

AUTISM SPECTRUM DISORDERS



Looking at Autism

W. Carl Cooley, MD, Medical Director, Crotched Mountain Rehabilitation Center

Welcome to the Fall Issue of the Rap Sheet devoted to autism spectrum disorders (ASD). Once considered a rare disability, autism now affects more than one in 166 children with the rate of incidence increasing each year. The Rap Sheet examines autism from a number of perspectives; service providers, researchers, advocates, parents, and a teen with Asperger Syndrome share their thoughts on the challenges presented by ASD.

"He just doesn't talk. At least, not so we can understand him. Sometimes there are these streams of gibberish – then, every once in a while, clear as a bell, there's some dialogue straight out of *Thomas the Tank Engine*. He doesn't look at us when we say his name. We thought he was deaf, but his hearing tested normal." It was 1987, and Jan Robinson was describing her 3 year-old son, Marty. I was starting a training fellowship to become a developmental pediatrician, and my fellowship director advised that I study Marty carefully. "You won't see more than a couple of kids like him during your entire fellowship."

By 1991 I was directing a network of child development clinics in New Hampshire and following almost 100 children on the autism spectrum. Now it's 2005, and autism spectrum disorders have become one of the most common developmental disabilities affecting more than one in every two hundred children. Autism has been the cover story for Time and Newsweek five times in the past three years. Controversies about its cause and treatment have fueled emotional debates among parents, professionals, politicians, and public health officials.

Defining Autism

Autism or conditions on the autism spectrum are not like strep throat or diabetes. There is no laboratory test to determine if a child has it or doesn't have it. The diagnosis of autism is based on how closely a child's past development and current behavior fit a definition that experts have agreed to use. That definition has three main elements:

- ◆ **Atypical language development** usually affecting both talking and understanding what others say and usually affecting both verbal and non-verbal communication
- ◆ **Atypical social behavior** that may range from seeming indifference to all people to selective difficulty relating to peers and problems playing or working cooperatively with others

SUSAN COVERT, EDITOR

(Cover story continued)

- ◆ **Atypical play and behavior** in which toys are interesting for their details, like the wheels on a toy truck, or for the opportunity to arrange them in a particular order. There may be a narrow range of toys or topics that are of interest, and these may become an obsessive focus.

Notice the word “atypical.” While some aspects of development in children with autism are delayed, there may be other areas that seem normal or advanced – sometimes remarkably so. However, there is always an atypical or unusual quality to development in these three areas as though development is not just delayed, but is following a completely different path.

Though not part of the “official” definition, many individuals on the autism spectrum have a dramatic response to their sensory environment. They may be disturbed by noises barely noticeable by others or by the sound of appliances or certain voices. They may have strong preferences about clothing or foods. Some children may be fascinated by patterns of light and shadow. Many may seek “high impact” stimulation of their muscles and joints or engage in repetitive movement like swinging or jumping. The failure of others to understand and respect the intensity of these sensory preferences may cause significant discomfort for a person with autism and contribute to a behavioral response.

The “labels” used to describe individuals with autism are often confusing. Professionals may use terms differently or even incorrectly. Autism spectrum disorder (ASD) is popular because it uses the familiar word “autism” and conveys the wide variability in how autism affects different people. Pervasive developmental disorder or PDD is an official psychiatric term and used by insurance companies paying for evaluations and treatment. PDD includes the whole group of conditions considered to represent the autism spectrum including classic autism, Asperger disorder, childhood disintegrative disorder, Rett syndrome, and pervasive developmental disorder – not otherwise specific (PDD-NOS) for those not quite fitting into other categories.

