

AUTISM SPECTRUM NEWS™

YOUR TRUSTED SOURCE OF INFORMATION, EDUCATION, ADVOCACY, AND RESOURCES

SUMMER 2009

FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 1 NO. 4

Education for Children and Adults with Autism Spectrum Disorders

Making Inclusion Work for Students with Asperger Syndrome

By Lynda Geller, PhD, Director
Institute for Cognitive Diversity
Bank Street College of Education

Anyone who knows many children and adults with Asperger Syndrome (AS) knows that every person's manifestation of the condition is very different. While they share significant social disability, some are very successful academically, some struggle with accomplishing work; some have intense intellectual interests that lead them to career paths, and others have intense interests that seem to have no practical use; some have a few friendships, others are desperately alone and lonely. Because Asperger Syndrome is an outcome of brain differences in combination with life experiences, no two individuals are exactly alike. Therefore, each student we encounter has different educational needs.

Least restrictive placement is an educational term that means that we want to provide students with the proper level of support for success without placing them in unnecessarily restrictive environments. For students with Asperger Syndrome, we want to provide the level of support that is



necessary to help them optimize their skills and strengths without removing them from typical school experiences, if possible. Some students may need a protective environment if the mainstream educational placement is not healthy for them, while others only need a little support developing their social skills or or-

ganizational issues in a regular education setting. Matching the individual need to the level of support is critical to helping a child gain self-esteem and independence.

What every family with a member with Asperger Syndrome needs to consider is, how are the following issues being addressed?

The Development of Basic Social Skills
and Social Relationship Abilities

School programs and community clinicians often provide social skills training. The quality and type of this training is critical to progress. Many activities called social skills are not based in solid research. Just because someone provides a child with opportunities for social interaction does not make the activity a useful social skills development experience. Specific skills at the child's level of need coupled with opportunities for generalization outside of the formal training situation are necessary components for skill development to occur. Children with Asperger Syndrome typically have had great difficulty acquiring these skills that typical children simply pick up from their environment. We know that those with AS need specific help to perceive, acquire, and generalize basic social skills. Parents should always ask social skills trainers if they are utilizing proven, evidence-based techniques and if their child's individual needs are being specifically addressed. If parents are not involved, a vital link for generalizability is

see *Making Inclusion Work* on page 32

View From the Spectrum - The Sea of Interventions

By Stephen M. Shore, EdD
Executive Director
Autism Spectrum Disorder Consulting

Which approach should I use for my child? Will a behaviorally oriented method such as Applied Behavioral Analysis (ABA) work? Might it be better to use Daily Life Therapy (DLT)? What about some of the developmental ways of working with children on the autism spectrum such as the cognitive systems-based Miller Method (MM) or the affective route that Developmental Individual-difference Relation-based intervention (DIR) Floortime takes? Maybe the Treatment and Education of Autistic and Com-

munication Handicapped Children (TEACCH) approach is more suitable?

These are common questions people ask me at conferences and through emails on which approach to use. Looking for an answer to this question of what approach or approaches to use is part of what inspired me to write my doctoral dissertation on comparing some of the more promising approaches for treating children with autism. All too often I would find persons espousing a particular method to the exclusion of others, and ultimately, to the detriment of children on the autism spectrum.

My literature review revealed a lack of research on comparative approaches. Part of the reason may be political. Another part may relate to the difficulties in find-

ing matched groups to compare different interventions on. While age, and to some extent cognitive functioning, can be matched, the futility of finding children matched for home lives, previous intervention experience, therapist efficacy, medical issues and other areas soon became apparent. Additionally, there are ethical issues in withholding badly needed interventions for the control group.

Rationale for the Study

As of 2008, there have been no studies on comparative approaches for working with children on the autism spectrum. One reason may center on controlling variables and the other is ethical in nature. An evidenced-based study with matched groups

for each of the five methods I studied is warranted. However, difficulties in controlling variables such as previous intervention experience of the child, home life, therapist efficacy, and medical issues quickly made apparent the challenges of obtaining valid and reliable results.

Then there is the ethical question of withholding intervention for the control group for a population where providing intensive support as soon as possible is critical for maximizing developmental potential.

Therefore I decided to open a line of research based on matching best practice to the needs of children on the autism spectrum by gathering information on

see *Sea of Interventions* on page 29

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Autism Spectrum News - Table of Contents

The Publisher's Desk

5 Our First Year - A Look Back and Our Vision for the Future

Autism Spectrum News Desk

6 PA Research Grants From Tobacco Settlement Funds

6 IACC Releases Federal Strategic Plan for Autism Research

7 Putnam ARC Launches Autism Library Collection

7 Autism Speaks Seeks Applications for Grants

Our Cover Story: Education for Children and Adults with Autism Spectrum Disorders

1 Making Inclusion Work for Students with Asperger Syndrome

1 View From the Spectrum - The Sea of Interventions

9 There's No Place Like the Medical Home

9 Finding the Ability in Disability

11 Parents and Professionals: Building Collaborative Partnerships

13 Reducing Behavior Difficulties to Help Children Learn and Grow

15 Team's Perspectives on the Progress of Two Boys

16 Creative Approach to Job Development Pays Off

17 Support Groups Build Connections and Skills for Adults

18 NYS OMRDD - Supporting Education Across a Lifetime

19 New Socialization Services for Children with ASD

20 The Autism Epidemic: A Report on Consultation Services

21 Improving the Generalization of Skills in Learners with Autism

23 The Education of Real Life

25 Planning for Children with Special Needs

26 The Daniel Jordan Fiddle Foundation 2009 Community Grants

27 Creative and Preferred Extracurricular Activities Provide Gains

29 Robin's Voice - A Resilient Mom's Commentary on Autism

30 Bringing Computer Technology to the Forefront in Education

31 Coping with Asperger's in the Home

33 Securing Appropriate and Effective Autism Programs

33 Providing a United Front

34 Premier HealthCare's Autism Fellow Dr. Maria McCarthy

34 YAI Autism Center Spotlight on Moira Lewis

35 Tips for Anxious Campers Preparing for Summer Camp

37 Educational Models Prepare Individuals for the Workforce

37 Autism Symptomatology - Development & Employment

Autism Spectrum News Upcoming Theme and Deadline Calendar

Fall 2009 Issue:

"Addressing the Needs of Adults on The Spectrum"

Deadline: June 15, 2009

Winter 2010 Issue:

"Understanding the Assessment Process: What Parents Should Know"

Deadline: September 15, 2009

Spring 2010 Issue:

"New Frontiers in Autism Science"

Deadline: December 15, 2009

Summer 2010 Issue:

"Understanding and Accessing Clinical Treatment Services"

Deadline: March 15, 2010

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Deadline Calendar*

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From The Publisher

Our First Year in Publication: A Look Back and Our Vision for the Future

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

This issue of *Autism Spectrum News* marks the final issue in our first year of publication. Three years ago when we decided to devote the summer 2006 issue of our sister publication *Mental Health News* to "Understanding and Treating Autism Spectrum Disorders," we had no idea that we would soon be launching a new publication devoted specifically to the autism community. In the weeks and months following that issue of *Mental Health News*, the autism community responded overwhelmingly and urged us to develop a separate publication devoted entirely to the spectrum. To answer the call from the autism community to launch a new publication, we conducted a year-long feasibility study and met with families and leaders in the autism community. We learned that parents were often frustrated by the overwhelming sea of information on autism spectrum disorders found on the internet. Many families were finding unsafe and unproven products and therapies that were being promoted as "the answer" by groups and practitioners looking to capitalize on many parents' willingness to try anything that might help their children on the spectrum. It was obvious that there needed to be a trusted source of science-based information and education devoted to helping families discover what the best therapeutic practices are and a roadmap to safe and effective resources available to them in the community. Out of this vision, *Autism Spectrum News* was created.

As we end our first year of publishing *Autism Spectrum News*, our vision to provide a trusted source of safe and effective information and education to the autism community has become a reality. It has not always been easy staying true to our science-based mission, as we have had to turn away many promising articles and decline much-needed advertising dollars from sources that were not in line with our strict evidence-based philosophy. In spite of these hardships, we have learned that a majority of families, research groups, medical and educational institutions, and service providers have come to appreciate the extra effort we make in ensuring that all educational content and advertising you find in each issue of *Autism Spectrum News* has been thoroughly evaluated by our distinguished editorial board.

As we move into our second year of publication, we look forward to continuing our mission of providing the autism community with the highest level of evidence-based information, education and resources from the local, state, and national news scene.

In this issue of *Autism Spectrum News*, we have put together a broad view of many issues devoted to education for children



Ira H. Minot, LMSW

and adults with autism spectrum disorders.

We lead off with an article from Dr. Lynda Geller who addresses the need for a tailored education plan for students with Asperger Syndrome. Dr. Geller states that, "Because Asperger Syndrome is an outcome of brain differences in combination with life experiences, no two individuals are exactly alike. Therefore, each student we encounter has different educational needs." Some recommendations for schools made in her article are: engaging a consultant to educate the student's school, hiring a trained paraprofessional, and providing support services when needed such as speech and language therapy, OT, PT, resource room, and counseling by professionals trained in specific interventions for the population.

Our second cover story from Dr. Stephen Shore provides much needed clarity to "the sea of interventions" available to parents and the multi-dimensional diversity of autism itself. Dr. Shore is frequently asked, "Which approach should I use for my child?" Shore explains that, "This great diversity of autism speaks to two main points. Firstly, individuals are going to have widely differing needs meaning that certain approaches will work for some but not others. Secondly, finding ways to subtype people with autism may help in the endeavor of matching best practice to the needs of children with autism."

On page 13, Dr. Adrienne Robek writes about one of the biggest challenges in working with children with autism: the severe behavior problems they exhibit. Dr. Robek recommends first understanding the function of the behavior, the three most common being, "escape from a demand, attention/alerting an adult to a need (such as hunger), and sensory – engaging in a behavior simply because it 'feels good.'" Robek recommends that "regardless of what the problem behavior is or what type of

intervention is used, remember that the intervention must be practiced in various settings (home, school, community) by everyone involved in the child's life in order to promote generalization of the newly-learned skill."

One of the wonderful added benefits of *Autism Spectrum News* is that it provides a trusted knowledge base that can be accessed by parents, treatment professionals, and providers of services who can now share vital information and learn from each other's research, experience and methodologies. The success stories you find in the pages of *Autism Spectrum News* serve as a resource and inspiration for other teams of educators and clinicians seeking to do their best in supporting children and adults with autism. On page 15, the Shield Institute shares success stories from two classroom teams supporting the education of two boys with autism. "Their stories reinforce the importance of team communication and consistent implementation of research-based practices and leadership."

Support groups are a vital resource for families and individuals with autism spectrum disorders. On page 17, Beth Myers, MEd, and Robert Myers, MEd advocate for the importance of support groups for adults with autism spectrum disorders. "The challenges of adulthood are many and varied, and many adults with ASD have few friends with whom to share those challenging experiences. Support groups for adults with ASD, when planned carefully and structured in a positive way, can provide the right venue for individuals to interact and receive much-needed support from each other."

On page 18, Dixie Yonkers of the New York State Office of Mental Retardation and Developmental Disabilities (NYS OMRDD) writes of the importance for supporting education across the lifetime of a child with autism and of the need for transition planning as the student with autism reaches 15 years of age. "Schools [by law] must start to develop employment and life goals for the student and a plan for attaining the education and supports needed to achieve those goals."

On page 21, The McCarton Foundation speaks of the need to improve the generalization of skills in learners with autism. "Generalization must be a priority in educational planning. It should impact how we conceptualize and define target skills, how we teach skills, and how we evaluate progress and mastery. We must program, plan, and assess for generalization throughout instruction. The ultimate indicator of successful instruction is the transfer of skills into natural environments and everyday interactions."

Please take a look at page 33 where Gary Mayerson, Esq. provides some helpful guidance on cutting through irrational fiscal fear and school's administrative paralysis to secure appropriate and effective autism programs for your child with

autism. He also stresses the importance for parents to enter an IEP meeting with thorough clinical assessments in hand that make professional recommendations for their child. "This approach helps to focus the meeting to the child's unique needs, the starting point for any appropriate educational plan."

Perhaps the ultimate goal of an education for people with autism is to prepare for "transitioning fully to an adult life that embraces work, personal relationships and independent living." On page 37, Dr. Ernst VanBergeijk discusses post-secondary educational models to prepare individuals with an autism spectrum disorders to enter the workforce. "Vocational, Supported Academic and Transitional programs are three different post-secondary educational models used to prepare individuals with an ASD to enter the workforce."

In addition to the articles mentioned here, there are many other wonderful articles by parents and 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 quarterly calendar of *Autism Spectrum News*. In our upcoming fall issue, our theme will be "Addressing the Needs of Adults on The Spectrum." Our deadline for articles and advertising for this important issue is June 15th.

Our calendar continues with our winter issue which will focus on "Understanding the Assessment Process: What Parents Should Know." Next spring we will take a look at "New Frontiers in Autism Science" and next summer our theme will be "Understanding and Accessing Clinical Treatment Services."

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 site you can subscribe to receive your own personal hardcopy 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*.

*You Are Not Alone
 Autism Spectrum News Cares About You*

Have a Wonderful Summer Season.

AUTISM SPECTRUM NEWS DESK

Pennsylvania Governor Edward Rendell Announces Health Research Grants From Tobacco Settlement Funds

Staff Writer
Autism Spectrum News

Health Secretary Everette James today announced four health research grants totaling nearly \$18 million will be awarded from Pennsylvania's share of the national tobacco settlement for 2008-09.

These competitive grants focus on specific research priorities established and reviewed annually by the statewide Health Research Advisory Committee, chaired by Secretary James. The priorities for 2008-09 are autism spectrum disorders (ASD) and antibiotic resistance. Each grant is required to establish a research training program for minority students and faculty in order to create a diverse applicant pool for high-level research positions.

"These grants will support research that seeks to find answers to some of Pennsylvania's most pressing health issues," said Secretary James. "This announcement also reaffirms Governor Rendell's commitment to use tobacco settlement dollars to improve public health and maintain Pennsylvania's internationally recognized leadership in clinical and health services research."

Antibiotic-resistant infections are a growing and serious public health problem, particularly in health care settings. While most bacterial infections can be effectively controlled using existing antibiotic drugs, there has



Governor Edward G. Rendell

been a significant increase in antibiotic drug resistance rates in health care institutions during the past 25 years. It has been estimated that more than 70 percent of the bacteria that cause health care infections have resistance to at least one or more antibiotic drugs. More than 27,000 hospital-acquired infections were reported in Pennsylvania in 2007. Patients that acquired a hospital infection stayed more than three times longer in the hospital and their admission was four times as expensive as any other hospital admis-

sion. Many of these infections are caused by bacteria resistant to most, if not all, currently available drugs.

Methicillin-resistant *Staphylococcus aureus* (MRSA) ranks among the most prevalent causes of infections in hospitals. It is easily transmitted within the hospital and is now found in the community. *Acinetobacter baumannii* (*A. baumannii*) and *Clostridium difficile* (*C. difficile*), other bacteria that have developed drug resistance, also cause life-threatening infections and are prevalent in U.S. hospitals. Research aids in better understanding the transmission of these deadly bacteria and developing improved strategies to prevent and control the spread in hospital and community settings.

Research is also needed to address ASD, which have reached unprecedented levels, affecting 1 in 150 children, according to the Centers for Disease Control and Prevention. ASD include autism and related pervasive developmental disorders such as Asperger syndrome, Rett syndrome and childhood disintegrative disorder. Currently, there is no cure for the disorders, and treatments are limited. Studies that investigate genetic factors, brain function and structure are needed to improve our understanding of how the minds of autistic children work.

The four grants that are being awarded under these two priorities during state fiscal year 2008-2009 include:

- The University of Pennsylvania, in collaboration with the Children's Hospital of Philadelphia, Lincoln University, and the Pennsylvania State University, will receive \$5.5 million to study why patients with MRSA infections frequently experience recurrent infections despite appropriate treatment. Researchers also will determine how often MRSA spreads among household members and the factors contributing to the spread of MRSA within the household. An intervention to prevent new and recurring MRSA infections will be tested.
- The University of Pittsburgh, in partnership with Carnegie Mellon University, will receive \$4.7 million to study new ways to reduce infections caused by *A. baumannii*, *C. difficile*, and MRSA in hospitalized patients. The project will assess the health and economic impacts of these novel strategies on the prevention and control of infections caused by these multidrug resistant bacteria. *A. baumannii* is a severe, difficult-to-treat infection in seriously ill hospitalized patients. *C. difficile* is resistant to numerous drugs and causes serious infection among patients already on antibiotics.

see Pennsylvania Grants on page 26

IACC Advisory Panel Releases First Federal Strategic Plan for Autism Research

Staff Writer
Autism Spectrum News

The Interagency Autism Coordinating Committee (IACC), a federal government advisory panel, has released its first blueprint for autism research. The IACC Strategic Plan for Autism Spectrum Disorder Research will advise federal agencies and Congress on needs and opportunities for research investigating autism, a complex developmental disorder that affects 1 in 150 children.

"This plan will help fill the gaps between what we know about autism and what we need to do to help affected families and communities," said Thomas Insel, M.D., chair of the IACC and director of the National Institute of Mental Health, part of the National Institutes of Health. "This document marks a signifi-

cant achievement in that it is the product of a truly collaborative effort involving the IACC, scientists, advocacy groups and the public."

In establishing the IACC, the Combating Autism Act of 2006 mandated that the body develop and annually update a strategic plan for autism research. The IACC, composed of both federal and public members, developed the plan through an extensive process engaging a wide range of federal agencies and public stakeholders. The IACC convened four scientific workshops to identify research opportunities as well as expert workgroups to recommend research objectives. The committee also sought extensive public input on ASD research priorities through means such as town hall meetings and Requests for Information. The resulting plan reflects a diversity of views and the breadth of research that will be required to address the needs of people with ASD and their families.

Autism is a complex developmental disorder characterized by repetitive behavior and pervasive impairments in language and the ability to relate to others. It is often grouped with related disorders, such as Asperger's syndrome and pervasive developmental disorder, all of which may be referred to collectively as autism spectrum disorders (ASD). The underlying causes of ASD are unclear and currently, there is no cure for the disorders. Prevalence of ASD has increased more than ten-fold over the past two decades, according to estimates from the Centers for Disease Control and Prevention (CDC) in 2007.

The IACC strategic plan is organized around six critically important questions for people with ASD and their families regarding 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 then states an aspirational goal and describes research opportunities and objectives in each area. Each objective includes a professional judgment budget estimate, provided by programmatic and agency experts.

Recommendations in the strategic plan include objectives to: develop new diagnostic tools; complete longitudinal and comprehensive studies of the biological, clinical and developmental profiles of children; identify genetic and environmental risk factors; conduct clinical trials of interventions; and assess the efficacy and cost-effectiveness of evidence-based services for people with ASD of all ages in community settings.

see IACC Strategic Plan on page 41

AUTISM SPECTRUM NEWS DESK

Putnam ARC Launches Region's Largest Comprehensive Autism Library Collection

Staff Writer
Autism Spectrum News

With a legacy of 55 years providing exceptional services and extensive programs which offer new and exciting initiatives to participants and family members, Putnam ARC (PARC) is pleased to announce the creation of the region's largest, comprehensive library collection dedicated to Autism.

With over 200 books, DVDs, magazines, and periodicals, the Autism Resource Center Library opened officially to the public on Friday, January 9, 2009 at Mahopac Public Library, located at 668 Route 6, Mahopac, NY. PARC leaders, local and state politicians, and honored guests were all a part of a ribbon cutting and grand opening celebration on January 9, 2009.

"Resources like this are critical for the growing number of families who find themselves surrounded by hurdles just to provide the bare and basic necessities for their children," said NYS Assemblyman Greg Ball, who attended the ribbon cutting. "I applaud the efforts of PARC and the whole team to once again go the extra mile for those families who are in special need for an advocate, a voice and a network of support."

The library collection marks the successful completion of phase two of the Regional Autism Resource Center. Phase one, launched to the public in March



2008, was the center's website, www.AutismResourceCenter.info. The website is a one-stop clearinghouse of information related to Autism Spectrum Disorders (ASDs), including autism, pervasive developmental disabilities (PDD), and Asperger's Syndrome.

