same asset test limitations as the Medicaid-only programs, but allow the person with disabilities to spend down excess monthly income on medical expenses until the remaining income is below the state's permissible income limits. Once the excess income is spent in any given month, Medicaid will pick up any additional medical expenses in that month.

These are only a few of the options available for medical coverage afforded to persons with disabilities. Many states have instituted other medical insurance programs for persons with disabilities, beyond Medicaid-only and Medically-needy programs. Always check.