Identifying Autism

When interventions begin as early as possible, the outcomes for children on the autism spectrum are improved. Early intervention requires early identification for which there are three main components – early suspicion, early screening, and early diagnosis. *Early suspicion* results from better awareness on the part of parents, grandparents, childcare providers, and others in our communities about “normal” development and about “red flags” for autism. (Visit First Signs at www.firstsigns.org) *Early autism screening* should be part of well childcare with parental concerns taken seriously and screening tools like the CHAT-M used during specific office visits like the 18-month check-up. *Early diagnosis* is more of a challenge. The professionals with the experience and skills to confirm a diagnosis have been overwhelmed by the demand for their services. While a well-informed primary care physician or nurse practitioner should make referrals for early intervention or preschool services based on a suspicion of autism, confirmation from a developmental pediatrician, child psychiatrist, child psychologist, child neurologist, or an autism team may take weeks or months to obtain. Soon, we may have better diagnostic tools that will enable us to recognize the beginning of autism in infants and young toddlers.

Whole books have been written to explain the definition and diagnosis of autism, but one thing is clear. There is no sharp boundary between someone whose development fits the definition of autism

and someone who only comes close. This can make the diagnosis of autism a challenge and can result in differences of opinion among parents, clinicians, educators, and other professionals.

Treating Autism

First, it is important to understand that autism is not a disease, and people with autism are not sick. In fact, some individuals who are mildly affected by autism do not regard themselves as having a disability and would prefer not to be “treated.” Second, there is no established, proven medical and dietary treatment for autism. Because our understanding of autism is incomplete, many ideas and theories exist about treatment – some have promise, some do not, and others remain uncertain.

Finally, a fairly intense or concentrated set of structured, planned interventions starting as early as possible makes a difference for nearly all children on the autism spectrum. Some children require a process of direct teaching of developmental skills (language, social, play) that are not unfolding naturally. This may occur through a concentrated one on one approach using methods like applied behavioral analysis (ABA), or it may involve more natural encounters aimed at chaining together interactions during play (e.g. floor time). Most children eventually will benefit from participation in natural early childhood settings with typical peers as role models for language, social interaction, and play. Addressing a child’s sensory challenges will help to reduce distraction and distress from unpleasant sensory exposures. Overall, these structured interventions should take place at least five days a week and involve up to four or five hours a day.

There is no “autism drug.” However, when the best positive behavioral supports are not enough, a number of medications may be used to modify behavior and mood. Medications can help to reduce anxiety, improve attention, moderate strong behavioral responses, or diminish obsessive or perseverative (repetitive) thoughts and actions. No medication can be the sole solution to a behavioral issue, but must be used together with thoughtful person-centered planning about the best approach for the individual.

Understanding Autism

So, now the question of the decade: “Why does it appear that there are so many more individuals experiencing autism?” Maybe we are better at identifying autism now. That may be true in 2005, but it wasn’t true when the increase in numbers began in the early 1990s. Maybe we include more people on this “autism spectrum” than we did when autism was more narrowly defined. Most experts are beginning to believe that there are simply more people with autism now. We know there is a genetic factor that makes some people more susceptible to autism, and we know that it can “run” in families. There is probably an environmental factor or exposure that plays a role, but no single culprit has been proven to exist.

So, while understanding autism as a neurologic or genetic condition remains a mystery, we can all understand autism as a human condition impacting friends, family members, fellow citizens, and ourselves. We can allow individuals affected by autism to inform us and join us in developing a community of acceptance and inclusion.



Inclusion: A gift to our children, A gift to our community

Karen Turner

The gulf between children with autism spectrum disorders and the educational and social worlds of their peers can seem at times insurmountable. We all have heard the arguments against inclusion of children with autism spectrum disorders and may have even made these ourselves. "Johnny has too many behavioral problems to be here." "Jimmy doesn't even talk." "The classroom is just too dynamic an environment." "He can't handle all those transitions."

Too often thinking about inclusive settings starts with a focus on deficits. We ask, "What is wrong with this child?" or "What is wrong with this program or system?" We concentrate on problems rather than developing a creative vision to build bridges for all children. By framing the issue in this way we fail to take full advantage of the gifts of children with autism spectrum disorders and the gifts in our communities.

How much more productive and energy-generating to start this process by posing the questions, "What is wonderful about this child?" and "What is wonderful about this community and this school?"