Autism spectrum disorders are developmental disabilities that cause significant impairments in social interaction and communication. The ability of individuals with ASDs to think and learn ranges from gifted to severely challenged. And rates for those affected by autism are changing rapidly. Autism now affects 1 in 150 children, and 1 in 100 male children.

Recognized as a 501 c (3) in 1954, PARC provides programming and advocacy for over 650 children and adults with developmental disabilities within Putnam County and in southern Dutchess and northern Westchester counties. PARC's extensive autism services include an autism-focused preschool in Mahopac, teenage educational services and support, workplace training and employment services, vocational training, and supported apartments and community residences.

The library collection and the website are just the first two components of the PARC-sponsored Regional Autism Re-

source Center. In the coming months, center staff will work to create support groups for parents and caregivers, and an annual, regional conference related to Autism care, advancements, research, information, and more.

The center received start-up funding from Provident Bank, The Thomas & Agnes Carvel Foundation, Senator Vincent Leibell/NYS Senate, and the Gannett Foundation.

The library collection is available by borrowing at the Mahopac Public Library or by using inter-library loan from any library in the Mid-Hudson Library System. For library hours or to search for autism-related books and publications, log on to www.mahopaclibrary.org.

"This partnership gave Mahopac Public Library the ability to build a current, quality collection on this very important topic and to make it accessible to the widest audience possible," said Library Director Patricia Kaufman.

According to the Centers for Disease Control (CDC), autism, which is classified as a developmental disability, is growing at a startling rate of 10-17% a year, with the prevalence level potentially reaching four million Americans in the next decade.

For more information about the Autism Resource Center and the center's website, www.AutismResourceCenter.info, please call 845-278-PARC or log onto our website, www.PutnamARC.org.

Autism Speaks Seeks Applications for New Round of Family Services Community Grants

Staff Writer
Autism Spectrum News

Grants Will Fund Education Programs, Community Activities, Supportive Technology and Services for Teens and Adults

Autism Speaks, the nation's largest autism advocacy organization, announced that it is seeking applications for its fourth round of Family Services Community Grants to promote services that enrich the lives of individuals with autism spectrum disorders (ASD). Grant proposals are being solicited that address one of the following areas of need: Education, Recreation/Community Activities, Equipment/Supportive Technology and Young Adult and Adult Services.

Successful applicants will apply

grant funding to support new programs or the expansion of existing projects. All applications must be submitted online at: <http://grants.autismspeaks.org/research/login.asp>. The due date for applications is June 25, 2009.

To date, Autism Speaks has approved more than \$1,400,000 in funding for seventy-one Family Services Community Grants to help community organizations across the country expand existing programs and create new ones that demonstrate true innovation.

"The goal of our Family Services Community Grant program is to facilitate the expansion of services for individuals with autism and work collectively to more effectively serve this growing community," said Peter Bell, Autism Speaks Executive Vice President for Programs and Services. "There are many great organizations doing remarkable work and improving the qual-

ity of life for our children. We want to bring attention and resources to these programs so the autism community can benefit from more and better services."

A two-tier review process will once again be used to assess each grant application. In the first tier, each proposal will be reviewed by both the parent of a child with autism who has experience in the area of need and an autism professional with expertise in that same area. To help ensure objectivity, proposals will be assigned to reviewers located in a different geographic location from the applicant. Proposals that earn an established minimum score will be reviewed by members of the Autism Speaks Family Services Committee (FSC).

The FSC members will consider the following criteria for each program:

- Field building – increasing services

(new opportunities) and the capacity of service providers;

- Number of individuals served; including the ability to serve individuals who had not previously been served by the organization.
- Innovation and creativity;
- Geography;
- Ability to address the needs of the underserved;
- Replicability;
- Services provided for individuals across the spectrum.

For more information about the Family Services Community Grants, visit www.autismspeaks.org.



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For People on the Spectrum, There's No Place Like the Medical Home

By Peter Della Bella, MD
Director of Clinical Programs
Premier HealthCare

Home — it's where we seek care, comfort and respite from the world outside. It's the one place where we can count on others knowing and accepting us. It's a not-so-new concept that is finally gaining momentum in medical circles. It's called the Medical Home Model and it has more to do with the philosophy of how primary care *ought* to be provided rather than with *where* medical services are delivered. And it has great potential for people with autism.

The Medical Home Model takes these concepts of home and packages them into a set of recommendations about what medical care ought to be. The result? Doctors whom you can rely on, along with a whole team of health care providers working on your behalf in a state-of-the-art clinical setting, complete with all the latest resources.

Both the American Academy of Family Physicians and the American College of Physicians have embraced this idea, which actually goes back to the 1960s, when it was first promoted by the American Academy of Pediatrics.

In this model, patients have their own primary care doctors who provide continuous and long-term care — doctors



Peter Della Bella, MD

know their patients, their medical vulnerabilities and idiosyncrasies, their preferences and patterns, their attitudes and values concerning health, illness and medications. A doctor and a medical team provide continuous care, learn about the entire family and home environment and the impact they have on health. The team

includes the medical specialists in the practice and a variety of doctors and other health care providers — nurses and therapists — who come together and talk with each other when the need arises.

In this model, the care is integrated and coordinated by the primary care doctor. Electronic health records are available quickly and efficiently at the touch of a button so that full histories can be readily searched. These health records push information to the doctors: abnormal blood tests, previous medication reactions and reminders for preventive screening. Tests are tracked and responded to in record time. Patient education is a rule, not a slogan, and people are taught self-management skills for their conditions. The latest of practice guidelines are obtained and integrated into medical care. And access to doctors and their advice is enhanced through e-mail and automatic call-back systems.

But what's the advantage of a Medical Home for someone with autism?

Because autism affects so many different areas of development, people with autism require a wide range of providers: medical professionals, special educators, rehabilitative professionals and mental health experts. Fragmentation of care is the rule, not the exception. For people with autism spectrum disorders (ASDs), health care is typically a discontinuous series of providers, places and appoint-

ment times. Records are scattered among family doctors and occupational therapists, gastroenterologists, behavior specialists and speech and language specialists, who don't speak with one another.

A recent study reported on in the December 2008 issue of *Pediatrics* recognized that families with children with autism have to endure greater financial, employment and time constraints than other families and concluded that "getting primary care in a medical home may reduce these burdens."

But how is this proactive, wellness-driven, personalized care model different from our current health care system? The current system is a reactive, illness-driven, episodic care model, top-heavy with medical specialists who only deal with parts of patients and do not focus on the whole.

We need to change our model and provide good primary medical care. But this is not going to be easy. A September 2008 article by Dr. Karen Hauer and colleagues in the *Journal of the American Medical Association* reported that only 5 percent of a large sample of fourth-year medical students plan to go into family practice and 2 percent into general internal medicine. The remaining 93 percent all specialize and sub-specialize. This is a problem.

This is in great contrast to my recent

see Medical Home on page 25

Finding the Ability in Disability

By Charles Cartwright, MD, Director and Moira Lewis, MS CCC-SLP
Speech and Language Pathologist
YAI Autism Center

Justin was 5 when he picked up his first set of markers and began drawing Disney characters. His parents, Maria Teresa and Briant Canha, would watch as he drew a single figure—from the Lion King or Winnie the Pooh—over and over again until another movie, show or character captured his interest.

"His drawings never included real people and were done simply out of enjoyment," says Maria Teresa. "Justin was always quite oblivious to his talent and abilities for drawing."

A few years before Justin began drawing, his parents learned that he had autism. He had little eye to eye contact, social interest and use of social gestures, as well as atypical social-emotional responses. His language development was significantly delayed, he demonstrated stereotypic motor movements and he had a marked restriction in his range of interests.

Throughout his life, Justin's art has been a true motivator for learning, communicating and feeling successful—essential experiences for all children. But his parents are quick to point out that they do not believe that Justin is a savant. Rather, he is a person with autism who is fortunate to have parents who identified a genuine interest and ability early in his



"Mother and Baby in Bath" charcoal on paper by Justin Canha

life, and who have consistently provided opportunities for him to practice and develop his skill. For Justin, that has made all the difference.

When Justin was 8, he was introduced to a therapist in Florida who realized that art was an essential medium that could be used for teaching, therapy and discussion. "Where words and language were not

coming to help Justin express his thoughts, he could express himself to others through drawing," says Maria Teresa.

Later at age 10, Denise Melucci, an art teacher Justin's parents came across, helped expand Justin's art beyond repetitively drawing characters with markers, developing his skills and his focus. "We wanted to see Justin challenged beyond his comfort

zone and after we established the goal of expanding his repertoire, Justin began using charcoals, pastels and water colors, and experimenting with different subject matter," says his mother.

With the help of Denise, Justin's parents organized a small art show to display Justin's work—and from there, Justin has never looked back. Soon after the art show, family members began asking Justin to draw portraits of their pets. He was so skilled at drawing animals that Maria Teresa arranged for a display of his drawings at a pet store, where his work was met with rave reviews. Once his family moved to New Jersey, Justin became involved with Arts Unbound, an organization that markets the work of non-traditional artists. His talent was recognized by the Ricco/Maresca Gallery in 2005 and since then his artwork has been featured in many exhibits, some of which include works of renowned artists without disabilities. Justin slowly came to realize that others recognize and appreciate his work. Now, at age 19, Justin carries a sketchbook full of drawings as a way of initiating social interactions with people he meets.

Justin's talent has provided him with a tool to navigate an otherwise confusing and difficult everyday life with autism. It is also his vocation, enabling him to earn money and have the potential to become increasingly self-sufficient.

see Finding the Ability on page 11



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Parents and Professionals: Building Collaborative Partnerships

By Amy M. Perrine
Information Manager
Autism New Jersey

When parents and the professionals who work with their children come together, children with disabilities benefit. The concept of a collaborative partnership between parents and schools in the design and implementation of special education is one of the six principles of the Individuals with Disabilities Education Act (IDEA) established by Congress (Turnbull & Turnbull, 2000). A collaborative partnership may lead to conversations and resolutions, preventing the need for mediation or litigation.

A partnership can be defined as two or more parties working together toward a goal. In order for partnerships to be effective, parties must understand and respect each others' roles. Both parents and professionals share some roles as providers of information about the child's strengths and needs and his or her disability. Both parents and professionals are decision makers, observers, project managers and quality control experts.

Blue-Banning, Summers, Frankland, Nelson and Beegle (2004) found that there were six themes of collaborative family-professional partnerships. With an over-arching principle of cultural sensitivity, these themes include: *communication, commitment, equality, skills, trust and respect*.



Amy M. Perrine

Communication should be clear, honest and tactful. Employing strategies such as active listening, where the listener paraphrases what was just said and repeats it back ("So, what you are saying is...") can be effective in clarifying topics. Another technique called neutral phrasing can create open-ended discussions ("Let's talk about options...") while using "I" statements can diminish defensiveness ("I feel..."). All of these options set the stage for brainstorming to occur.

From there, practical choices can be made that satisfy everyone's needs.

Commitment reflects each member's sense of assurance about each other's loyalty to the child and belief in the importance of the pursued goals. (Blue-Banning et al, 2004).

Parents are to be *equal* members of the Individualized Educational Program (IEP) team. Parents can describe what goals are most important to them and their child, share their concerns and suggestions for enhancing their child's education and give insights into their son's or daughter's interests, likes and dislikes, and learning styles. By being an active IEP team member, parents also can add to the IEP planning process with thoughts about long-term needs for the child's successful adult life.

As equal members of the IEP team, parents can be seen as "experts in the field of their child" just as the team relies on other professionals to be skillful in their areas of expertise. Demonstrating competence and *skills* deemed as best practices enhance the family-professional collaborative partnership.

When parties respect what each person says and does, as well as how he or she makes decisions, they build confidence in each other. Trust depicts the confidence we feel in placing a situation in another's hands and hoping that our expectations will be met. Reliability and dependability contribute to a sense of *trust*.

Respect encompasses the thought that members of the partnership regard each other with esteem and demonstrate that

esteem through their actions and communications. (Blue-Banning et al., 2004).

Despite the best laid plans, at times, things can and do go awry. Unfortunately parents and professionals are all too aware of what happens when trust is lost between parties. It is understandable that the expectation of a "free and appropriate public education" varies between parents and professionals. Parents and professionals are at times pitted against each other as competitors. One may ask, "How much can we get out of them?" The other may ask, "What can we get by with?" What parent would settle for second best for his or her child despite the provision of an appropriate education? Competition has its place in being an effective technique in dealing with conflict. Competition is a way to approach conflict knowing that eventually someone wins and someone loses. Competition often is about power. Acknowledging that parents and professionals start off on unequal footing to begin with, and that professionals often are viewed as the ones with all of the power, illustrates that competition will not enhance a group's ability to work together. It reduces cooperation.

Parents who may not have chosen the path that they are on, and professionals who did choose this path, should remember the words of the late Henry Ford regarding collaborative partnerships, "Coming together is a beginning; keeping together is progress; working together is success."

To contact Autism New Jersey, visit www.autismnj.org or call 1-800-4-AUTISM

Finding the Ability from page 9

Finding Abilities

Justin's story raises many issues that are relevant to all people on the autism spectrum. When repetitive, stereotypic behaviors appear, they tend to be viewed as "stim" behaviors that can interfere with the child's ability to respond to intervention programs. In addition, cognitive ability is difficult to evaluate because of the impact of the social, language and behavioral manifestations of autism. The results of formal testing procedures are difficult to interpret because of these factors.

However, a child's ability, skill, and talent may initially present in the form of these repetitive behaviors. One of the core aspects of autism is a restriction in the range of preferred activities and the engagement in repetitive behaviors, with the presence of routines and rituals. Parents describe how, from the time of early development, their children show repetitive motor mannerisms and engage in repetitive activities, such as spinning objects or lining up toys. In addition, children with autism spectrum disorders often develop intense circumscribed interests that may involve repeatedly draw-

ing certain objects. In many cases, parents recognize that these circumscribed skills or interests actually reflect their child's intelligence. They often assert this perception despite being told by professionals that formal cognitive testing procedures have shown that their child is functioning at a low cognitive level.

Individuals with autism have a strong tendency to focus on detail. In contrast, they often have difficulty in developing a sense of the whole picture, or the gestalt. The theory that defines this style of viewing the world is referred to as "weak central coherence." This implies a cognitive deficiency and underplays the presence of cognitive strengths. It is concerning that cognitive assessments report mental retardation in up to 70 percent of people on the autism spectrum. In a study by Dawson et al. (2007), intellectual assessments using the Ravens Progressive Matrices (Mackintosh, 1998) and the Wechsler Intelligence Scale for Children (Wechsler, 1991) were administered to children with autism and compared to typically developing children. The scores of the Ravens in the children with autism were 30-70 percentile points higher than their Wechsler scores. In contrast, the typically developing children showed no discrepancy in the two sets of scores. This find-

ing supports the concept of atypical cognitive processing in these children, rather than mental retardation.

"The Intense World Syndrome," as described by Makram et al. (2007), hypothesizes that individuals with autism spectrum disorders have excessive, rather than diminished, cognitive functioning. The authors describe the phenomena of "hyper-perception, hyper-attention and hyper-memory" that may manifest clinically, for example, as acute sensitivity to noise, excessive focus on detail and impressive ability to memorize certain details. The theory proposes that individuals with autism have very intense perception of fragments of the sensory world with very clear and persistent attention to the detail. The theory proposes that there is an excess of neuronal information processing and storage in local microcircuits of the brain. They conclude that that these circuits are hyper-reactive and extremely plastic, driving the development of new learning, the formation of intense memories and often exceptional skill for a particular task. The negative consequence of this form of cognitive style is the marked restriction of behavioral responses to stimuli in the environment.

How is this all relevant to the development of Justin's artistic ability? His desire

to draw was first evident in early childhood, at a time when his ability to communicate was hampered by his language delay. His cognitive ability at that time was very difficult to assess and his repetitive stereotypic drawing could easily have been seen as interfering with his development and the acquisition of important social and language skills. However, given the encouragement and reinforcement of those around him and the opportunity to develop his drawing skill, he responded by rapidly expanding his skill, showing a keen eye for visual details and an ability to focus for sustained periods of time. He was drawn to novel subject matter and media, thus expanding his knowledge of how to draw and developing his artistic skills. Justin's pattern of learning and his response to environmental stimulation appear to reflect this exaggerated brain plasticity, as hypothesized.

Maria Teresa and Briant hope that Justin will someday live independently in their hometown of Montclair, NJ, a community that now knows him well and admires his work. They hope that Justin's talent will continue to allow him to grow as a person, and foster his future social life, friendships and happiness. This is the wish of all parents whose children are faced with the challenges of a life with autism.

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Reducing Behavior Difficulties to Help Children with Autism Learn and Grow

By **Adrienne Robek, PhD, BCBA**
ABA Clinical Director
Los Niños Services

One of the biggest challenges in working with children with autism is the severe behavior problems they exhibit. These behavior problems not only make it difficult for their parents to care for them but also make it difficult to take them out in public. Many of these children have unpredictable behavior and will tantrum when encountered with various stimuli such as loud noises, crowded places, or small enclosed areas such as elevators. Countless parents have stated that one of the biggest problems they encounter when raising a child with autism is the sense of isolation they feel. Because of the behavior problems exhibited by their children it is difficult to invite people to their house, go to social functions, or simply run errands. Additionally, teachers have a difficult time teaching these children new skills because of behavior problems such as tantrums, self-stimulatory behavior, aggression, and/or self-injurious behavior. The following are simple points to help a parent or teacher understand why the behaviors continue and some simple and effective behavior management techniques that work to reduce and eliminate negative behaviors such as biting and tantrums.

The first and most important step when dealing with behavior problems is to understand the function of the behavior. The easiest way to do this is to collect $A \rightarrow B \rightarrow C$ data where the "A" stands for "antecedent," which is what happens immediately before the onset of the behavior, the "B" stands for "behavior," and the "C" stands for "consequence," which is what happens immediately after the onset of the behavior. The reason $A \rightarrow B \rightarrow C$ data are collected is because one behavior can have many different functions depending on the child or the context in which it occurs. The three most common functions of be-



Adrienne Robek, PhD, BCBA

havior when dealing with children with autism are: 1) escape from a demand, 2) attention/alerting an adult to a need (such as hunger), and 3) sensory – engaging in a behavior simply because it "feels good." The following examples illustrate how one behavior can serve different functions:

1. A parent/teacher asks the child to sit down. The child bites him/herself so the parent/teacher removes the request.
2. A child sees a cookie on a high shelf. The child bites him/herself so the parent/teacher gives the child the cookie.
3. No clear pattern of antecedents. The child bites him/herself. No clear pattern of consequences.

As you can see in example one, the child is engaging in the problem behavior to escape from a demand, in example two the child is engaging in the problem behavior for attention/alerting an adult to a need that needs to be met, and in example three the child is engaging in the problem behavior simply because it feels good.

Furthermore, the consequences in examples one and two are reinforcing the problem behavior. In other words, the consequences are making it more likely for the problem behavior to occur in the future since these children are learning that biting themselves is a way for them to get what they want.

There are several techniques that are very effective to reduce or eliminate behavior difficulties. When dealing with problem behavior that serves the purpose of avoidance, it is usually best to try and work through the behavior. This entails NOT removing the demand that triggered the problem behavior in the first place. In the above example, the child is asked to sit down only to have that child bite him or herself. An effective way to intervene is as follows: first, require the child to sit down even if he or she is biting him or herself. The child will then learn that biting him or herself is not going to help him or her escape from the demand. If the child bites him or herself and the parent or teacher withdraws the demand, then the child is given reinforcement (a reward) for the biting and that behavior is likely to continue. Second, give the child a reinforcer (reward) once they sit down to teach them that when they comply with simple requests good things happen.

In example number two the child bites him or herself in order to obtain a cookie. An effective strategy for this example is to teach the child a more appropriate way to communicate, whether it is saying "cookie", signing "cookie", pointing to the cookie, or giving the adult a picture of a cookie. Although implementing these strategies is always easier said than done, they will help the child and their caretakers enormously.

When children with autism engage in problem behaviors simply for sensory input (it feels good) it can be very challenging to reduce the problem behavior. Sometimes it is possible to teach children alternative, more socially appropriate ways of occupying themselves but other children may not respond to this type of

intervention. They might need their teachers and parents to implement a formal behavior treatment plan.

Regardless of the problem behavior that is being displayed by a child, the most important thing to remember is not to treat it with a "blueprint." For example, simply because a child is biting him or herself does not automatically mean he or she should be put in time-out. If the child is biting him or herself to escape from a demand, putting the child in time-out will reinforce the biting behavior and make it more likely to occur in the future since the goal of the behavior was to escape from the demand. When the child is placed in time-out, he or she has just accomplished the goal of escaping from the demand. It is also important to collect data on the problem behavior to make sure the strategy being used is working. Keep in mind that the problem behavior will usually increase for the first few days before it starts to decrease. This is known as an "extinction burst" and is quite common when implementing behavioral strategies. Don't quit your strategy during the extinction burst or else the behavior will continue or possibly stay even worse than it originally was.

Finally, regardless of what the problem behavior is or what type of intervention is used, remember that the intervention must be practiced in various settings (home, school, community) by everyone involved in the child's life in order to promote generalization of the newly-learned skill. This is done because many children with autism are unable to generalize skills taught in one setting to a different setting. For example, teaching a child not to tantrum at home does not guarantee he or she will not tantrum in the car, supermarket, or school. Thus, the more people and settings the child has access to during the intervention, the more successful the child and caretakers will be.

For more information on this topic feel free to contact Adrienne Robek at adrienne.robek@losninos.com or go to www.losninos.com.



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Photo by Matthew Septimus, 2008

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Interdisciplinary Team Perspectives on the Progress of Two Boys

By Susan Provenzano, EdD,
Mary McKillop, MA, CCC-SLP and
Suzanne Kucharczyk
The Shield Institute

For interdisciplinary teams of teachers, assistants, therapists and administrators, understanding what works for children with autism may sometimes seem elusive. Why is one child progressing in therapy, but not transferring these skills to the classroom? What was different in classroom supports for a child who has responded suddenly to circle time? Often even the questions remain unasked, let alone answered as the day-to-day classroom activities go on.

Recently, two classroom teams supporting the education of two boys who have autism sat down to discuss what has been working for these children. They were brought together in order to celebrate their successes and learn from their work. Their stories serve as a resource and inspiration for other teams of educators and clinicians seeking to do their best in supporting children with autism. Their stories reinforce the importance of team communication and consistent implementation of research-based practices and leadership.

Ben is a preschool boy with autism who has been in Antoinette's classroom for almost two years. At the beginning, the classroom and clinical team experienced Ben as a boy who "couldn't get out of his own skin"- flailing, screaming and slamming dolls on the floor. Camille, the assistant in his classroom would leave each day exhausted from pulling out all the tools she knew for supporting Ben. Today, Ben is using a visual schedule to navigate the school environment. He is using a visual placemat at mealtime to make choices and ask for help. He's a "smart little boy" who is checking in with his assistant to gain more information about which center time he should participate in first. He's a nonverbal boy with autism rolling cars across the classroom rug and rocking and pretending to feed dolls.

What has worked for Ben? According to his teacher, assistants, and clinicians the following have been central in Ben's progress: (a) the team being on the same page, (b) incorporating visual supports using structured teaching, aided language stimulation approaches and positive behavior supports, and (c) using the expertise of all the members on the team.

The three instructional methods discussed by the team have been incorporated into classrooms within The Shield Institute for many years. Structured teach-



Shield Institute team members enthusiastically discussing the progress of their clients

ing methodologies, developed by Division TEACCH at the University of North Carolina - Chapel Hill, utilize our understanding of how children with autism experience the world. Through this understanding of the culture of autism, the child's learning is supported through the strong use of visuals and environmental structure. Aided language stimulation, developed by Carol Goossens' is a methodology for supporting the communication of young children through visual support. Positive behavior support seeks to understand the purpose of a child's negative and positive behavior and assess those strategies that will support behaviors, which enhance learning and independence. Along with expertise and a common mission these instructional approaches have proven to be most effective for Ben, as well as other children that attend The Shield Institute.

Antoinette, the teacher, says that everyone being on the same page has been critical to Ben's and the other students' success. She and the other team members speak of the importance of having classroom and clinical members who believe in the power of visual supports and sensory approaches for children with autism. For example, Ben's occupational therapist took the time to evaluate his needs and create a sensory diet. While this diet has changed over time as Ben has changed, the classroom team has become proficient at knowing when Ben needs sensory support; For example, when he needs to sit on a bounce ball in order to attend to the task - like sitting in circle time with the rest of his peers. In addition, the team believes

that Ben has progressed quickly because he now is able to communicate his wants and needs. Whereas before he would snatch at what he wanted and use his teacher and assistants as tools, now he uses visual supports (such as schedules, first/then boards, mealtime placemats, etc.) to make himself heard. Both assistants, Irene and Camille, speak of the positive behavior supports they use as seamless and integrated into the rest of the classroom processes. Finally, and importantly, the team recognizes the incredible role Ben's parents play in helping him progress in the school environment. His family is involved, available and committed to his success. When his teacher was asked how she feels about Ben's progress, she responded that she feels like "(she's) in the right field."

Walker's teacher, assistants and therapists are also in the right field. Over this past school year Walker, a teenager with autism, has made incredible gains. In September, Walker would often use his body to get what he wanted and would run from the classroom to escape unpleasant activities. Now, seven months later, he is using a voice output device to make choices, he is engaged in the classroom activities, he independently takes care of his free choice time, and he's appropriately making his opinions known and has a "strong work ethic" to get things done.

What comes through as most critical for Walker's team's success is the leadership of his teacher, Elaine. In half a year's time she has shifted the team's expectations of Walker. The team expects Walker

to be responsive. The team expects Walker to engage in his day in productive ways. The team expects Walker to communicate. The team expects Walker to be independent. Walker hasn't disappointed these expectations. Strong expectations are followed by strong supports for Walker. Walker's classroom and clinical team members use structured teaching approaches and positive behavior supports throughout the day. Walker receives one-to-one structured instruction throughout the day. There is very little down time in the classroom. The free time Walker has is highly structured. He is always engaged in a productive, appropriate activity. These activities are purposeful and have a focus. Visual supports are available throughout the day. In modeling these expectations and supports the teacher has led the team in developing their own leadership.

This dispersed leadership is evident in the authority from which each of the team members speak. Each member has a clear responsibility for the classroom as a whole and each of the students, including Walker. No one member is responsible for one task or student. This shared responsibility ensures that everyone is committed to the classroom's success.

While there are differences in the ways these teams approach Ben's and Walker's education, both use structured teaching methodology, visual supports and positive behavior supports as instructional pillars. These pillars are held by a strong foundation of: (a) teacher and team leadership, (b) team members with shared beliefs about what works, (c) each team member sharing their expertise, and (d) allowing the child to lead the team in making decisions. These success stories have validated the good work of each team member, each classroom, each team, and the school within which these boys learn. In 2001, The Shield Institute began to use structured teaching because of the approach's capacity to: (a) support children at different ages, (b) incorporate other compatible approaches, used as aided language stimulation, (c) use positive behavior supports, and (d) focus on visually supporting students. The importance of these capacities has been born out in the success stories of Walker and Ben.

Susan Provenzano, EdD, is Executive Director of The Shield Institute. Mary McKillop, MA, CCC-SLP, and Suzanne Kucharczyk are with the Shield Institute Staff Development and Training Department. The Shield Institute is a JBFCSS affiliate. For further information, please contact Mary McKillop, Director of Staff Development and Training at 718-269-2044 or mmckillop@shield.org.

Provide Autism Spectrum News to Your Clients and Staff

See our Group Subscription on Page 43

Creative Approach to Job Development Pays Off at Chapel Haven

Staff Writer
Autism Spectrum News

When Ed Carney first started as director of job development at Chapel Haven, he spent his first months on the job pounding the pavement, trying to get local employers to hire Chapel Haven clients.

"No sooner would we place an individual in a job then we would find out that the individual did not really have the skills to sustain the work and the match was just not compatible," Carney noted. "Even before the tough economy hit, we were aware that we needed a new approach."

A decision by management at Chapel Haven to think outside the box, to sharpen its job assessment tools and to put a premium on building relationships with local employers has paid off. Of the clients who take vocational services from Chapel Haven, 85 percent are working, with jobs at more than 30 companies and agencies, either competitively for employers like Lowe's, Staples and Bed and Bath, or in supported, or team, employment situations. Chapel Haven has found particular success in one fulfillment project at a local paper factory that has blossomed into steady work for more than 20 clients in an integrated work setting.

"We have been so impressed with the



Chapel Haven's creative approach to finding work is paying off in the current tough economic climate. Two who are bullish about the prospects of employment for persons with disabilities are James T., left, a graduate of Chapel Haven, who loves his job in the mailroom of a local bank, and Ed Carney, director of job development at Chapel Haven.

work record of our Chapel Haven team, we have significantly increased the quantity and skill level of the work we ask them to do," said Richard Wilk, owner of Hudson

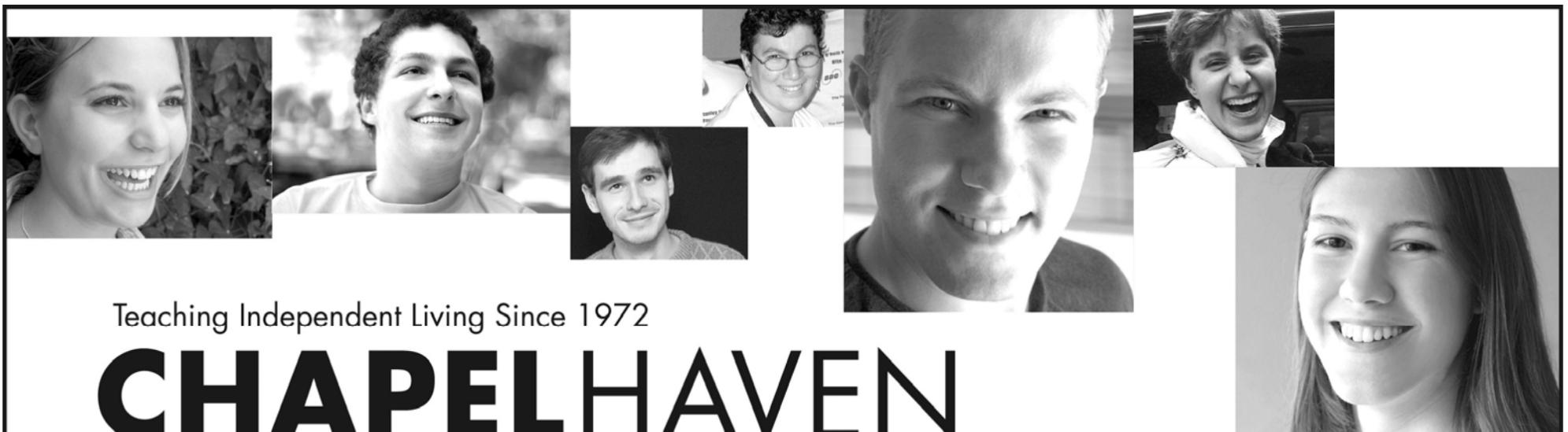
Paper in Stratford, Connecticut, where Chapel Haven clients perform small hand assembly jobs. "I wish all my staff had the same positive attitude toward their work."

Founded in 1972, Chapel Haven is a New Haven, Connecticut based residential transition program that teaches adults with cognitive disabilities, Asperger's Syndrome and those on the autism spectrum to live independent and productive lives. An important part of Chapel Haven's program is to help adults with disabilities transition into work. Considering the old adage that the person with a disability is often the last to be hired and the first to be fired, the nation's recessionary climate clearly presents challenges but some see a silver lining.

"Don't let the tough economy turn you away from your job search," counsels James T., 24, a Chapel Haven graduate who loves his job as a mailroom clerk at NewAlliance Bank. "Be vigilant, tough and diligent and hopefully you will find the perfect job that suits your life. Don't let your disability turn you away. Just press on with your job search and you will be lucky."

Much has been made of the current economic downturn. The U.S. Bureau of Labor Statistics, for the first time in its history, has begun tracking and reporting statistics on employment of persons with disabilities. In January 2009, the unemployment rate of persons with a disability was 13.2 percent, compared with 8.3 percent for persons with no disability, not seasonally adjusted.

see Creative Approach on page 40



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Support Groups Build Connections and Skills for Adults with ASD

By Beth Myers, MEd, Director Programs and Education Services and Robert E. Myers, Director Consultation and Behavioral Services The Kelberman Center

Many adults with autism spectrum disorders (ASD) experience stress in their daily lives and feel socially isolated. The challenges of adulthood are many and varied, and many adults with ASD have few friends with whom to share those challenging experiences. Support groups for adults with ASD, when planned carefully and structured in a positive way, can provide the right venue for individuals to interact and receive much-needed support from each other.

For many adults on the spectrum, structured learning typically focuses on daily living skills or vocational preparation but does not provide directed opportunities to learn specific social skills with peers. One of the greatest difficulties for many adults with ASD is social communication, which has been tied to problems with friendship, employment, and leisure (MacLeod & Johnston, 2007). Complicating matters is the notion that social and emotional issues have been shown to increase with age (Howlin, Mawhood, & Rutter, 2000).

Additionally, several studies have



Beth Myers, MEd

shown that adults with ASD have difficulty making and keeping friends. In a study by Howlin, Mawhood, & Rutter, which defined a friend as a same-age peer who shares activities and interests, half of the adults with ASD who were studied had no friends and only 15% had at least one real friend (Howlin, Mawhood, & Rutter, 2000). Another study found that only 8% of adults studied had at least one friend of the same age with whom they participated in activities outside of programs or organi-



Robert E. Myers, MEd

zations. About half of the adults studied had no reciprocal relationships that met their criteria for friendship (Orsmond, Wyngaarden Krauss, & Selzer, 2004).

Compounding these issues for adults is that many of them find that their support systems change drastically after high school. They enter the adult world with barely any of the same supports they had when they were in school. Some adults are in programs that link them to the community or to others with similar profiles,

like vocational, day therapy, or post-secondary programs, but many others are not enrolled in community programs at all. In childhood, parents can play a large role in facilitating friendships (Hillier, Fish, Cloppert, & Beversdorf, 2007) but that largely changes in adulthood as well. Some studies have found that adolescents with ASD are more likely than adults to have peer relationships, perhaps because of these changing supports (Orsmond, Wyngaarden Krauss, & Selzer, 2004).

So what can be done to adequately support adults with ASD so that they can make social skill gains and maintain friendships? Programs aimed at social and recreational participation with peers have been found to be highly successful (Orsmond, Wyngaarden Krauss, & Selzer, 2004). In particular, support groups that teach social skills and then practice their application in real-life situations can be very effective. Hillier and Fish found that adults who participated in support groups such as these had improved levels of empathy, increased personal expression, and friendships that extended beyond the group. They also found that members of the groups had more positive attitudes about employment and community participation as a result of the group (Hillier, Fish, Cloppert, & Beversdorf, 2007). Other studies have found support groups

see Support Groups on page 41

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NYS OMRDD - Supporting Education Across a Lifetime

By Dixie Yonkers
Senior Administrative Analyst
NYS OMRDD

Matthew Altieri wanted to follow the expected course of action for many young adults after high-school. He wanted to go to college. But Altieri, who is autistic, needed more than classroom education to prepare him for a career. He needed self confidence and job readiness skills in order to succeed. He found those skills through assistance from the College Works program.

The Arc Oneida-Lewis Chapter's innovative College Works program effectively blends education in work and life skills for people with autism and other disabilities. This two-year, on-campus program of higher education allows individuals with developmental disabilities to attend college at Mohawk Valley Community College and graduate with a two-year certificate.

The courses focus on life and work skills and on exploring specific career tracks in care-giving, hospitality, janitorial maintenance, and office retail. They are taught by employment specialists and professional experts from the community, and over the course of two years, help students explore possible career paths and develop fundamental knowledge and skills in a particular area. In year two, the



Dixie Yonkers

program also includes an internship with an employer.

The Arc developed the program in response to the need for students who were aging out of high school to explore career options, prepare for employment, and experience college life as a normal transition to adulthood.

"We follow our graduates, often working with New York's Vocational and Educational Services for Individuals with Disabilities (VESID) to provide transi-

tional and pre-employment services as they approach their graduation and beyond," said The Arc's Director of Employment Services, Joanne Donaruma. "We've found that College Works gives them the college experience and prepares them for employment with some specific job skills. But, more importantly, it provides them with the essential soft skills needed to retain a job – team work, work ethic, and the ability to relate successfully to co-workers and supervisors. It also introduces them to different career options so they are more likely to find employment that suits who they are."

Matthew's mother, Cindy Altieri, says that through College Works, Matthew became very involved with campus life, and made friends – with and without disabilities – who he still keeps in touch with today.

College Works also showed her son that it's possible to have a job doing what you like. With the skills he learned through this program, Matthew was able to intern in the computer graphics and design department at a local newspaper, where he made a real contribution. While no full-time job was available there after his internship, he still hopes to work for the paper again one day.

Vicky Yarwood and her son, Mark, also realized the benefits of this college program.

"Without exaggeration, College Works changed all of our lives – his dad's, mine

and Mark's, but even his siblings'," said Vicky. "Mark is so much happier. He's proud of what he's accomplished. We all are. There isn't any medicine that can give you that."

Mark credits College Works with helping him with his social skills, something he struggled with his entire life. He is now employed as a dietary aide at a local nursing home. Mark says he enjoys his work and his co-workers, but, perhaps equally important, he now reports, "For the first time in my life, I have a real girlfriend!"

Education Equals Opportunity

No matter who we are or where we are, education equals opportunity. And opportunity can make the difference between simply living and "having a life." For people like Matthew and Mark who have ASDs, however, attaining an education takes extra hard work and help from others – early in life, during the school years, and well beyond.

The mission of New York State's Office of Mental Retardation and Developmental Disabilities (OMRDD) is to help people with developmental disabilities live richer lives. While that involves many things, it very clearly involves supporting people in their dreams of pursuing education. With the right level of support, people with developmental disabilities can

see *Supporting Education on page 40*

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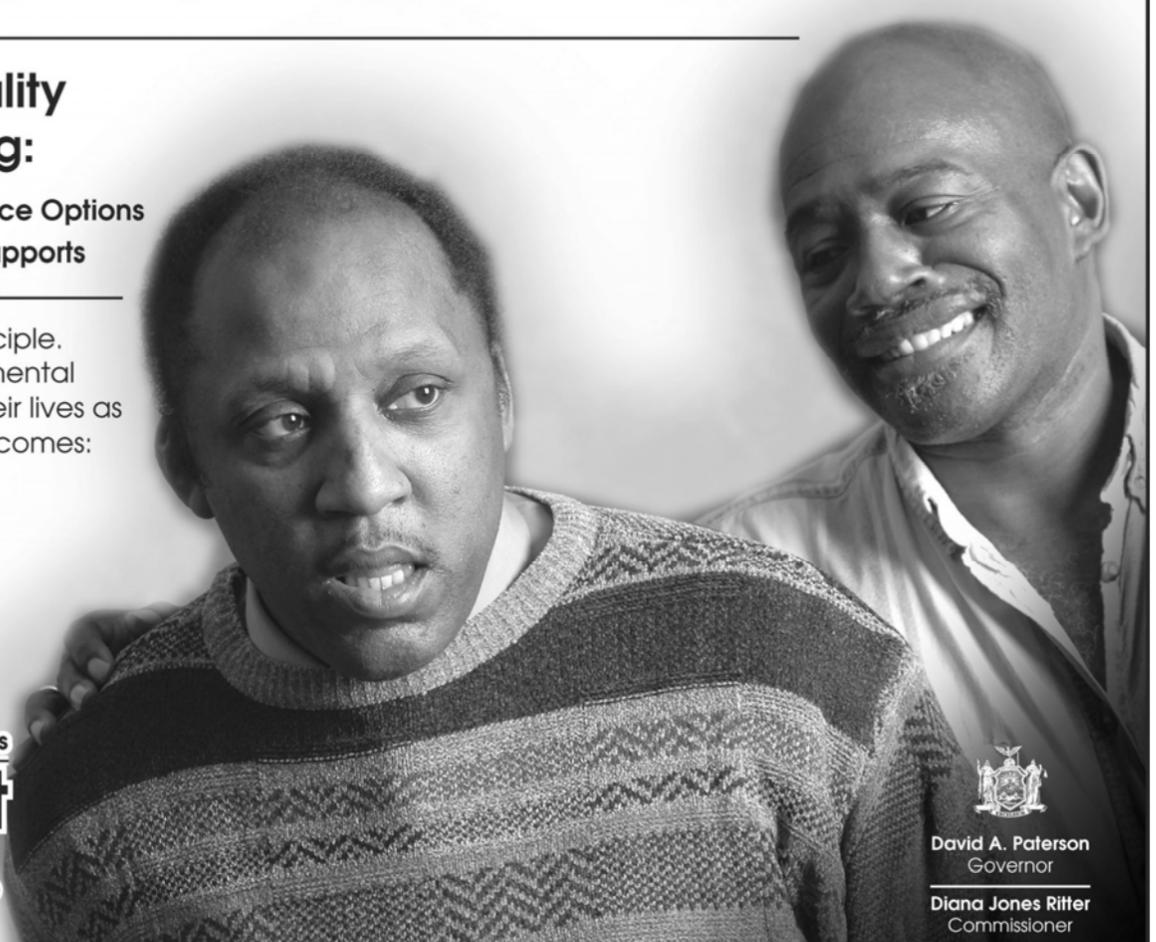
And simply put, it means giving people with developmental disabilities as much individual choice and control over their lives as possible, as well as a chance to achieve four basic outcomes:

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New Socialization Services for Children with Autism Spectrum Disorders

By **Kenneth Popler, PhD, MBA**
President and CEO
Staten Island Mental Health Society, Inc.