When I reflect on what is wonderful about my son, I see his magical qualities of openness, creativity, intensity, and innocence. I realize he *must* be included in school and community settings. His gifts are too magnificent to not find a home for them. Like all children, he needs to be part of the larger fabric that gives community its texture. He needs to experience a sense of belonging, friendships, and shared learning. He needs to be included in academic pursuits and extracurricular activities.

When I think about my son – or any child with an autism spectrum disorder – I realize inclusion is as important for his peers as it is for him. Inclusion and the resulting social bridges enable all children to be more fully themselves. We need to view the world not through a "disability" lens, but through a lens of shared humanity. The challenge turns from our children to ourselves. Can we work with others in our schools and communities to create openings for children with labels of autism spectrum disorders?

In Newmarket, our recreation department offers a dynamic and popular summer camp program. Parents, our recreation department, and our school district formed a community partnership to make the camp an inclusive setting for children with autism

spectrum disorders. We developed a framework for inclusion that we termed Friendship Facilitation, based on the beliefs that 1) inclusion is good for all children, 2) all children at times need bridges and support to be successful, and 3) we need to work together to make this vision a reality.

With support from the Institute on Disability and the Greater Piscataqua Community Foundation, we hired a Friendship Facilitator whose sole responsibility is to build social bridges among children. We held workshops on autism spectrum disorders that were attended by people representing school, recreation, and community interests. We focused on providing positive behavioral support and building on relationships. We involved parents of children with autism spectrum disorders and held regular meetings to develop individualized strategies to ensure their children had a successful camp experience. Strategies included building in breaks, offering choices, and preparing social stories to explain camp activities.

Children with autism spectrum disorders attended camp in their own community, having opportunities for fun, social learning, and even friendships that would not otherwise have been possible. I am happy to count my son among the group who this summer learned that he is good at dribbling a basketball. Creating this inclusive setting has expanded the vision of what is possible for both children and our community.

Reflecting on her son's first summer camp experience, the mother of a child who experiences autism stated, "He seems very happy. He seems to have made friends and that makes a world of difference in him. He seems more outspoken and was introduced to many skills and games he never had before. People like and love my son. It makes me feel good to see his relationships with others and for others to see how beautiful he is."

As a community, we have learned that not only is inclusion possible, it's good for all children. Jim Hilton, the director of our recreation department, observed, "We are recreating what a typical recreation department will look like.... (We are) pioneering something that should have been pioneered a long time ago." The challenge of inclusion provides us both the opportunity and the responsibility to create bridges in our schools and communities. Given the opportunity, our children will surprise us and open hearts and minds in our communities.

“Oh, the Places You’ll Go!”

Kirsten Murphy

So promises a favorite children’s book that I used to share with my two boys when they were still young enough for Dr. Seuss’s happy-go-lucky poem:

*Congratulations! Today is your day.
You’re off to Great Places! You’re off and away!*

Oh, the Places we would go! It’s true. When my second son Josh, just three at the time, began faltering developmentally, we never imagined the places his diagnosis of autism would take us.

*There are some, down the road between hither and yon,
That can scare you so much you won’t want to go on.*

Oh, the Places we would go! Our wandering has taken us through full inclusion in a Montessori school, to supported inclusion at our local elementary school, and finally to a self-contained classroom. We have explored dietary intervention and metabolic testing – promising paths that led us nowhere. We’ve gone down the road of psychotropic medications and found it surprisingly helpful. We’ve weathered stormy times with IEP teams and been rescued by them on other occasions. We’ve seen our sons both taken away in police custody, and we have navigated the torturous path of involuntary hospitalization, twice. Along the way, we’ve marked the toll exacted on other family members – diminished health, career constraints, even trauma.

By the time Josh’s older brother Leo was identified as having Asperger Syndrome, we had come to expect ironic twists and turns. How, for example, could it be possible that Leo, whose diagnosis is not sufficiently “serious” to merit home supports, is in fact our more fragile child?