One out of every 150 children born in the United States was diagnosed with autism or an Autism Spectrum Disorder last year, according to the National Centers for Disease Control, compared to one-in-166 children in 2004. Despite differing theories as to why autism has been increasing so steadily during the past two decades, there is agreement that children experiencing these challenges require more access to innovative therapeutic services that will improve their functioning.

To increase access to these services for our Staten Island, New York children, the Staten Island Mental Health Society (SIMHS) has teamed up with Kids Connect USA to launch Club Saturday, a therapeutic socialization program at the Elizabeth W. Pouch Center for Special People, the SIMHS division that provides services for children with developmental challenges. The program is geared toward Staten Island youth challenged by autism spectrum disorders - such as Asperger's, PDD, or mild intellectual disability - that interfere with social development.

On eight consecutive Saturday mornings at 10 a.m., about a dozen children, ages 8 to 11, gather at the Pouch Center in West Brighton for an hour of structured



Kenneth Popler, PhD, MBA

activities that have been designed by Kids Connect USA staff, to help them improve their social functioning. The children are guided to participate, at their own pace, in social activities with other children of a similar age. "At all times, program staff offer a positive, understanding approach to the children, making the session a supportive and emotionally nourishing experience," according to Pouch Center Director Dr. John Munk.

The second session of Club Saturday will begin in the spring. There are also groups for younger and older children

planned. To participate in Club Saturday, children must be enrolled at the Pouch Center. For more information, call Dr. Munk at 718-448-9775. Fees are modest and the Pouch Center accepts both Medicaid and third party insurance.

Upon arriving at Club Saturday, the children are individually greeted by the leaders of their group. Each group is led by a staff person from Kids Connect USA, a licensed therapist from the Pouch Center, and an aide. The session begins with the children sitting in a circle and talking to each other, using "conversation starters" provided by the staff. The beginning exercise sets the stage for the rest of the session when the children are paired off and guided into performing various activities in a cooperative manner.

During the activities, each child is encouraged and steered by the staff into conversing productively with his/her partner about the task or project at hand. The primary purpose is to "promote and shape appropriate social interactions between the members of each pair," Dr. Munk explained. "In so doing, the participants are helped at sustaining eye contact, maintaining boundaries, staying on topic, as well as learning how to share, take turns, tolerate frustration, express feelings, etc.," he said. "At the end of each session, the children leave feeling good about themselves because they have had positive interaction with a peer and have accomplished at least one cooperative task."

Over the course of the program, each child is paired with different participants in the group so their new skills are carried over, Dr. Munk said. "The program teaches children how to interact and communicate in socially appropriate ways with a variety of peers. As the children progress, their ability to play and communicate effectively with others improves," he added.

The curriculum encompasses seven separate lessons; an eighth session is held to recap and practice all of the skills learned. Children may continue in the program when it begins a new cycle.

Club Saturday staff leaders meet with parents three times during the eight-week cycle in order to provide feedback about their children's progress. In addition, a Pouch Center clinician meets with parents and/or children on an as-needed or extended basis, in order to address emotional and/or behavioral issues. There is also an option for parents to meet with a Pouch Center therapist in a group setting, which enables them to share their concerns about their children's development, functioning and progress, and learn from each other. The parents group meets in the Pouch Center, concurrently with the children's group.

Kids Connect USA provides services for children with autism and similar challenges, in a group setting with typically developing peers. Sessions encourage children to socialize through play, conversation, and expressive activities.

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Public Schools and the Autism Epidemic: A Preliminary Report on Consultation Services

By **Jamie Pagliaro, MBA, Executive VP Rethink Autism** and **Hannah Hoch, PhD, BCBA, Director REED Academy**

With the recent rise in the incidence of autism, there is a growing need for effective, ABA-based intervention programs in public schools. In 2006, the number of students with autism ages 6-22 in New York State alone was reported as 13,951 (Part B IDEA). Various agencies and programs that serve students with autism have developed Outreach programs which provide comprehensive consultation services to public schools and district programs. Consultation services typically take one of the following forms: (a) trainings and workshops offered to school personnel, parents, or the community at large; (b) on-site consultation provided on an individual or classroom-wide basis; or (c) partner or model classroom programs, in which the outreach agency sets up a partner or model classroom within the public school/school district. In many cases a school district will contact the agency and request assistance with their autism program in the form of one of the aforementioned services.

The benefits of using techniques based on Applied Behavior Analysis (ABA) for educating children with autism have been



Hannah Hoch, PhD, BCBA

well documented in the empirical literature (Lovaas, 1987; Eikseth et al., 1992; Fenske et al., 1985; McClannahan & Krantz, 2001; McEachin, Smith, & Lovaas, 1993). Much of the research that has been published demonstrating the effectiveness of ABA-based programming has examined the effects of early, intensive behavioral intervention (EIBI), focusing on children below the age



Jamie Pagliaro, MBA

of seven receiving individualized instruction. This body of research has confirmed that children who participate in both home- and center-based programs make substantial progress in learning new skills. However, there is a paucity of research documenting the effectiveness of consultation programs serving public school students with autism above the age of seven.

In an effort to gather preliminary information regarding outreach program successes, challenges, and outcomes, a structured interview was designed and administered to three directors of outreach programs that provide comprehensive consultation services to public school programs for children with autism. Each of the programs surveyed provide all three of the consultation services described above. All directors provided similar accounts regarding the resources and effects of the various methods of consultation. Trainings and workshops require the lowest amount of resources, and reach the greatest number of people. The interviewees all reported that it remains unknown what, if any, effect conducting these trainings and workshops in public school settings has for individual students with autism, due to the lack of follow up after the trainings and workshops. Indeed, research has demonstrated that while classroom-based didactic training can be effective in increasing staff members' ability to describe concepts, terms, and procedures, generalization to teaching and improvement in student behavior is typically not seen until hands on, direct training is provided (e.g., Ducharme & Feldman, 1992).

In contrast to trainings and workshops, on site consultation and model classroom

see Consultation Services on page 41

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Improving the Generalization of Skills in Learners with Autism

By Cecelia M. McCarton, MD,
Mary Jane Weiss, PhD,
Ivy Feldman, PhD and
Jackie Hickie, MA, BCBA
The McCarton Foundation

Individuals with autism spectrum disorders have many difficulties in learning. One of the consistent characteristics of learners with autism is that they have difficulty transferring skills to new situations and environments and maintaining skills they have mastered. Such difficulties in the maintenance and generalization of skills have been noted since the disorder was first identified, and continue to be a source of clinical concern and a focus of educational programming.

Everyone who has worked with or known many individuals with autism can think of examples of their lack of generalization. For example, a student may be able to respond when someone greets him or her saying "hello," but not when he or she is greeted with an equivalent but different greeting such as "hi," "what's up," or "how is it going?" Similarly, they may be able to make a sandwich adequately, but fail to do so if the type of bread or brand of jelly is changed.

It is certainly a characteristic of learners with autism that such transfer of



Cecelia M. McCarton, MD

skills is a challenge. Such characteristics make it necessary for teachers to train with variability.

Students need to be prepared for the diversity of circumstances that they are likely to encounter in the natural environment. Teachers can use a variety of educational strategies to facilitate the generalization of skills.

As Baer (1999, p. 1) said, "No one learns a generalized lesson unless a generalized lesson is taught." Since generalization often does not occur without skillful planning, it is imperative that such planning occurs in educational programming for learners with autism.

Instructional Strategies

The field of Applied Behavior Analysis has studied the transfer of skills in individuals with autism for many years. It is clear that generalization is enhanced by incorporating variability into instruction. ABA instruction has emphasized the importance of varying instructions, varying materials, and teaching functionally equivalent responses. Whenever possible, learners are taught with variability from the earliest stages of instruction.

Stokes and Baer (1977) outlined a number of specific strategies to improve the transfer of skills, and emphasized that generalization should not be a "train and hope" approach. They suggested that behavior analysts must plan for generalization in a systematic manner to ensure that the target behavior occurs in similar settings and that desirable responses are strengthened. They suggested a variety of instructional approaches to aid generalization. We will discuss two of these strategies in this article – training loosely and programming common stimuli. One procedure for increasing the likelihood of generalization is what Stokes and Baer refer to as *training loosely*.

Excessive standardization of instruction (i.e., having every aspect of the instructional situation the same every time) impedes both stimulus and response generalization. *Training loosely* involves varying

as many noncritical dimensions of the antecedent stimuli as possible during instruction and accepting a wide range of correct responses to increase the likelihood that skills will generalize to the natural setting.

When behavior analysts train loosely, they vary antecedent stimuli in a systematic manner. Baer (1981, 1999) suggested varying such stimuli as position (therapist or student), tone, words, how stimuli are presented (e.g., from different angles), settings in which instruction occurs, clothing worn by the therapist, reinforcers offered, time of day of instruction, and other environmental characteristics such as persons present, lighting, temperature, smells, and noise. To maximize the benefits of training loosely, these variations should occur as unpredictably as possible. When a student is learning how to match pictures, the teacher may change the pictures, the area of the classroom or school in which the skill is practiced, and whether the task is done on a table or on a vertical board. Each variation does not significantly change the task itself, but all of the changes help the learner to tolerate minor changes in the instructional context. In general, this helps to prepare the learner for the wide variety of situations that he or she may encounter outside of the instructional context.

Training loosely is often a challenge

see *Generalization of Skills* on page 39



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The Education of Real Life

By Marianne Clancy
Board Member, ASAT

As parents of children with autism, we continually search for the answer to the question, "What does my child need in order to reach his or her potential in life?" Our children's potential is greatly determined by the quality of education they receive. Education for our children takes place not only through the efforts of teachers and therapists, but also through experiences at home and in the community. Life is filled with learning opportunities, in all environments in which our children participate. The most significant aspect of parenting for us to consider is the role we parents take in orchestrating an education for our children that uses learning opportunities in the school, home and community.

The ideal educational approach for our children with autism relies on professionals and parents working together and consistently toward a whole life education. Ideally, this begins with the use of teaching strategies that are proven effective for learners with autism (see the gray box at the end of the article for resources). For most useful results, relevant goals are identified by both teachers and parents as those needed in the school, home and community. These goals should be taught to our children systematically using effective



Marianne Clancy

teaching strategies that consider our children's own particular learning needs, rely on their strengths and abilities, and incorporate effective motivation. Subsequent teaching plans should enable teachers and parents to help our children use their learned skills in increasingly independent ways in all environments.

The more we parents understand how our children learn, plus the better we

grasp the proven-effective teaching strategies, the more empowered we are to give our children what they need to reach their potential through a whole life education. By educating ourselves as parents:

We can advocate for our educators and therapists to accommodate our children's needs. Scientific studies provide proof about the effectiveness of treatment and teaching methods for children with autism. Studies are powerful tools we can use in our endeavor to obtain truly effective services. Our children deserve treatments that are shown to be effective. We need to appreciate how proper teaching works for individuals with autism and we need to speak knowledgably and confidently about our children's own particular needs. The more capably we can equate proven teaching methods to our children's individual needs, the more successfully we can advocate for quality services.

We can collaborate with teachers and therapists in the teaching process to promote the carryover of skills. Through ongoing collaboration with our children's educators, we develop a framework in which our children's relevant evolving real life needs are identified, directly taught, and are then taught to be used in various environments. Through this collaboration, educators help us parents enable our children to apply their learned skills in a very real way in the real world.

For example, the ability to "wait" can be applied when waiting for the teacher's next assignment, waiting on line for school cafeteria food, waiting for dinner at home, waiting alongside mom while she chats with a neighbor, "waiting" throughout a religious service. An equally important component of collaboration is our ability as parents to identify to the educators those "real life" needs that are significant in our family life, so that plans may be developed to teach to those needs. Due to the structure and other variables that differ between home/community life vs. school, educators may not be aware of some of the issues that exist for families. Collaboration should involve: informing educators about the needs that exist in our family life; discussing how we can hope to use skills that educators are teaching our children; sharing materials and methods when appropriate; and keeping our educators aware of progress and informing them when generalization does not occur. On-going collaboration provides the opportunity for us parents to enable our children's education to target very relevant real-life goals as they evolve and are shaped throughout stages of life.

We can incorporate effective teaching strategies into our parenting approach. In addition to implementing the educators' plans for skills they teach, we can

see *Real Life* on page 30

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Volunteer for Research on Autism Spectrum Disorders

IAN, the Interactive Autism Network at the Kennedy Krieger Institute, is looking for volunteers to participate in an online research study. To participate, parents of children with an Autism Spectrum Disorder will answer questions online about themselves, their affected child, and other family members. The study's purpose is to increase knowledge about Autism Spectrum Disorders (ASDs) and help find effective treatments. IAN will also match willing families affected by ASDs with other research studies locally or in the United States.

Who Can Participate?

The following people and their immediate family members can participate in this study – Anyone who is living in the USA and who is less than 18 years of age, who has ever been told by a professional that they have any of the following: Autism Spectrum Disorder (ASD), Autism, Asperger Syndrome, Autistic Disorder, Pervasive Developmental Disorder (PDD), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder (CDD). By "immediate family members" we mean biological or adoptive parents and full or half siblings. Step siblings are not included in the IAN Research Database at this point.

Principal Investigator: Paul Law, MD MPH • Contact: ResearchTeam@IANproject.org
JHM IRB#: NA_00002750



Approved 07/08/2008

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Planning for Children with Special Needs

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

Our special children with disabilities need our love, devotion, energy, compassion and patience. However, this is not enough. Their special needs also demand special planning. Parents of children with special needs know that their child will require lifetime care, care that can be both complex and expensive.

Parents also realize that there is a very good chance their special children may outlive them. Yet many parents have not planned for this eventuality. In many cases, parents have not even made wills! It is not surprising that many parents have not provided for the care of their special children when the parents can no longer care for them.

For the child with special needs, the consequences of failing to plan properly can be nothing short of disastrous. Many children with special needs cannot take care of themselves. They may be vulnerable. Who will care for the child? Where will the child live? Who will pay for the child's expenses? Who will administer necessary medication? Take the child to the doctor? Feed the child? You must plan for all aspects of care for your disabled child, and you should do it now.

Often, the parents are the only ones with the specific knowledge of the child's needs, medications, physicians, likes/dislikes, routines and habits. Absent proper planning, if you die suddenly, no one will know how to care for your special child. You must ensure that a transition will be as seamless as possible, to protect the special child from dislocation



Raymond J. Falcon, Jr., Esq.

and disruption and assure a continuum of care and safety.

Many parents say they don't know where to begin. One excellent start is to take the following systematic approach: identify the special needs of your child; develop information about each need and a specific plan to address each need; and plan methods for paying the costs of meeting those needs.

In short, prepare a user-friendly road map, sometimes called a "Letter of Intent," containing as much information as possible on caring for the special child. Give the roadmap to the person who will care for your special child when you can-

not. This way, whoever takes over as caregiver will have the necessary guidance and information to care for the child from the very first day.

Where to begin? First, visualize what the "letter of intent" or "roadmap" should look like. Imagine you are no longer around and someone has come to your house in order to care for your special child. What would you tell that person if you could? Pretend you are writing a letter to the caregiver. At a minimum, your letter must address the following areas:

Medical / Physical - Specify in detail the nature of each of the child's disabilities. Provide a complete medical history starting from early childhood. If possible, list names and contact information for every doctor the child ever consulted. Identify current physicians and other care providers, medicines (with a schedule for dispensing them), pharmacies where the prescriptions are held. Provide addresses and telephone numbers. Specify the child's eating habits. What is her clothing size and taste. What kind of food does she like or dislike. Can she dress, feed, move, bathe or toilet himself. If not, what type of help does she need. Does the child have special transport needs.

Psychological / Emotional - Identify any psychological or emotional issues the child may have. Does he anger easily. Is he shy? If the child is receiving therapy, include details on the therapist and the type and frequency of treatments.

Safety - Is the child safe to leave alone. Are there any alterations to living arrangements that are currently necessitated by the disability or may become necessary

if the disability worsens. What other steps must be taken by the caregiver to protect the child.

Social - What does the child like to do. Read. Watch TV. Play video games. Listen to music. Paint. Travel. Equally important, what does the child not like to do. If the child has friends, identify them, with addresses and telephone numbers.

Spiritual - Does the child have a faith life. Identify the spiritual counselor - rabbi, minister, priest - with contact information. If the child does not have a spiritual counselor, consider establishing a relationship among yourselves, your child and a counselor. This will assure the child will have spiritual comfort upon your passing.

Economic - Will the child have money to live, to pay medical expenses. Where will the money come from - inheritance, government benefits. Does the child have a job. If so, where, and what are the work hours. Where will the child live. Is the child receiving any government benefits. If so, which ones. Provide details on the benefits, along with contact information at the relevant agencies. If the child is expecting to inherit money from parents, grandparents or others, will the inheritance cause a loss of any government benefits that are based on financial need, such as Supplemental Security Income (SSI) or Medicaid. If so, have provisions been made for special needs trusts or other vehicles to receive the funds, instead of the child, in order to avoid losing those benefits.

see *Planning for Children* on page 42

Medical Home from page 9

experiences working in New Zealand, where most medical students plan on going into primary care and where specialization was the exception. Access to doctors seemed easy and doctors got paid the same, regardless of their specialty. In every country, there are cultural and monetary factors that influence the direction of new doctors' medical careers. But year after year, we see that lifestyle is one of the leading factors influencing young doctors' career choices.

The demands on a primary care physician are many, the supports few and the monetary rewards are far less than for those who specialize. The states have been taking this lack of interest in primary care seriously and the Obama administration is showing interest in this problem. Reimbursement reform to rebalance the medical services pyramid by adequately supporting primary care is being investigated in a number of states, including New York, where I work.

A Team Approach

Much like a Medical Home, my own New York City-based agency, Premier HealthCare (PHC) provides on-site access to a full range of coordinated services to

meet the needs of people with disabilities. Each patient has an ongoing relationship with a personal physician, who oversees continuous and comprehensive care. As a member of the YAI/National Institute for People with Disabilities Network, PHC collaborates effectively with other agencies within the Network to provide other services to our patients. Through our Network, our patients get medical care, rehabilitative services, mental health care, case coordination and access to a variety of other New York State-sponsored supports. We offer multiple service locations in the Bronx, Brooklyn, Manhattan and Queens and open scheduling, including evenings and weekends.

When a person visits Premier HealthCare, he or she is likely to be greeted and seen by the same physicians, therapists, nurses, social workers and other trained professionals on each visit. We understand that a person's care is intricately tied to other factors, such as familiarity and continuity. This is one of the many reasons PHC was cited by the U.S. Surgeon General as a national model for the provision of health care for people with developmental disabilities.

In our new Weight and Health Management Program, for example, a PHC primary care physician makes referrals to

a nutritionist, physical or occupational therapists and counselors. All of these take place are overseen by a care manager under one roof, with a team of dedicated professionals sharing the responsibility for patient care and communicating with one another through a centralized database. This comprehensive approach is helping people with developmental disabilities reach their weight and health goals.

An advanced Medical Home will improve the access, communication and coordination of care, which is so essential to working with people on the spectrum. One health care professional will see the whole picture and oversee all of the care. The team will talk with one another, and the model will have to expand to include teachers, job coaches, and home health personnel. Reimbursement will have to recognize the heavy load of care management necessary for this group of vulnerable people. A new model to reinvigorate and modernize the delivery of primary medical care for people on the spectrum - and all Americans - is desperately needed.

Peter Della Bella, MD is Director of Clinical Programs for Premier HealthCare. Premier HealthCare is a member of the YAI/National Institute for People with Disabilities Network.

Practice Standards Addressed in the Patient-Centered Medical Home

- Patient access
- Patient registration and tracking
- Care management and evidence based guidelines
- Patient self-management support
- Electronic prescribing
- Advanced electronic communications
- Test and referral tracking
- Performance improvement

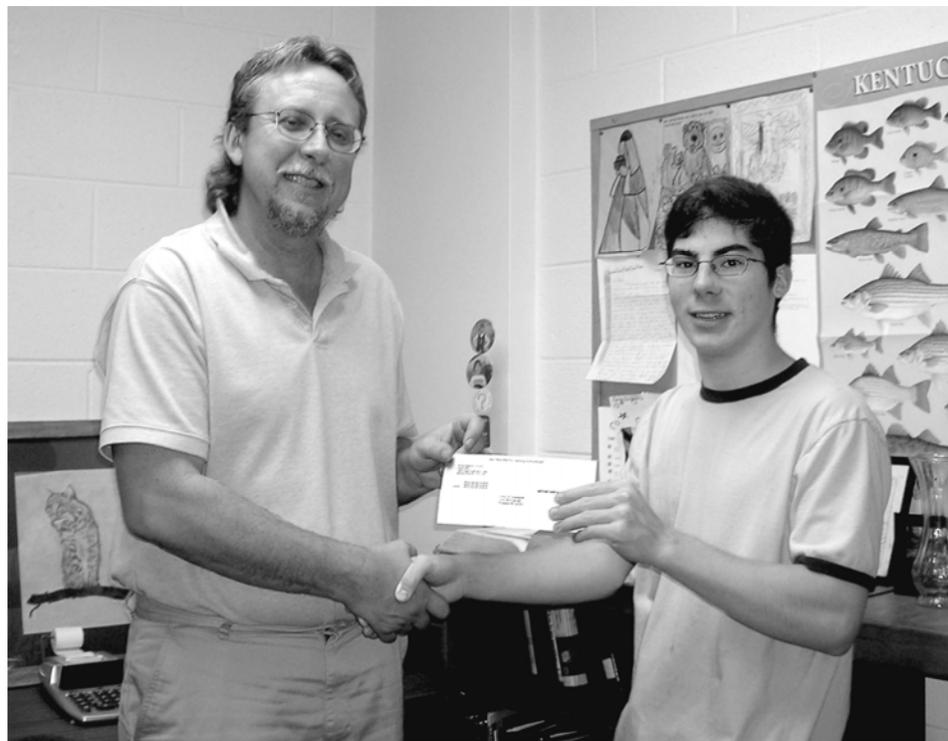
From the National Committee on Quality Assurance, PPC-PCMH Standards and Guidelines, 2008.

The Daniel Jordan Fiddle Foundation Announces 2009 Community Grants

18 Programs Throughout the United States Provide Opportunities For Adolescents and Adults with Autism to Participate in Community Life

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

The Daniel Jordan Fiddle Foundation, a 501(c)(3) national autism organization, based in Ridgewood, New Jersey has announced its eighteen 2009 grantees from across the United States. The Daniel Jordan Fiddle Foundation (DJF) 2009 Grantees represent outstanding and innovative role model programs and exemplify the organization's mission to develop and support residential, recreational, vocational, educational and family programs that provide suitable and sustainable opportunities for adolescents and adults with autism to participate in community life. The 2009 grantees showcase success stories that offer promising practices that can be replicated in communities around the country. Each program provides an avenue for its participants to obtain hands-on experiences that can travel with them throughout adult life while enhancing skills that advance productive futures. Importantly, each program provides a support system that maximizes independence and values the individuality of each person. Linda Walder Fiddle, Founding Executive Director of DJF, sums up the organization's philosophy



A young man from the Kelly Autism Program in Kentucky, a 2009 Daniel Jordan Fiddle Foundation grantee, receives a paycheck in the school-to-work program funded by the foundation.

as "accepting and meeting individuals with autism where they are," and she states that,

"the goal is to provide the necessary training and supports that will lead to successful

outcomes and the best lives possible for all adults with autism."

The DJF 2009 grants provide opportunities for young adults as they age out of school programs into adult life, adult programs geared towards addressing residential, vocational, educational and recreational needs, and programs that provide mentoring and volunteer opportunities, including ones where individuals with autism are the mentors. Examples of the types of innovative programs awarded grants include: a decision-making skills program for teens with Asperger's Syndrome that also provides training about legal and acceptable community behavior; a cookie-making business owned and run by adults who reside in a rural farm setting; master art classes and arts related job placements for adults in an underserved community; and music and art programs for residents of group homes. Other 2009 DJF grants awarded were for: an entrepreneurial endeavor where participants will make and sell furniture; theater and film-making workshops; and a variety of social skills and support groups in suburban and urban communities. Several programs provide vocational assessment and training including job placement guidance. For specific information on The Daniel Jordan Fiddle Foundation 2009 Grantees visit www.djfiddlefoundation.org.

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THE MISSION OF THE DANIEL JORDAN FIDDLE FOUNDATION IS TO DEVELOP AND AWARD GRANTS TO RESIDENTIAL, RECREATIONAL, VOCATIONAL, EDUCATIONAL AND FAMILY PROGRAMS THAT ENRICH THE LIVES OF ADOLESCENTS AND ADULTS WITH AUTISM. OUR EXPERTISE ENCOMPASSES DEVELOPING, IDENTIFYING, SUPPORTING AND SUPERVISING EXEMPLARY PROGRAMS THAT HONOR THE INDIVIDUALITY OF EACH PERSON WITH AUTISM.



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Pennsylvania Grants from page 6

- The Children's Hospital of Philadelphia (CHOP), collaborating with the University of Pennsylvania, Temple University, Lincoln University and the Philadelphia Public School system, will receive \$4.7 million to conduct research aimed at gaining a better understanding of the biological causes of ASD. The studies are based at CHOP's new Center for Autism Research, a collaborative center of emphasis that draws upon faculty and staff at CHOP and Penn in more than

ten different disciplines. Researchers will study how recently discovered genes for ASD affect the brain and behavior of children with an ASD, including a study of how genes, brain structure and brain function impact treatment response. Findings from the research project will facilitate the development of more effective tests for diagnosing ASD and will lay the necessary groundwork for major advances in the clinical care of ASD.

- The University of Pittsburgh, in association with Carnegie Mellon Univer-

sity, will receive \$3 million to identify cognitive and genetic mechanisms underlying the abnormal development of brain circuitry associated with ASD. Recent research has demonstrated altered information processing by the brain of persons with autism. Researchers will develop and test a new intervention to enhance thinking capacity and meaningful integration of information and brain circuitry. Researchers will also conduct gene expression studies to identify genes potentially responsible for the development of altered brain cir-

cuitry in ASD. This evidence will be used to guide a more refined search for ASD candidate genes.

These grants are awarded as part of the Commonwealth Universal Research Enhancement Program (CURE), which supports clinical, health services, and biomedical research.

More information on the use of tobacco settlement funds can be found at the Pennsylvania Department of Health's Web site for health research grants program at www.health.state.pa.us/cure.

Creative and Preferred Extracurricular Activities Provide Gains to Students with Special Needs

Denise Ann Watson
Director of Public Relations
The Glenholme School

On educational campuses, student involvement in creative and preferred extracurricular activities is an essential tool in each student's personal development. The diverse experiences these activities provide can positively impact their emotional, intellectual, social, and interpersonal progress. Decades of research routinely demonstrates that these experiences are particularly beneficial when educating students challenged with social skills and motivational deficits.

The Glenholme School, a center of the Devereux Foundation, is among the many facilities studying the various methods of enhancing the social learning of students with special needs. Of the nine outcome studies conducted at the school over the past eight years, two provide valuable information on engaging students in creative or preferred activities. These studies are "The Effects of Engagement in Instructional Extracurricular Activities on Children's Behavioral Functioning," and "The Impact of Preferred Activities on Residential Programming on Children's Behavioral Functioning."

"The Effects of Engagement in In-



Denise Ann Watson

structional Extracurricular Activities on Children's Behavioral Functioning," which concluded in May 2000, indicates that when students are positively engaged in activities of high interest, they exhibit more consistent and on-task behavior. The activities of this study included the equestrian program, fine arts and drama instruc-

tion, and the community service program. These findings demonstrate that educational facilities can reduce the frequency of disruptive behaviors and the need for negative or corrective behavior techniques by consistently involving students in instructional extracurricular activities. By doing so, the adults in the treatment environment can find more opportunities to reinforce positive behaviors, which research has consistently shown to be the most effective means of modifying behavior. One useful application of this study, aside from the feedback that the decision to fund creative engagement activities appears to be warranted, is that it provides empirical evidence of the positive impact interactive activities have on students.

More recently, "Measuring the Impact of Preferred Activities in Residential Programming on Children's Behavioral Functioning," which concluded in April 2005, demonstrates that the use of special treatment procedures can be reduced by creatively engaging students in instructional extracurricular activities. The continued focus on positive programming for students and providing a high concentration of preferred activities has led to the broadening of the scope of extracurricular activities at the school over the course of the past several years. The activities of this study involved the artistic, athletic, technological, and intellectual strengths

and interests of the students that Glenholme serves. A sampling of the activities include music, dance, chorus, sports, technology, art, drama, equestrian, cooking, ropes course, and yearbook.

The Glenholme School's outcome studies discussed here demonstrate that participation in creative, instructional extracurricular activities reduces problematic behaviors. When problematic behaviors are reduced, students are more available for learning to occur. Creative and preferred extracurricular activities are a contributing factor to the success of Glenholme's Milieu Therapy, which is present in every aspect of student life. This program utilizes positive behavioral supports, attends to motivational deficits, and fosters self-dependence. A sampling of the current activities include equestrian, art, drama, dance, music, choral, athletics, graphic design, TV broadcasting, programming, photography, robotics, student government, community service and much more.

Involvement in creative and preferred activities provides much more than a simple creative outlet for students; it assists students in gaining experience in a variety of areas. Participation in athletics and organized activity instills cooperation, teamwork, time management, responsibility,

see Activities on page 39

Carolyn Reinach Wolf, Esq. **Douglas K. Stern, Esq. of**

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Our firm regularly contributes to a number of publications concerned with Autism and related Health Care issues and participates in seminars and presentations to professional organizations and community groups.

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Robin's Voice

A Resilient Mom's Commentary on Autism



Education is a Two-Way Street - Rules of Engagement in Autism

By Robin Morris
Freelance Writer

Eye contact. Social recognition. Interaction. What are goals for children of autism? I silently answer the *Jeopardy* clue in my soul. Every hour of every single day is consumed with navigating the repartee of autism.

While I stress the responsibility of social rules with my son, I am forever cognizant of his frailties. We have no latitude for his slip-ups in fear that others will shun him. Concurrently, what strikes me as remarkable is the "slack" that we cut for the general population who simply go for what they want and get it. Along this journey are stunning examples of rude behavior portrayed in the typical world.

Our son recently participated in a ceremony where a father spoke candidly about his view of autism. "Imagine walk-



Robin H. Morris

ing down Madison Avenue in New York City without the gift of sight," he said. "Close your eyes and walk without relying on the red or yellow or green

lights." When we open our eyes, we appreciate those colors with more intensity. How in the world does a blind person navigate through life? It is a rhetorical question, unbearable; however, we recognize seeing-eye dogs and Braille as tools for existence.

How in the world does a person with autism navigate through life? I often ponder on what resources my son draws upon, as he filters sounds and the world around him. How does the kaleidoscope of senses collide and erupt with anxiety and despair? How does society accept these hidden wounds that present as bad behavior?

Our family attended a function last spring where the guests were young children who were educated in private schools. Irregardless of age, gender or intellectual status, all of these children were direct, friendly and looked straight in the eye when spoken to. Wow! These kids could teach social skills classes to children on the spectrum...hey, they could even

teach these skills to typical children.

A cousin remarked that private schools are tantamount to finishing schools in how they teach appropriate social interaction. Sounds good to me.

I remember years ago a scenario where my mother-in-law addressed a child while singing her words: "Thank you and please are two little keys, that open the door to happiness."

This morning I made a poached egg for my son Paul who has autism. Finishing his last bite with great relish he exclaimed, "Thank you Mom, for such a delicious breakfast!"

No finishing school here; simply a desire to please. I'll take it. Today my door to happiness is wide open.

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

Can You Teach Fear to Your Child with Autism?

By Robin Morris
Freelance Writer

In the book *The World According to Garp*, there was a memorable quote when Garp's son said, "Watch out for the undertoad." Thirty years ago, when I read John Irving's novel, I hardly recognized the level of anxiety a parent suffers for his child. I embraced the irony of the text, when Garp's son mistakes the word "undertow" for "undertoad" as he imagines a giant reptile lurking the ocean floor. My kudos along with the critics praised the genius and the comedy.

I now join Mr. Irving who gave a voice to T.S. Garp as he agonized for the safety of his children. My recurring mantra "be careful" resonates in my children's ears as they move into their everyday ventures, as

if my words will make the difference.

Last fall I visibly shuttered as I read about Christopher Marino, a child with autism, who escaped drowning — a miracle they said. According to the article, 12 year old Christopher and his dad Walter were swimming in the Atlantic and were separated by a riptide. Apparently 12 hours passed while the father and son drifted apart. Mr. Marino detailed the agony as he treaded water, along with his son. The only tool available to keep Christopher attentive was reciting quotes from Disney's *Toy Story*. "To infinity" Walter yelled, as Christopher shouted, "and beyond" until darkness fell and there were no more voices to be heard.

The miracle arrived the next morning as a group of fishermen rescued Walter Marino. The coast guard arrived and helped a weeping Marino onto their boat.

He believed his son was dead; refusing to stand on the top deck, for fear of seeing his child face down in the water. Ultimately he was summoned up top as one man pointed to a helicopter saying that Christopher was on board. The circle complete, Dad and boy were united.

When interviewed, Walter Marino detailed the perils of autism and the absence of fear. Christopher was unaware of the danger in those shark infested waters; he only balked at the sting of jelly fish. It begs the question — can you teach fear?

I remember a time when Disney was our bible. I remember the years when our son Paul talked in riddles and communicated with song. I cried as I videoed his joyous grin, while watching *Oliver and Company*. The lyrics from *Good Company* are close to my heart: "You and me together we'll be...Forever you'll see...We

two can be good company You and me...Just wait and see."

Twenty years later, I still want to protect Paul and keep him safe from harm. Last summer, riptide stories were broadcast on local news and at a beach in Rhode Island, I repeatedly cautioned him to swim sideways if he felt a pull of water.

John Irving's final words in Garp articulate a parent's fears of the world: "If Garp could have been granted one vast and naïve wish, it would have been that he could make the world safe, for children and for grownups. The world struck Garp as unnecessarily perilous for both."

Although my silent pledge to Paulie remains "you and me together," I am forever cognizant of a chilling reality. The best we can do is enlighten the world, while reinforcing and supporting our children as they grow and learn at their own pace.

Sea of Interventions from page 1

how key developers of some of the more well known, promising educational/developmental/behavioral approaches think about persons with autism. We are at a crucial moment of time where autism has been recognized as a diagnosis for only about 60-65 years combined and most of these key theorists are still alive.

Diversity of Autism

There is great diversity within the

autism spectrum. So many different types of people have been collected into our concept of the autism spectrum that the diagnosis of autism itself has become almost useless. This great diversity of autism speaks to two main points. Firstly, individuals are going to have widely differing needs meaning that certain approaches will work for some but not others. Secondly, finding ways to subtype people with autism may help in the endeavor of matching best practice to the needs of children with autism.

One Theorist's Response to the Diversity of Autism

In fact, some of the key developers from the more well known, promising approaches are already doing so. For example, Arnold Miller has divided children with autism into two predominant types. The first, termed "Closed System Disorder" (Miller, A., 2007) refers to a child overly involved in the need for order in his systems. This is the child who may tantrum when an activity or routine is disrupted without a proper transition.

This child may also insist that doors be closed. He or she may get so focused on an activity that the world is shut out.

In contrast, a child with "System Forming Disorder" (Miller, A., 2007) may seem to have a big dose of ADHD where they seem to orient to salient stimuli in the environment but fail to engage. A child of this nature presents as having a very short attention span.

These two types of children express autism very differently and require different

see Sea of Interventions on page 38

Bringing Computer Technology to the Forefront in Autism Education

By Dana Battaglia, MPhil, CCC-SLP and Mary E. McDonald, PhD, BCBA Eden II/Genesis Programs

Individuals with autism often do not learn in the same way that their typical peers do (Geurts & Embrechts, 2008; Perkins, et al., 2006; Boucher, 2003; Wilkinson, 1998). To succeed when teaching an individual with autism, a teacher must capitalize on the learner's strengths. Historically, treatment methodologies have demonstrated that students with autism typically benefit from visual, rather than auditory teaching strategies. In keeping with this modality, we have recently made attempts to teach new skills to some of our students across a variety of curriculum domains. Some areas include expressive language, activities of daily living, speech, socialization, academics and vocational skills. We believe that by integrating technology into our curriculum that we can maximize our intervention time and make education more fun for everyone involved. (Yes we do have fun creating the curriculum!) In the year 2009, technology is so prominent in our daily lives that it is important for educators to introduce technology to individuals with autism spectrum disorders early on in their educational career, beyond the point of using a computer game. As a teacher and clinician, one of the strengths



Dana Battaglia, MPhil, CCC-SLP

of using technology within curriculum is its versatility (Goldsmith & LeBlanc, 2004; Hetzroni & Tannous, 2004). Using technology can allow teachers to individualize curriculum easily and update it. Updating materials is essential, especially if the student has difficulty or is progress-

ing well and needs to be challenged.

One particular computer program which has been very successful in accomplishing this has been PowerPoint. PowerPoint® is a Microsoft Office® program well known in the business world for more formalized presentations. This powerful program allows one to insert sound, pictures, and video clips. Font styles and background coloring can be manipulated to keep with a given theme. There lies the ability to animate words, pictures and actual slides for added effects. We have taken the capabilities of this program and applied it to our own curriculum objectives for our students. We are using it specifically for children with autism in educational and therapeutic interventions. Students' individual goals can be addressed through the use of PowerPoint presentations. Some examples of how we are using PowerPoint have recently included: targeting learning of irregular past tense verbs, identifying actions, improving rate of speech, initiating "hi," imbedding video models, and activity schedules (Rehfeldt, Kinney, Root, Stroman, 2004).

More recently, individuals with autism have been using virtual reality websites (i.e. "second life") to improve social skills. While technology is certainly exciting and (sometimes) unpredictable, once thing is for certain: The future for children with autism in use of technology

is certainly bright! There are both challenges and benefits of using computer-based technology with our learners with autism spectrum disorders (Bosseler & Massaro, 2003; Herrera, Jordan & Vera, 2006).

Challenges When Using Technology

Although we as teachers are finding use of technology to be a successful teaching tool, with all things in life, there are challenges. When moving from computer to computer, different versions of programs must be compatible. In addition, technological breakdowns can cause a student to be unable to address a given goal, should it only be in a one format. Finally, there may be times when a child is unable to access a computer. In addition, creating items to embed within a PowerPoint may be time consuming, such as video clips or pictures. However, the pros have been shown to outweigh the cons, and can certainly be worked around.