*You can get all hung up in a prickly perch.
And your gang will fly on. You’ll be left in a Lurch.*

Autism spectrum disorder (ASD) is a disability uniquely without an institutional home. A medical condition, its primary treatment is conducted through educational methods. A developmental disability, it is nonetheless beholden to the authority of psychiatric diagnostic criteria. For the most part, intervention is not billable to insurance, and most children with ASD do not qualify for Medicaid-funded home supports.

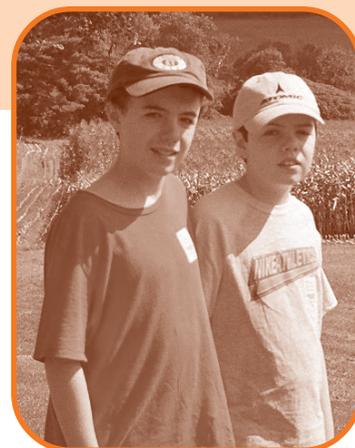
ASD is the disability that no one in the healthcare system wants to own. With the cost of lifetime support for a highly impacted child estimated to be in the millions, the economic reasons for this are obvious. But I’ve come to believe that there are other, more subtle factors at play too.

Autism and related disorders bring new challenges to the disabilities community. By its very nature, ASD requires a multidisciplinary approach that is still unfamiliar territory to most providers and policy makers. ASD is a truly *pervasive* developmental disability. It colors every aspect of one’s life and personality, shaping the choices that ultimately define one’s experience. It raises uncomfortable questions and asks all of us who advocate along side individuals with disabilities to re-examine some of our most cherished assumptions.

*You will come to a place where the streets are not marked.
Some windows are lighted. But mostly, they’re darked.*

As my sons move into adolescence, I find myself wrestling with questions that I didn’t expect to ask when I first graduated from the Institute on Disability’s Leadership training. How do I balance

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Leo and Josh Murphy at a favorite place, Billings Farm, Woodstock, VT.

Kirsten Murphy lives in Hanover, NH with her husband and three children – Leo (13), Josh (11), and Nora (8). She is a member of the NH Developmental Disabilities Council and the founder of ARCH of the Upper Valley, which is working to build regional capacity to address the needs of individuals with ASD in Grafton and Sullivan County. Poetry is taken from Oh, the Places You’ll Go! by Dr. Seuss (Random House, 1990).



Institute On Disability At UNH Launches Resource Center For Autism

Unites Teaching, Research, Service Initiatives on Autism Spectrum Disorders

The Institute on Disability (IOD) at the University of New Hampshire has combined its expertise and services in the study of autism spectrum disorders (ASD) to create the NH Resource Center for Autism.

"The IOD has long been a valuable resource for learning about, diagnosing, and working with individuals with autism. Bringing these various services together as the NH Resource Center for Autism will help us communicate our capacity and, ultimately, better serve people in the state with autism and their families, teachers, and caregivers," said Jan Nisbet, Director of the IOD and Associate Professor of Education at UNH.

The NH Resource Center for Autism comprises professional development and technical assistance, evaluation and diagnosis, and academic and research initiatives, including one of the nation's few Ph.D. programs in the study of autism spectrum disorders.

Specific projects and initiatives of the NH Resource Center for Autism include:

- ◆ **The Early Markers Project**, a research project to identify characteristics associated with the development of ASD in babies who have an older sibling with ASD.
- ◆ **Beyond Access**, a four-year project that promotes improved learning of general education curriculum content by students with the most significant disabilities. Funded by the U.S. Department of Education, Beyond Access works with schools in Windham-Pelham, Raymond, Somersworth, and Pembroke.
- ◆ **Seacoast Child Development Clinic**, which provides interdisciplinary evaluation and consultation to families of children who have developmental challenges, including autism.
- ◆ **Jumpstart: Early Success with Autism**, which assists NH families and providers in supporting young children who have autism or autism-like characteristics.
- ◆ **Annual Autism Summer Institute**, a five-day event providing state-of-the-art information and strategies in educating students with ASD in general education classes.
- ◆ **Ph.D. Program in Education** with a focus on ASD as well as Graduate Certificate in Autism Spectrum Disorders, providing post-baccalaureate education to educators, social workers and psychologists, medical personnel, and policymakers.