Benefits of Using Computer Technology

There are several benefits to using technology in one's educational planning. For example, objectives can be targeted, regardless of whether the clinician is physically present. Written, auditory, or visual prompts can be manipulated very

see Technology on page 38

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Real Life from page 23

also consider a lifestyle approach of parenting our children more effectively. We can parent more proactively and more successfully by stating our expectations clearly beforehand in a way our children understand best, and by helping and motivating our children to meet our expectations. Without conscious planning, it is easy to habitually "hover and help" our children, which can create prompt dependent and stifle autonomy. If we understand effective parenting (teaching) strategies and motivational approaches, we can enable our children to perform skills and complete tasks to their greatest degree of independence.

We can apply the same parenting approach in various settings in the community. We can teach our children to use their skills in more and more situations and environments in greater ways and with increasing independence. We can solicit the efforts of members of society. When we are in the market, there are available employees with whom our children may interact: clerks at stores, librarians, waitresses, children at the bus stop, friendly families at our religious services and other community engagements. These are all people who can help our children interact more meaningfully and successfully in society, if we parents facilitate our children's ability. It is a productive parenting process that is borne from a pattern of successes between ourselves and our children, beginning in the home and

familiar environments, then expanding into other environments, involving members of the community as needed. It's a brilliant recipe to successfully enable our children to interact meaningfully with the people and places in their lives.

Assessing our children's needs, teaching to them, motivating them, systematically furthering them based on a pattern of successes, coordinating our efforts with those of the educators, teaching our children to use their skills in various settings, involving other people when possible, giving the support our children need in order to function to their greatest degree of independence by fading our help as parents and enabling our children to become their most capable self. Those are our goals as parents. That's what we want for all our children, not just those with autism. The be-all and end-all is the approach we use to lead our children there. It requires planning and forethought. It's a systematic process that begins with our very first successful interaction and builds from there. Their future begins today. Once we find the pattern, we can take the systematic steps to apply it as needed, orchestrating a "whole-life" education for our children with autism.

Marianne Clancy is the parent of a teenager with autism. She is president of the Autism AIMS LLC - www.autism-aims.com - and a board member of the Association for Science in Autism Treatment - www.asatonline.org.



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Coping with Asperger's in the Home

**By Betsy Ern, MA
Parent of a Young Adult
With Asperger's Syndrome**

After graduating from high school Andrew, our son with Asperger's, headed off to DigiPen Institute of Technology in Bellevue, Washington, the only college in which he was interested. I had, in fact, accompanied him to the school his sophomore and junior summers so that he could attend two-week workshops there.

DigiPen seemed the perfect fit; Andrew enjoyed the workshops and the instructors observed that he exhibited the drive and talent necessary to succeed at videogame design, one of DigiPen's programs. I had always promised Andrew that once he finished high school his real life would begin, and I had high hopes that this would be his time.

My husband, our younger son and I all went out to Bellevue with Andrew to set him up in an apartment. Although he would be far from home, Andrew's world in Washington State would be small with everything he needed in walking or bus distance. We felt comfortable he would be able to manage.

I'd seen Andrew interact with other students at the summer workshops and observed that they appeared similar: introverted, heads held down under hooded



Betsy Ern and her son Andrew

jackets, not much facial expression. I hoped that a common passion would help the students find a way to relate to one another and that Andrew would make the social connections he hadn't been able to make in high school.

We attended an orientation barbecue for new students and their families. The president of the school spoke, warning of a demanding program that would require many hours of hard work and focus. He threw out a scary statistic, that less than 50 percent of the freshman class would make

it to graduation. How we prayed Andrew would be one in the successful group.

For a while, Andrew held his own. Ultimately, though, it became apparent that he did not have the life or organizational skills to complete the rigorous program. He attended classes regularly, but couldn't get the assignments completed, falling further behind as the semesters progressed. He misunderstood instructions and got stuck in his misinterpretations. He couldn't approach instructors to ask for help. He missed appointments with student services personnel because he was uncomfortable with people he did not know. He said things or behaved in ways that made sense to him but bewildered or inadvertently offended instructors.

Even though he hadn't been asked to leave, we brought Andrew home at the end of his second year. Although he had the intellect and interest to succeed at DigiPen, he needed more support than the school was equipped to give him. It seemed ironic considering that Andrew was the typical example of a student who would be drawn to such a program and that, I suspected, at least some of the instructors might have shared Asperger's traits as well. (Although DigiPen was unable to support Andrew's needs at that time, the school was promoting awareness of autistic spectrum disorders and had begun to develop student services to meet special needs by the time we had left).

Andrew was home for about six weeks before my husband and I realized that we had to find something else for him to do. My husband called an educational consultant, named Daria Rockholz (drockholz@aol.com), who specialized in matching special needs students to the right schools. Through her we found College Living Experience (CLE), a private student support program based in Florida. The whole family took another trip, this time to see whether CLE might be the right next step for Andrew.

At that point CLE, with a long standing reputation of success providing support and instruction to special needs college students, was being purchased by ESA, Educational Services of America. ESA was expanding the program beyond its Florida location, which was a good thing for us because although Andrew agreed that the program sounded right for him, he "hated Florida."

We enrolled Andrew at CLE's then brand new Denver, Colorado location, where Andrew would take classes at the Community College of Denver. The CLE team offered full scale support to Andrew in academics, including mandatory tutoring and interfacing with instructors, and independent living skills, everything from cleaning an apartment to managing finances. The CLE team also provided

see Coping with Asperger's on page 41

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Making Inclusion Work from page 1

lost and families should be somewhat suspect of the program. For adolescents, direct parent involvement may be somewhat less, but they need to know what social thinking skills are being practiced and what opportunities there are for real-world generalization.

Sometimes social skills programs are too simplistic, teaching only the basic instrumental skills such as eye contact and greeting. Helping individuals understand social norms and develop more sophisticated social cognition skills are critical for relationship development, which is what is critical for long term social success and independence. So, although a parent may be overjoyed that there is any social skills opportunity, it is still necessary to be a critical consumer and request a detailed statement of philosophy and curriculum, whether it is a school (Bellini et al., 2007) or a private practitioner in the community (Rao et al., 2008, White et al., 2007). Secondly, even if basic social skills have been acquired, children with AS may continue to experience difficulty developing authentic relationships. Their interests may be atypical or age inappropriate or they may have all their social overtures rejected by others. Here, supportive adults can have an important impact. Teachers and related service providers can facilitate interactions in the real life situations that school provides, particularly on the playground, at lunch, and in other unstructured situations. Parents can help by assisting their children find others with shared interests. Parents often ask what to do when their children are unable to make friends. Finding another who loves Warhammer, entomology, or fantasy goes a long way toward starting a relationship. Parents and teachers can be creative in finding appropriate peers with similar interests through clubs, internet sites, or other personal resources. Putting random children together who share only the diagnosis of AS (and consequently poorly developed social skills) is far less effective than finding two children who are both fascinated by the same activity and can talk endlessly about it together. Even when an appropriate peer has been found, and the children seem to be a good match, adults should bear in mind that their facilitation of social interaction can help immensely, especially in the early stages of acquaintanceship.



Lynda Geller, PhD

Organizational Problems Within the Context of Good Academic Skills

Problems with disorganization are very common for students with Asperger Syndrome and frequently have a very negative impact on achievement. If a child has these problems, asking him to just be more organized or providing negative consequences are ineffective and painful interventions. A neuropsychological evaluation can help us understand exactly what underlying skill deficits are causing these students to lose their initial academic advantage. A student who is processing information more slowly than others, or who can't set priorities, or who doesn't understand the passage of time, or who over focuses on details and never finishes work (and these are all fairly typical of individuals with AS) may find less and less success with academics over time and lose that important source of self-esteem. If the underlying problems are identified and specified on an IEP, finding a way to support the student's organizational difficulties becomes an educational imperative, rather than a source of personal criticism. For an unclassified student, the specific recommendations a neuropsychological evaluation can provide may still lead to more specified help and a less likely tendency to blame rather than sup-

port. Be ready to suggest a consultant who can educate teachers and other school staff in fundamental brain differences and how they manifest in this population. Many educators do not know this important information.

Immature or Inappropriate Emotional Expression

It is a fairly common outcome of having limited friendships that emotional maturity is slow to develop and sometimes develops oddly in the face of daily social pain or anxiety. Emotional regulation is a developmental skill that arises as an interaction between one's basic brain mechanisms and the daily experiences with others that children have (Geller, 2005). Children with AS often have differences in the neural circuitry responsible for emotional development. These differences may color their experiences in the world. Furthermore, through self isolation, limited numbers of relationships or peer rejection, the opportunity for social-emotional learning may be less than for typical children. These difficulties play out in school as immature social regulation, inability to modulate response to disappointment or frustration, or anger in response to any deviation from expectancy. Immature behavior further distances the student with AS from others, and may jeopardize the school placement. School personnel often have not been trained in specific techniques to support children having these problems. A behavior plan that is too simple tends to exacerbate rather than help a child who is losing emotional control because of complex brain-related issues. A consultant, who is highly experienced in the emotional development of children and adolescents with AS, may be invaluable in helping a school develop a protocol to manage and support this kind of student. This may help a child maintain school placement and contribute to the development of more socially appropriate emotional regulation.

Isolation, Anxiety, and Depression

Often children or adolescents with Asperger Syndrome retreat to the internet or a fantasy world to avoid social anguish. Families are often at a loss as to how to change these behaviors. Sometimes schools are punitive when students cannot attend, blaming the student for being manipulative or the parents for not

exerting discipline. Students with AS who are showing excessive isolation should be evaluated for an anxiety or mood disorder. Changes from their typical functioning, such as an increase in irritability or aggression, should also be evaluated from a mental health perspective. These are treatable problems that require close cooperation between the school and the family. Schools need to try to help families find appropriate professionals, cooperate in treatment protocols, and investigate sources of fear and anxiety such as bullying or overwhelming situations. Families need to take potential anxiety and depression seriously, not view these issues as an inevitable part of AS, and seek appropriate treatment.

Wide Variations in Development

Students with AS characteristically exhibit wide disparities in basic abilities. Typical difficulties directly attributable to brain function include poor coordination, handwriting difficulties, slow processing, inattention, and extremes in academic ability. It is more difficult to be a person with widely varying abilities because expectancies are often unrealistic. Just because a student can solve any arithmetic problem mentally does not mean that keeping order in long division is accomplishable. Just because a student can speak eruditely about history does not mean that writing mature compositions about history is possible. So it is critical to understand strengths and weaknesses so that weaknesses can be identified and supported and, just as importantly, intellect can be challenged. Sometimes language or motor function can sabotage other skill areas. Consequently, even for older students, regular Speech and Language, Occupational Therapy, and Physical Therapy evaluations are critical to addressing unevenness of academic performance and helping us develop important interventions to support ongoing academic progress.

Families need help making an honest appraisal of what specific strengths and challenges their children face and if the student's school is willing and able to address these needs. We know from experience that children with Asperger Syndrome cannot develop these skills on their own

see Making Inclusion Work on page 42

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Cutting Through Irrational Fiscal Fear and Administrative Paralysis To Secure Appropriate and Effective Autism Programs

By Gary S. Mayerson, Esq.
Founder and Director
Mayerson and Associates

Even during our most recent period of unprecedented, if not unbridled economic prosperity, the cost of providing special education was treated as an unwelcome burden that taxpayers were “mandated” to support. Congress had enacted IDEA (now known as IDEIA) with assurances to foot 40% of the cost of special education, but had come through with less than 20%. This shortfall put increased pressure on local funding sources, creating inevitable conflicts at school board meetings where some vocal parents would regularly demand to know why the cost of special education was such a large portion of the annual budget.

Looking back with the benefit of hindsight, it is ironic that this grumbling was heard during boom times, well before the world economy ran itself off a cliff after being ignited by the combined “match” of the housing bubble and evaporating credit facilities.

What initially started as a malaise quickly turned into a kind of virtual paralysis, with banks that stopped lending, manufacturers that stopped manufacturing, and



Gary S. Mayerson, Esq.

consumers who stopped consuming. This feeling of numbness is all too familiar for many parents of children with autism, at least in the first weeks after the initial diagnosis. Then comes the epiphany that your child needs you to get up and dust yourself

off, to get down to the hard work at hand. Parents of children with autism learn quickly that paralysis is not a very effective response to an emergency.

Prior to the election, promises had been made by both parties concerning the need to increase funding for autism research and special education initiatives for children with autism. The economy, of course, continued to falter in a big way. Accordingly, after President Obama took the oath of office, a common fear was that all the campaign promises might be forgotten, or at least deferred, as the nation focused on the economy and other threats and issues believed by some to be more “pressing.”

Incredibly, however, this is not what happened. While the SEC and Alan Greenspan missed by a county mile Bernard Madoff, the subprime mortgage crisis, widespread bank failure, and other situations of spectacular financial collapse that would seem to be matters fairly discernible upon a meaningful analysis of data, our new president clearly knew and understood the impact of our own numbers—1 in 150. He apparently saw the autism epidemic for what it is, and the even greater threat that it could become. He kept his campaign promise to take the “long view,” and to implement long term solutions to address multiple threats at the

same time. Ironically, as autism is universally accepted as a “pervasive” developmental disorder, this is the only approach that would ever be expected to succeed.

The 2010 budget unveiled by the Obama administration includes \$211 million in funding for the Combating Autism Act. This is in addition to a truly meaningful increase in IDEA funding that is being allocated as part of the overall increase in funding education. The new administration’s message is unmistakable. As a nation, we are not going to let go of the hand of the child with autism even as the nation crosses a dangerous intersection. To put it another way, we are all in this together.

The declines in local tax revenues are real, to be certain, but they are being offset by unprecedented increases in funding at the federal level. Although the financial sky may be falling generally, at the moment, the financial sky is actually a lot brighter for children with autism than any of us might have reasonably expected. This is the first message that parents need to communicate to those school district administrators who continue to refer to declining local tax revenues as a reason to cut an individual student’s program. Fiscal fear, at least for the time being, is

see *Secure Programs* on page 41

Providing a United Front

By Sheree Incorvaia
Director of Recruitment
New York Institute of Technology
Vocational Independence Program

As an educator for the past 20 years, I have been afforded a unique view of the parent-student-teacher relationship. As a parent myself I have been on two sides of this triangle. At times, I can honestly say, it has not been easy. I always wanted the best for my child and believed that as a parent I knew what was best. After all, most parents know intimately their child’s likes and dislikes, strengths and weaknesses, reactions to positives and negatives, and most importantly we persist in the belief that we know what our children need. How could a classroom teacher know some facet of my child that I don’t? Surely parents know best, don’t they? It’s when this question arises that I need to remind myself of the varied roles I play as an individual in the many components of my life and how differently I operate in each.

Parents are keenly aware of how children act inside the home, but in situations outside the home, including school, children behave differently. At home a child may be argumentative with a parent or exhibit negative behaviors, while at a friend’s home the same child is never disrespectful of authority. This, most psychologists will tell you, is quite normal,

and signifies a healthy parent/child relationship. The child knows the rules and the limits at home. The child knows the parent. The child knows what will be tolerated but feels safe enough to test those limits. But a friend’s home or the classroom is a different place with different expectations and limits. During my children’s education, I only knew second-hand what occurred at school. I knew because they told me. Perhaps it is children’s nature to exaggerate the truth of a situation to make themselves appear less complicit, or more in control of their actions. Perhaps not, but a child’s perspective and recollection of events must always be appreciated for what it is. On occasion, a teacher may express an alternate view of a situation, and that view might be in sharp contrast to what the child recounts. The initial and natural reaction of most parents is to believe their child and suggest that the teacher misunderstood the student’s action or explanation in any particular circumstance. This may result in what amounts to a double image, a kind of perceptual dissonance, a blurred appreciation. Short of accompanying their children to school, how are parents to know the truth?

This dilemma is compounded when dealing with a special needs student who may not be able to make a viable decision or whose emotions color judgment calls. When placed in a situation where one’s peers are pronouncing their friendship or enmity if one doesn’t conform, it’s easy

for emotions to unduly influence a decision. For parents the results can be frustrating if not downright maddening. Situated between the child and the professional, a parent must appreciate rather than rue the paradoxical nature of the position. When seen this way, the strong response is to be empathic, to understand where each party is coming from, and to assist in working together to correct the situation. Ideally, both teacher and parent working together can convert a disciplinary instance into a learning experience for the student. Empathy involves taking the perspective of another person, inferring his or her thoughts and feelings (Ickes, 1997). Empathy on an affective level involves experiencing emotions such as sympathy and compassion (Batson & Shaw, 1991). When both parent and teacher work together to make one another feel understood, the consequent openness vitiates most problems and strengthens the relationship between the adults who both place paramount importance upon the child’s best interests.

Citing an example of a situation in a post-secondary program for students with special needs, a student took the ATM/debit card she was being taught to use effectively and went on a shopping spree, incurring overdraft expenses. The student is impulsive and has emotional issues and poor math comprehension and judgment skills. The teacher is aware of and can empathize with this, but needs to make the parent see the importance of having

the student take responsibility for their actions. Having dealt with this predicament before, the professional educator has had firsthand experience, not just theoretical textbook practice with this problem. If a parent continually bails the child out by sending more money and paying the overdraft fees, what has the child learned? Perhaps she’s learned the power of parental manipulation, rather than the life skill necessary to survive on her own. If the child suffers a consequence of not being able to go to the movies on the weekend or not going to the concert with friends she’s been looking forward to because she wasn’t bailed out, then perhaps she learns something. Perhaps she’s now learning that certain actions have a consequence. More importantly, she’s understanding that her parents and her teachers are powerful allies. Manipulation becomes a less effective choice in the future. The student must accept responsibility. Is it uncomfortable? Sometimes. And sometimes more for the parent than the child. But by working together, as a team, the teacher and parent help turn the child into an adult that can become self-reliant.

When parents and teachers form home-school partnerships, children are more likely to see a unified front...When school and family unite in a partnership for children, their overlapping spheres of influence (Epstein, 1995) foster a positive attitude...that help children learn...at

see *United Front* on page 42

Meet Premier HealthCare's Autism Fellow: Dr. Maria McCarthy

Staff Writer
Autism Spectrum News

Premier HealthCare (PHC) is proud to announce Dr. Maria McCarthy as its new Autism Fellow. Dr. McCarthy joins PHC as part of our ongoing partnership with Mount Sinai School of Medicine (MSSM) and its Seaver and New York Autism Center for Excellence.

As a PHC Autism Fellow, Dr. McCarthy shares duties between both organizations, performing clinical work, including evaluations; serving as a liaison to facilitate patient referral and coordination of care, sharing up-to-date autism spectrum disorder research and information with our clinical staff, and contributing to newsletter articles and presentations at YAI/NIPD Network conferences and lecture series.

"I was particularly interested in this fellowship because Premier HealthCare is the model for providing patient care to people with developmental disabilities," said Dr. McCarthy.

Dr. McCarthy brings with her a vast knowledge of autism spectrum disorders. She was previously a Fellow of Child and Adolescent Psychiatry, and Psychiatry Resident, at the Western Psychiatric Institute and Clinic in Pittsburgh. She was a



Dr. Maria McCarthy

contributing author to a chapter on Child and Adolescent Psychiatry in the Oxford Handbook of Psychiatry and wrote articles on developmental biology and neuroscience for several other peer-reviewed publications. Additionally, Dr. McCarthy has done extensive research on the effects

see Autism Fellow on page 42

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YAI Autism Center Spotlight on Moira Lewis, M.S. CCC-SLP

Staff Writer
Autism Spectrum News

Moira Lewis is a speech-language pathologist at the YAI Autism Center, where she performs clinical speech and language evaluations and develops social skills groups for children and adolescents with ASDs. Moira received a master's degree in communication disorders at Miami University, and completed her clinical fellowship at the Yale Child Study Center's Developmental Disabilities Clinic. While at Yale, Moira worked on a number of research studies examining the unique communication and social patterns of development among children with autism. Her involvement in research surrounded the areas of early identification and diagnosis, speech treatment for nonverbal children and parent training.

"As a clinician who works primarily with children with autism spectrum disorders, I constantly see the importance of involving the whole family in the diagnosis, assessment and intervention proc-



Moira Lewis, M.S. CCC-SLP

esses," Moira said. "By empowering and educating parents, especially surrounding communication, I feel I can go above and beyond my own work within assessments and therapy."

Moira looks forward to continuing her work in providing comprehensive autism evaluations and treatment at the YAI Autism Center.



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Tips to Help Anxious Campers Prepare for an Amazing Summer at Camp

By Debbie and Eric Sasson
Directors of Camp Akeela

Millions of parents give their children the gift of camp every summer. Camps offer youngsters extraordinary opportunities to learn independence and resilience – and to build self-esteem in a fun-filled community. Stated plainly, camp can change a child’s life. For campers on the spectrum, these life-changing experiences are even more dramatic – as is the level of anxiety these campers (and their parents!) typically feel before going away to camp. For both parents and children, being prepared for new experiences is always helpful. Below is a letter to campers about how they can best plan ahead to ensure a less anxious pre-camp experience (Parents might find it useful as well!).



Eric and Debbie Sasson

Dear Campers,

It’s hard to believe that summer is only a few months away! With so much going on at home and at school, it’s easy to put off thinking about things to come. When we do stop to take a break, we may become a bit nervous about the upcoming summer at camp.

It’s very normal for adults and kids to get anxious about a new experience and camp is no exception. That’s OK! Many of you

may be excited and nervous at the same time. Here are a few things that you can do to help get ready for camp. We think they might make you feel less nervous:

- Make a list of worries you have so that you can talk about them with your family or with us! You can always email or call your camp director

to ask any questions or to share your concerns.

- Practice makes perfect! It’s true that the more you practice something, the easier it gets. So, start making some dates to have a sleepover with friends or extended family. It’s important to practice being away from your home

and family before you come to camp.

- Start getting used to the camp schedule. Lots of kids tell us that they’re concerned about adjusting to the routine at camp. Just like sleeping out, you can start “practicing” your camp’s schedule. Ask your family to help you try out the camp routine – including wake-up and bed times, meal times and rest hour. Ask your camp director for a print-out of your camp’s schedule so you can put it up in your room.
- Look at your camp’s website and start thinking about what types of things you’re excited to try this summer! Remind yourself how much fun you are going to have and how many great people you’ll meet! Jot down any goals you may have for yourself and look at them once in a while to see if you have anything else to add.
- Your parents may get a packing list from your camp and you can start thinking about what you’re going to want to bring with you to camp...a favorite photo, book or pillow? Maybe a stuffed animal? Bringing special things from home may help you feel more connected to your family when you’re away.

see *Anxious Campers* on page 41



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For further information contact the facilitators:

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

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For further information contact the facilitators:

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

These support groups serves families located in the New York Metropolitan area. We usually meet on the Fourth Sunday of each month from 10:30 AM - 12:30 PM at Blythedale Children's Hospital in Valhalla (Westchester County). Blythedale Hospital is located close to White Plains just off the Sprain Brook Parkway and also near the Valhalla Metro North train station (about 45 minutes from Grand Central Station).

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Post-Secondary Educational Models Prepare Individuals with an ASD to Enter the Workforce

By Ernst O. VanBergeijk, PhD, MSW
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Vocational Independence Program

In the last 50 years, there have been large changes in the labor market. Many of these changes are related to advances in technology- computers, the internet and a specialization of skills. These have fundamentally changed the educational requirements of many entry level positions. In the recent past, we have witnessed a movement from a manufacturing based economy to a "knowledge based" economy. The education level of the labor force has increased dramatically.

This is an important trend to watch because unemployment is strongly impacted by educational level. Prior to our current recession, the unemployment rate for young workers who did not complete high school was about 6.4%. For high school graduates, it was about 3.5%. The unemployment rate for individuals with some college credits was about 2.7%. For bachelor's degree recipients, the unemployment rate was about 1.7% (Congressional Budget Office, 2002). The unemployment rate for people with learning disabilities, in general, is 63% - almost 10 times greater than the general population. Unfortunately, there are no



Ernst O. VanBergeijk, PhD, MSW

autism-specific unemployment data available. With our current recession, this discrepancy may be even greater than previously documented.

Research suggests that individuals with an ASD will struggle with the developmental tasks at every age (Billstedt, Gillberg, & Gillberg, 2005). Many will

have notable difficulty transitioning fully to an adult life that embraces work, personal relationships and independent living (Howlin, Goode, Hutton, & Rutter, 2004; Sperry & Mesibov, 2005). Research shows that about 70-80% (Billstedt, Gillberg, & Gillberg, 2005; Fombonne, 2003) of individuals diagnosed with an ASD at childhood will continue to demonstrate marked cognitive impairment in adulthood.

Changes in the labor economy require any young person to be as educated as possible if they are to access a wide range of occupational choices. Vocational, Supported Academic and Transitional programs are three different post secondary educational models used to prepare individuals with an ASD to enter the workforce.

Vocational Programs

Within the vocational rehabilitation field there are different kinds of programs. Supported work programs offer the least restrictive environment and are the most appropriate for higher functioning individuals. Supervision is provided by trained staff at an off-site work place. Supported employment is defined as "competitive work in integrated work setting...consistent with the strengths, resources, priorities, concerns, abilities, capabilities, and informed choices of the

individual" (Rehabilitation Act Amendments, 1998). The goal of these vocational programs is to enable the individual to integrate into normal adult functioning in terms of work and relationships, thereby improving his/her quality of life.

Supported employment programs have been found to be effective (Bond et al., 2001; Torrey, Clark, Becker, Wyzik, & Drake, 1997). Very little of this outcome research has been conducted with ASD populations, but instead with individuals living with a mental illness. The characteristics of the effective programs are: helping a client to find paid employment at a work site committed to employing individuals with a disability; providing support to the individual in maintaining his or her job in terms of problem solving and advocacy; and helping the individual to disclose their disability to an employer (Drake, 1998). In the outcome research, psychiatric services are integrated with the vocational service (Becker and Drake, 1993) and, given the high rate of psychiatric co-morbidity within the ASD population, this would be relevant. Supported employment has been found to work better than group skills training, sheltered workshops, and other vocational services (Lehman et al., 2002, McFarlane et al., 2000) with competitive employment rates as

see Workforce on page 42

The Influence of Autism Symptomatology on Development & Employment

By Oren Shtayermman, PhD, MSW
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New York Institute of Technology

The current Diagnosis and Statistical Manual of Mental Disorders-Fourth Edition, Treatment Revision (DSM-IV-TR) identifies three main features that are associated with autism: impairment in social interaction, communication, and behavior. Examples of the impairments in social interactions include poor use of body language and nonverbal communication, such as eye contact, facial expressions, and gestures, lack of awareness of feelings of others and the expression of emotions, such as pleasure (laughing) or distress (crying), for reasons not apparent to others, and difficulty interacting with other people and failure to make peer friendships. Examples for impairments in communication are: delay in, or the total lack of, the development of spoken language or speech, difficulty expressing needs and wants, and verbally and/or nonverbally inability to initiate or sustain conversation. Finally, examples of impairments in behavior are: insisting on following routines and sameness, resisting change, preoccupation with parts of objects or a fascination with repetitive movement (spinning wheels, turning on and off lights), and narrow, restricted interests (dates/calendars, numbers, weather, movie credits, etc.).



Oren Shtayermman, PhD, MSW

According to Erikson (1994), during adolescence around ages 18 or 20 years old, the task is to achieve ego identity and avoid role confusion. Ego identity means knowing who you are and how you fit in to the rest of society. It requires that you take all you have learned about life and yourself and mold it into a unified self-image, one that your community finds meaningful. In the initial stage of being an adult we seek one or more companions and love. As we try to find mutually satis-

fying relationships, primarily through marriage and friends, and we generally also begin to start a family. If negotiating this stage is successful, we can experience intimacy on a deep level. If we are not successful, isolation and distance from others may occur. And when we do not find it easy to create satisfying relationships, our world can begin to shrink as, in defense, we can feel superior to others. These tasks could be challenging or even impossible for some individuals diagnosed with autism spectrum disorders. The abovementioned impairments in social interaction, communication, and behavior can place significant difficulty on the ability to achieve ego identity (Orsmond, Krauss & Seltzer, 2004). Many of the symptoms related to autism spectrum disorders are likely to lead individuals diagnosed with autism spectrum disorders to role confusion which will impact their ability to function in society.

Educational Curriculum and Capacity for Employment

Nuehring and Sitlington (2003) stated that transition to adulthood is the process through which students leave high school and become members of an adult community. Several studies conducted during the 1970s and 1980s suggested that individuals diagnosed with autism spectrum disorders had no indication of independence as expressed by work, education, and inde-

pendent living in early adulthood (Billstedt, Gillberg & Gillberg, 2005). Many if not all individuals who are diagnosed with an autism spectrum disorder receive an Individualized Educational Plan (IEP). An IEP is designed to meet the unique educational needs of the child, as defined by federal regulations. The educational plan must be tailored to the individual student's needs as identified by the evaluation process and must help teachers and related service providers understand the student's disability and how the disability affects the learning process. In other words, the IEP should describe how the student learns, how the student best demonstrates that learning and what teachers and service providers will do to help the student learn more effectively. This is especially important for individuals who are diagnosed with autism spectrum disorders since no two individuals will present with the same severity of symptoms or level of functioning. According to Hume and Odom (2007), the deficiency in independent functioning has substantial implications for students diagnosed with autism spectrum disorders, as it is impediment to classroom and community inclusion. The IEP should assist in modifying the content of educational curriculum that is being taught in the classroom. The educational curriculum can assist in the transition to the community

see Symptomatology on page 39

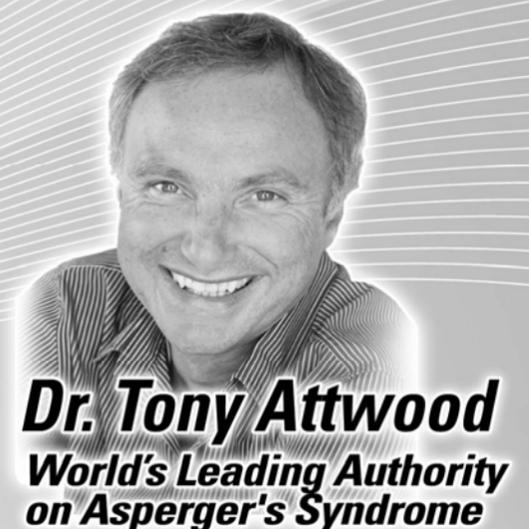
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Sea of Interventions from page 29

interventions. Similarly, Serena Wieder and Stanley Greenspan have parsed children with autism into four subtypes.

Five Promising Approaches

ABA, TEACCH, Daily Life Therapy, DIR, the Miller Method, and RDI - When implemented by competent professionals well versed in both the method and the characteristics of the child they are working with, all of these approaches can offer great benefit. The challenge is to match the method to the child's needs as close as possible. This decision has to be made by the parents and/or other significant caretaker along with others who are familiar with both the child's needs and the methods available.

Given that autism initially was thought to be behavioral in nature (Rutter, 1999), the behavioral method is the oldest of approaches. The ease of measuring and assessing physical behavior also contributes to the popularity of this method. Although commonly thought of as a method even though it is not, the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) places its main thrust on preparing the person with autism to function in the typical community and work environment (Trehin, 1999).

A third approach, Daily Life Therapy, as developed by Dr. Kiyo Kitahara (1984), of Tokyo, takes a more Platonic (1968) view by stressing an order of the physical, emotional and intellectual parts of the child. Further, the pharmacological approach sees autism as stemming from chemical imbalances that can be corrected via medication. An offshoot of this approach is the use of medicine to address secondary psychological issues such as excess anxiety and depression that can arise from being on the autism spectrum.

The developmental models more closely address the developmental delay aspects of the autism spectrum. Believing that those with autism get stuck at a particular developmental level, progress is encouraged by techniques to spur development on. Developmental Individual-difference Relation-based intervention (DIR), of which Floortime is a part, as developed by Stanley Greenspan, stresses building an emotional bond (Greenspan & Wieder, 1998) with the child, whereas the Miller Method, while sharing a developmental component with DIR, takes a more cognitive-systems approach with the implementation of elevated structures (Miller & Eller-Miller, 1989; 2000).

What Comes Next

This brief overview of the approaches studied lay the groundwork for further dis-

cussion of these interventions in terms of their areas of efficacy, contrasts, and similarities, as well as recommendations from the very persons who have been key in developing this approaches. Stay tuned for these and other topics of discussion in the next issue.

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To learn more, please visit his website at www.autismasperger.net.

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Technology from page 30

easily; changes can be made with ease, such as lengthening or shortening a slide show, depending on level of student success. In terms of collaborating with the

home-based team, PowerPoint presentations can be sent home for use with parents and or other therapy providers. Incidentally, they can be sent home using email, and now with cell phone technology, our personal advances in technology

include the use of the iTouch and Blackberry, which now afford options for taking photos, videos, and voice notes on the fly. How wonderful these advances have been for teaching our students with Autism!

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Generalization of Skills from page 21

for teachers, as it seems counter-intuitive and inconsistent with the emphasis on consistency in instruction. The art of ABA intervention involves understanding which instructional components must be consistently presented and which components can be varied.

Another strategy that can be incorporated into instruction is programming common stimuli. Specifically, programming common stimuli involves incorporating stimuli and typical features of the generalization (natural) environment into the instructional setting to increase the likelihood of generalization. For instance, if a learner is being taught to purchase food in a grocery store, it may be appropriate to teach the component skills necessary for this complex skill in a controlled setting such as a classroom initially (quickly moving into the community). When this is done, it is important to use actual stimuli that the learner may encounter in a store (e.g., real food found on shelves in a supermarket, a counter, real money, a cash register, a cashier). One of the benefits of programming common stimuli is that it allows for repeated practice in a controlled setting. Practitioners need to identify the critical elements and objects present in the target environment to ensure that the learner is exposed to them in training. This eases the process of transferring skills to the natural environment.

Activities from page 27

and problem solving. Cooperative activities employ communication, negotiating, conflict resolution, and leadership skills. The various extracurricular activities can assist students' social maturity develop-

Symptomatology from page 37

and adulthood of individuals diagnosed with autism spectrum disorders. In the past decade, our understanding of the autism spectrum increased, which assisted many researchers, educators and mental health practitioners as well as family members to better manage and treat more effectively the social challenges these disorders presented to individuals and

Preparing the Learner for the Next Setting

In order to prepare the learner well for other environments, it is important to know information about those environments. Specifically, it is helpful to know how assistance is given to learners (i.e., prompting) and how learners are given feedback on their performance (i.e., reinforcement). For example, if students in an included classroom are never helped to respond with physical guidance, we can ensure that the learner is responds to other types of prompts that are used in that setting (e.g., verbal prompts, gestural prompts).

In addition, it is helpful to know how reinforcement is delivered in the target setting. It is usually the case that learners transition to environments with learner schedules of reinforcement. Teachers in the current environment can fade the use of extrinsic rewards and provide rewards that are commonly available in the target environment. If these changes are made prior to the transition, it eases the difficulty for the learner. If a student has been reinforced for participating in group instruction with edible treats, the teacher might fade this out and replace it with the kinds of rewards that will be available in the next environment, such as positive teacher attention, and nonverbal gestures of praise). Similarly, if a learner has been used to a rich and predictable schedule of reinforcement, it may be important to thin the schedule and to make it more intermittent and less predictable. It is important

ment by providing a socially appropriate setting for interaction, discussion and relationship formation. The result is a comprehensive experience which produces a positive school environment and a strong integration to academics. Where there is improved behavior and increased aca-

their family members (Giddan & Obee, 1996). The recent emphasis on independence during adulthood highlights the immediate need for research and intervention in this area. Because of the multiple challenges individuals diagnosed with autism face, it is necessary that intervention should be focused on strengths (Hume & Odom, 2007). Supported employment is an accommodating approach for hiring and retaining individuals diag-

to have the natural contingencies of reinforcement available in that environment maintain the behavior. Toward that end, the types and schedules of reinforcement available to the learner can be altered while the student is still in the current environment. In this way, the learner is well-prepared for the kinds of rewards they will be offered.

The Individual as the Source of Change

It is possible to involve the individual him or herself in generalization training by equipping them with skills that will increase their success in other environments. One way to accomplish this is to teach the individual to recruit their own reinforcement. Many learners have been taught to recruit teacher attention. A variety of procedures have been used in this context, including teaching students to request feedback and teaching students to show teachers their work products.

This approach has several benefits. It increases the reinforcement delivered to the learner. It also serves to cue the teacher that attention is needed. Perhaps the best element of this approach is that it ensures that teacher attention is given for appropriate behaviors. This is important, as many students receive more attention when they misbehave than they do when they behave. Finally, it is a bridge to other kinds of self-management.

Self-management facilitates the transfer of skills by equipping the individuals

demic success, there is an atmosphere brimming with accomplishment and enthusiasm.

Participation in the creative, preferred activities is not merely a pleasant opportunity, but is essential for students with learning differences. Students who partici-

nosed with disabilities. A specialized trainer, also known as job coach or employment specialist, provides individuals training for the supported employee. The supported employment is highly adaptive to individual and organizational need (Garcia-Villamizar & Hughes, 2007; Schaller & Yang, 2005), which is consistent with the need to focus on individualized education and individualized vocational services which will better prepare

themselves with skills in monitoring and managing their own behaviors. Self-management involves making learners aware of and responsible for their own behaviors (Cooper, Heron, & Heward, 2007). Skills taught include planning (e.g., schedules and checklists), self-recording, and self-reinforcement. Self-management allows for more independence and decreases the need for an external agent of behavioral change.

Summary

Generalization must be a priority in educational planning. It should impact how we conceptualize and define target skills, how we teach skills, and how we evaluate progress and mastery. We must program, plan, and assess for generalization throughout instruction. The ultimate indicator of successful instruction is the transfer of skills into natural environments and everyday interactions.

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pate in the various forms of activities often experience an improvement in achievement in other learning domains. Success for life can begin with a well balanced education, one that includes a healthy involvement in creative and preferred extracurricular activities.

individuals on the autism spectrum towards independent living.

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Creative Approach from page 16

While that may seem discouraging, Martin Horan, President of Production Providers, Inc., who has helped connect Chapel Haven clients to jobs, said especially now, employers are eager to find ways to cut costs but still get basic tasks done.

"Using clients with disabilities for less skilled or entry level work has been a winning formula for the employers I deal with, who are watching the bottom line," Horan notes. "They may not need to pay a legal secretary \$25 an hour to shred documents, when we have people who are delighted to do that work for less. There are many benefits. Employers gain a competent corps of people who work reliably and with enthusiasm, whose attendance record is superb and who are so pleased to have a steady job, they don't make nuisance claims. We have seen time and again where employers are able to lower disability insurance rates because our clients are committed and help the company meet its bottom line."

Carney and staff have learned some lessons about how to navigate during a recession and are pleased to offer these job tips:

Expectations for employment: Know thy client! - At Chapel Haven, the job development department developed a tool called Expectations for Employment to assess the skills of clients, based partly on established models but fine-tuned for clients with disabilities. The assessment tool uses 100 variables to measure each individual's 'soft' and 'hard' skills. "This gives us a realistic template and has been invaluable in finding the right kind of work for our students and graduates," said Carney.

Supporting Education from page 18

not only obtain diplomas and degrees, but also, the skills and confidence that will allow them to fully contribute to their communities.

"OMRDD's commitment to education means we make a *lifelong* commitment to raising an individual's capacity for living fully, whatever their age and ability," said OMRDD Commissioner Diana Jones Ritter. "That means we must partner with school districts and the State Education Department - in both Special Education and Vocational Education - to find the unique blend of services that will allow each individual to live their best life."

OMRDD provides individualized supports and services to more than 125,000 individuals with developmental disabilities across New York State. These individuals range in age from infants to senior citizens. They receive residential services, therapies such as Speech and Occupational Therapy; clinical services such as psychology, nursing and nutrition; family supports such as caregiver respite and crisis intervention; supported employ-

Follow the money: many federal and state government contracts have a provision requiring subcontractors to hire persons with disabilities - Companies doing business with the federal and state governments have contractual obligations to provide job opportunities for persons with disabilities. That sounds good on paper. But following the paper trail of work and knowing which companies will bid on them is all about relationship building. Who will get the work when the state police squad cars need to be washed? Who will help maintain state transportation buildings? Get to know the businesses bidding on those jobs and when the contracts will be awarded. "We spend a great deal of time tracking where the work needs are, getting to know employers in this region and then training our clients to fill those needs," said Carney.

Start with volunteer placements - they may grow into a paid job - Many Chapel Haven clients start out in volunteer, unpaid positions, to gain some experience. Sometimes employers are so pleased, they extend an offer for paid work.

That's what happened when John D., who is enrolled in Chapel Haven's Asperger's Syndrome Adult Transition Program, landed a volunteer internship helping Yale University's athletics department maintain athletic equipment for the university. The internship was so successful, Yale offered to pay the intern for his work during the football season.

"It was a great experience for the student and for us," said Jeff Torre, an athletic attendant with Yale Athletics. "He was at every home game. He made friends and got to know a few of our coaches.

ment; and habilitation services that focus on building the skills a person needs to pursue their life goals.

Currently, OMRDD supports approximately 18,700 individuals with a diagnosis of Autism Spectrum Disorder. More than 11,000 of those people are under the age of 22 years. For those 11,000, OMRDD provides services that supplement the educational services provided by local public school districts. Families and their children with autism receive supports like Medicaid Service Coordination; Family Support Services such as crisis intervention, family training, and caregiver respite; or additional clinical services that add to what the students receive through school. Essentially, OMRDD assists students and families in securing needed services and navigating the challenges of living with autism so that the student can better achieve in school and the family can succeed at home.

The Importance of Transition Planning

When a person reaches age 15, schools must, by law, begin transition planning with

Along with having a working relationship, we had fun talking about video games, music and sports, and many other common interests that we shared. We would love to do this again next year."

Look for opportunities to employ many - Finding fulfillment work where clients can work together as a team is helpful. Chapel Haven's highly successful supported employment placement at Hudson Paper has 22 clients gaining valuable knowledge about work etiquette in a professional factory setting while fulfilling work needs of various companies who contract out their projects. Chapel Haven job developers provide transportation and ongoing job-coaching at the site, and graduates are paid commensurate wages. The fulfillment work is a great launching pad for Chapel Haven clients looking to move on to competitive work.

Don't underestimate the ability of your job seekers to find work - James T. had lots of help from Chapel Haven's job development department in developing a resume and learning the etiquette required to successfully interview for a position. But he also had drive and spent all of his free time actively looking for jobs online. When he saw an opening in the mailroom of a local bank, he immediately called the human resources department to land his first of two interviews. After the first interview, he promptly fired off a thank-you note. "I was honest and concise in my interview plans. And I dressed up nicely," Trimble says. He also credits "honest, good looks" for helping him land the job.

Simply placing a client in a job is not enough. Follow-up by informed staff,

monitoring and job coaching, especially in the first week, are critical - Landing work is important, but even more important is following up, providing some on-site job coaching and checking back in regularly with the employer. In the beginning, Chapel Haven's job coaches are onsite to observe and to help the new employee acclimate. He or she also will communicate with the employer. "We use both scoring and intuition to help decide if a placement is working out. Sometimes additional training is needed," said Carney. "Job monitoring is crucial."

Network, network, network - even purely social engagements can lead to job opportunities - Carney and his staff put a premium on personal connections. He attends business networking functions, works closely with Chapel Haven board members who can open doors to work, and even found a number of significant jobs while schmoozing with a business owner on a cruise along the Connecticut River.

"In this wonderful world of ours, there is a job match for everyone," says Horan. "We know of a college student who got a summer job at a pen factory. He was assigned to Quality Assurance on the assembly line. Specifically, his job was to pick up pens and check the 'clicker mechanism' by clicking the pen twice. The student quit at lunchtime, he couldn't take it anymore. We know people who would happily do that job day in and day out for years, and do it better and faster than anyone else. Probably they would only be upset if we changed the job!"

For more information about Chapel Haven, please call the Office of Admissions at (203) 397-1714, X113.

each student with a disability. That is, they must start to develop employment and life goals for the student and a plan for attaining those goals. It is *crucial* at this time that students understand what both the educational system - through New York's Vocational and Educational Services for Individuals with Disabilities (VESID) - and the OMRDD system can provide them as adults. It is also imperative for transitional age students to be evaluated for eligibility for these services. The services and supports available beyond the school years depend entirely upon this determination of eligibility.

VESID services help people prepare for employment and vocational independence. They may help someone obtain the college education needed for a particular job or profession or help them receive the vocational training needed for a trade. They can also assist someone to obtain supported employment. But, disabilities like autism don't disappear at the end of a work day. People working to have a life in spite of autism face significant challenges in their social and personal lives, and OMRDD offers a range of services that can support them in achiev-

ing their professional and personal aspirations. If further education does not take the form of a classroom or a vocational "shop," OMRDD may provide continued learning and skill building through residential and day habilitation services, pre-vocational services, and supported employment. These services meet a person where they are and support a continuum of growth in the abilities needed to succeed at home and in the community, to obtain a job, and to succeed in long term employment.

Clearly, education is classrooms and textbooks, but it's also experience and practice at life itself. As ASD diagnoses increase, OMRDD will continue supporting students with ASDs in formal education and in continuing lifelong learning and advancement.

For more information on OMRDD eligibility contact your local Developmental Disabilities Services Office (DDSO). For contact information, go to www.omr.state.ny.us. Click on "About OMRDD" and then "Developmental Disabilities Services Offices." For information on VESID services, visit www.vesid.nysed.gov.

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Support Groups from page 17

for adults with ASD to improve self-confidence and self-advocacy skills (MacLeod & Johnston, 2007).

Top programs across the nation have some common threads. Social support groups for adults with ASD should meet regularly in a community setting, have a format that is structured, and should at least partially control themselves (MacLeod & Johnston, 2007). Many groups are facilitated by a professional, but others, such as those run by the Global and Regional Asperger Syndrome Partnership (GRASP), are often led by individuals with ASD themselves. Both have their advantages; the key is for the facilitator to be able to promote acceptance of others, provide modeling of appropriate group behavior, and provide appropriate social feedback. A facilitator should also be able to manage the logistics of the groups, such as meeting locations, agenda items, acceptance of new members, and other issues to keep the group running smoothly.

Most successful educational support groups for adults with ASD focus on three main components: support, skill building, and recreation. Starting each meeting with a sharing time can be helpful. During the group share, individuals can discuss issues they faced, problems that have arisen, or personal successes they've experienced. In this way, the group can learn from each other and offer one another advice and support. Often when a member shares a difficult experience, others in the group find that they have faced a similar issue or can help the others in some way. This sharing also allows the group to see that others are struggling and can help diminish feeling of isolation or diminished self-worth.

Skill building can also be an important focus of the support group. By addressing topics requested by the group, the facilitator can be sure that specific needs are being addressed. Once a topic list is generated, the group can decide whether they can learn about the skill internally, or whether guest speakers or information

should be brought in from outside the group to address the skill. Topics can be in a wide range of skill development, such as money-management, health and exercise, dating, or job interviews.

A third main component of quality support groups for adults with ASD is recreation. Many adults on the spectrum report that they have few opportunities for leisure with peers, and this can be an important part of building friendships. Groups can devise an agenda that includes activities that many members enjoy, or something new for everyone to try. Activities like game night, bowling, dinner at a restaurant, or live music at a coffee house have all been successful recreational opportunities for some groups.

Many established groups are available across the nation, particularly in metropolitan areas, but there are adults who can benefit from educational support groups in every community. National resources like GRASP have regional support groups, or contact your local autism provider to request a group in your area.

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The Kelberman Center is a 501(c)3 non-profit agency affiliated with Upstate Cerebral Palsy in Utica, New York. The Kelberman Center was established as a regional center of excellence for individuals with autism spectrum disorders and related learning challenges and provides a wide range of diagnostic, consultation, educational and support programs for children and adults from the Central and Upstate New York region. For more information about the Kelberman Center, please visit www.kelbermancenter.org or call 315-797-6241.

Coping with Asperger's from page 31

social activities and social skills instruction through group counseling.

Andrew spent two years in the CLE program and with the team's unwavering support, completed an Associate's Degree this past December. It was not an easy road for Andrew or CLE. Andrew's ri-

gidity continues to stand in the way of his progress, yet he has grown and matured and demonstrates that his CLE experience has moved him forward. He has become more confident and has ongoing friendships, albeit with students who live around the country. We welcomed home a happy boy, proud of his accomplishment. For that we gratefully shared in his joy.

Anxious Campers from page 35

- Ask your camp directors if there are any opportunities to visit camp before the summer or to meet other campers who will be with you when you're there. Maybe you can email or call a future bunkmate. It's nice to know someone before you arrive!

Remember, camp is all about having fun and making friends and there will be lots of people at camp available to help you as you settle in to your summer "home." Have a great summer!

Debbie and Eric are the directors of Camp Akeela, a coed, overnight summer camp in Vermont for children and teens with Asperger's and NLD. Debbie has a Masters in School Counseling and a Doctorate in Clinical Psychology; Eric has a Master's in Education from Harvard University. Akeela focuses on building a community in which campers feel great about themselves, make friends, try new things and have fun! For more information about Camp Akeela, see www.campakeela.com or call Debbie and Eric at 866-680-4744.

Consultation Services from page 20

programs require a substantially greater amount of resources, and typically have a smaller scope, reaching fewer individuals. The impact on individual students, however, can be directly and objectively measured (e.g., calculating the number of new skills learned by each student). The interviewees reported that although these services are more challenging to implement, they have been shown to be extremely effective at increasing the quality of services and learning opportunities afforded to individual students.

Participants of the structured interview reported similar predictors of success for their outreach program. All participants specified motivation of administrative and teaching staff as being a key factor of success. More specifically, they stated that in order for the consultation services to be implemented effectively the administration of the public school (e.g., superintendent, director of special education services, building principal) as well as the direct teaching staff (teachers, instructional aides) all had to be motivated to provide the services as dictated by the consultants, as well as committed to providing ABA-based autism treatment and teaching interventions. A second factor mentioned as being crucial to success was the need for ongoing collaboration between the consultant, district administrators, school supervisors, and teachers. Regularly scheduled meetings attended by all four groups were noted as a necessary component for long-term success of consultation services.

When discussing recommendations for building a new outreach program, the participants all made similar suggestions. First, they all highlighted the importance of beginning with a systematic model,

with responsibilities and expectations of all involved parties (e.g., the school district administration, the outreach program, the teaching staff, etc.) clearly outlined from the start. Second, they all strongly emphasized the need to start small (e.g., one classroom with 6 students). The participants mentioned cases in which they started in-district programs with larger numbers of classrooms and students. In those cases they did not achieve the same levels of success, and in some cases had to cut back on the number of students served the following year. They all reported having substantially more success beginning with fewer students and expanding the program slowly and systematically. Third, all participants specified the importance of making use of the inclusive setting of an in-district program, specifically being sure to include regularly scheduled opportunities for the students with autism to socialize with the typically developing public school students (e.g., peer mentoring programs). Fourth, all participants advised that administrators of the outreach program carefully select the site of their program, and attempt to collaborate with motivated staff at all levels.

While the best method for implementing effective consultation services in a public school setting remains unknown, the information garnered from this interview provides a starting point for continued investigation.

This study was completed at the New York Center for Autism Charter School, through funding provided by the New York State Education Department. Special thanks to Mary McDonald, Amy Geckeler and Rita Gordon for their participation in the structured interview.

IACC Strategic Plan from page 6

Over the next year, the IACC will monitor the implementation of the strategic plan and update the document for its annual release.

The Interagency Autism Coordinating

Committee Strategic Plan for Autism Spectrum Disorder Research is available on the IACC Web site at <http://iacc.hhs.gov/reports/2009/iacc-strategic-plan-for-autism-spectrum-disorder-research-jan26.shtml>.

Secure Programs from page 33

highly overstated, if not irrational, at least for purposes of special education funding.

Once a parent cuts through the fiscal paralysis issue, a parent's best defense against inadequate IEP proposals, as always, is to be forearmed with detailed and comprehensive assessments that have teased out the child's unique mix of strengths and deficits. This is the pathway to a truly "individualized" IEP.

When parents walk into their child's IEP meeting without assessments, the dynamic starts off as "this is what we as parents want." This approach can be problematic, since it makes it easier for the school district to be dismissive. The dynamic can change entirely, however, when parents have provided their school district with quality assessments. The dynamic then becomes "this is what in-

formed professionals are recommending for our child." This approach helps to focus the discussion back to the subject of the child's unique needs, the starting point for any appropriate educational plan.

Gary Mayerson, a graduate of the Georgetown University Law Center, is the founder of Mayerson & Associates, the first law firm in the nation dedicated to representing children and adolescents with autism spectrum disorders. Attorney Mayerson also has testified before Congress on the subject of funding autism programming is the author of the book, "How To Compromise With Your School District Without Compromising Your Child" (DRL Books). He also serves as the Director of the Autism Speaks Federal Legal Appeals Project, a pro bono initiative at the federal level.

Planning for Children from page 25

As you engage in this process you will uncover areas that are as yet unaddressed. Once you have completed your road-

map, review and update it regularly.

Some of the issues you must address are very complex, particularly areas involving financial planning, estate planning and government benefits.

Avail yourself of the expertise of financial advisors, attorneys who deal with special needs issues, and other knowledgeable professionals. A simple mistake can have costly consequences.

The more complete your planning, the more information you can provide, the easier it will be for a caregiver to take over. Don't leave your special child exposed. Most of all, don't delay.

Making Inclusion Work from page 32

and the earlier that appropriate interventions are in place the more likely it is that their independence potential is maximized and positive outcomes will be achieved. Possible school solutions include:

- Engaging a consultant to educate the student's school and help with specific strategies that address such issues as seating in the classroom, developing peer mentors, identifying a safe person and place for relief of overstimulation, creating a system of concrete social rules that all person-

nel can encourage, encouraging a student's special skills more systematically, and helping teachers become models of caring support through their own education about AS (Safran, 2002).

- Hiring a trained paraprofessional to work with the student
- Providing support services when needed: Speech and Language (pragmatics and social cognition), OT, PT, resource room, counseling by professionals trained in specific interventions for the population

- Having an honest discussion with a professional who understands whether the student's needs can realistically be met in a mainstream setting and talking about alternatives

A professional who is very familiar with the wide array of expression of the condition can help families make a professional assessment of a child's real needs and how they are currently being addressed. Each stage of development brings new challenges to all children. We need to be cognizant of the match between the student's needs and strengths and the academic situation at

hand. A school system that provided a wonderful environment in third grade may not be able to address the new challenges that middle school brings. Therefore, reappraisal of educational situations and the student's maturity and appropriateness for them is a critical part of academic and personal success from preschool through college. Objective observations can be especially helpful in gaining an unbiased assessment of the success of the match of a school setting and the student's current needs and bring a fresh eye to creative solutions to maintaining life in the mainstream.

United Front from page 33

School (Ford, Follmer & Litz, 1998, p.312).

If we always make our children's beds, do their laundry, make their appointments, or run interference for them, are they learning how to take care of themselves? Are we really doing the best for them when we constantly assist and don't let them learn by making mistakes, or perhaps failing at something?

Cognitive psychologists have shown how central failure is to learning. For example, Collins and Brown (Engines for Education, 1989), have found that errors are essential to the creation of mental strategies in problem solving. Van Lehn

(1999), has shown that real learning only occurs at an impasse during a problem-solving episode. Research by Foss (1996), has shown that not only do students learn when they encounter errors, but they also improve their ability to "detect errant solution strategies." In other words, when faced with errors, students learn not only about the subject at hand but also more generally how to plan solutions to similar problems.

This teacher/parent partnership is not always easy and it's always important to maintain a professional tone when communicating. It is never purposeful to place blame or show anger when trying to work as a cohesive unit. Inevitably it is the student who suffers from flared tempers and

emotional outbursts. As students progress in their education, parents find themselves dealing with a different teacher each year and new relationships need to be developed. By the time a student has graduated high school, most parents have had contact with numerous educators in their child's academic life.

When a child reaches 18 years of age, parents now become a third party to their educational records according to FERPA (Family Education Rights and Privacy Act). A teacher is no longer allowed to share information about the student without her consent. The student with a special need is strongly encouraged to allow contact between the teacher and the parent and most often this is agreed to without

consequence. The student needs to understand that without cooperation of those involved with him, he cannot reach his full potential.

Communication is an art that takes practice, as many married couples will attest. The key ingredient to an effective teacher-parent association is the ability to listen and really hear what the other party is saying. Understanding each other's points of view is imperative if there is to be positive growth in the student.

Sheree Incorvaia is the Director of Recruitment for New York Institute of Technology's Vocational Independence Program and has worked with special needs students for the past 20 years.

Autism Fellow from page 34

of various medications on children and adults with autism.

"Dr. McCarthy's extensive background is helping PHC gain a deeper understanding of treating people on the autism spectrum. Her work, and our partnership with

Mount Sinai, is pivotal," said Dr. Peter Della Bella, Director of Clinical Programs.

Premier HealthCare provides high quality, well-coordinated medical, dental, mental health, rehabilitation and specialty care to children and adults with disabilities and their families. Recogn-

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Workforce from page 37

high as 78% over 1 to 2 years for supported employment (McGurk & Mueser, 2004).

Supported Academic Programs

For individuals who have the ability and interest in a college degree or certificate programs, there are supported academic programs. Most of the research has found that for these students to succeed, they will require some type of remedial services (Cowles & Keim, 1995; Strichart & Mangrum, 1985). With a legislative mandate, all universities and colleges must provide reasonable accommodations to any student determined eligible. However, there is a tremendous range in the level of support made available. The variation rests likely on budgetary considerations, but also on differences in each institution's interpretation of their require-

ment to provide "equal access" to the educational experience. Assistance can range from general workshops in study skills to multi-faceted individualized programming.

There are two general approaches to the kinds of programs utilized by post secondary academic institutions (Rath & Royer, 2002): those that attempt to modify behaviors and/or skills of the student and those that attempt to modify the environment to accommodate the student. There is much debate over the relative merits of each approach that abut issues of student ability, responsibility and the extent to which college education is a privilege (Navicky, 1998). Unfortunately, there is not a body of evidence examining the effectiveness of either approach.

Although many individuals with an ASD have the intellectual ability to succeed in a post-secondary academic environment, they often fail because these programs are unable to design interven-

tions to ameliorate the students' impairments in social skills and executive functioning. The college experience is more than the academic classes. It includes living in a dorm, managing one's own schedule, eating in cafeterias, and meeting a wide array of people. Furthermore, there is very little direct connection between course content and the skills necessary to obtain and maintain a job.

Transitional Programs

Transitional programs combine elements of both vocational and academically supported program models. They permit students with an ASD to learn job specific social skills, independent living skills, and academic skills necessary to complete a degree. Students may or may not leave with a bachelor's degree depending on the program and the student. Most programs include 4 primary compo-

nents: (1) supported employment and work skills training; (2) adult life skills training including financial management, grocery shopping, laundry, and home maintenance; (3) social and personal relationships counseling and training, and; (4) encouraged social involvement in the community. Transitional programs offer students with an ASD interventions that directly impact their areas of weakness and provide the most hope for successful employment.

Dr. Ernst VanBergeijk, is the Associate Dean and Executive Director of New York Institute of Technology's Vocational Independence Program. He is also a research associate at the Yale Child Study Center's Developmental Disabilities Clinic and is assigned to the autism unit. The publication of this article was made possible by a grant from the National Institute of Health, LRP grant (Number, L30HD053966-01).

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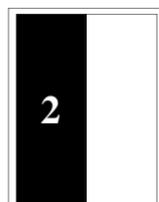
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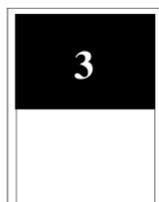
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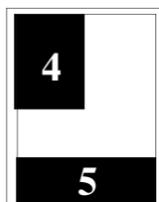
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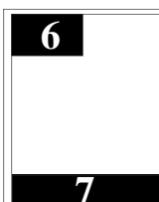
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