The mission of the IOD is to advance policies and system changes, promising practices, education, and research that strengthen communities and ensure full access, equal opportunities, and participation for all persons. Established in 1987, the IOD is a federally designated University Center for Excellence on Disability (UCED).

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Josh's right to make choices with his desire to live apart from the mainstream? What am I to make of Leo's marked preference for the company of other "Aspies" and his aversion to typically developing peers? How do I support each of them as they grow in self-understanding, when I may be uncomfortable with the goals they choose?

*I'm afraid that some times you'll play lonely games too.
Games you can't win, 'cause you'll play against you.*

Josh has been in an entirely self-contained classroom for well over a year. He has his own teacher and his own aide. He accesses virtually none of the opportunities afforded his peers. For example, when his class took an overnight trip to a marine research facility, we spent no time in deciding as a team that Josh would not be going. We're lucky – our district has not denied Josh's right to any of these activities. Rather, it's been a matter of his choice, and, ultimately, ours. Still, I struggle with my misgivings – how can we pass up the very opportunities for which so many of my fellow parents and colleagues have fought? Indeed, are still fighting.

*You'll look up and down streets. Look 'em over with care.
About some you will say, I don't choose to go there."*

What, finally, defines a life of dignity? Is it one's connection to a wider community? Or is it the capacity to exercise meaningful choice, the right – in short – to say "no thank you" to the community around one.

*So be sure when you step. Step with care and great tact,
And remember that Life's A Great Balancing Act.*

Certainly, I can envision ways of balancing inclusion and choice for my sons: telecommuting as a web designer, working at home as a scientific illustrator. What I mean to express is simply my surprise that such fundamental questions are still a part of our daily struggles.

My work, these days, includes advocating for the development of resources for individuals with ASD. Without options, there cannot be any choice. There are times when I have faced the judgment of colleagues in the disabilities community who disagree with some of the models – adaptive and separated from the mainstream – that I and other parents have found to work the best for our kids. These are painful conversations. Where I would most like to find fellow travelers, I encounter misinterpretation and hasty dismissal.

In the end, my sole companions – in fact, my guides – are the same two boys to whom I promised a decade ago:

*Be your name Buxbaum or Bixby or Bray or Mordecai Ali Van Allen O'Shea,
You're off to Great Places! Today is your day!*



Why Are More and More Children Being Diagnosed with Autism?

Michelle Sullivan, Ph.D. and Alan Kurtz, M.Ed. Institute on Disability

Rising Rates of Autism Diagnoses in America

Rates of autism and autism spectrum disorders (ASD) diagnoses have increased dramatically in recent decades. In the 1960s, autism was estimated to occur in 0.5 individuals per 1,000. In the 1990s, rates had increased to 1 per 1,000. Today the Centers for Disease Control and Prevention (CDC) estimate that 3-4 individuals per 1,000 have autism. For the broader category of ASD – including autism, Asperger syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) – rates have increased from 2 per 1,000 to 6 per 1,000. Possible explanations for this rising prevalence include: 1) improved public awareness, 2) expanding diagnostic criteria, 3) services linked to diagnoses, 4) increased genetic risk, and 5) exposure to environmental toxins.

Improved Public Awareness

Over the past decade, there has been a massive change in the public's awareness of autism. In 1993 when Michelle first started working with children with autism, any talk about her work was followed by the question, "What is autism?" Mentioning the movie *Rainman* gave people a frame of reference, although it also gave the mistaken impression that everyone with autism was a savant. It has been years since she has been asked this question. Description of her work is now met with, "My – neighbor, friend, sister, teacher – has a child with autism." It seems that everyone knows someone with autism.

Earlier this year, the CDC launched a national campaign "Learn the signs. Act early." to promote the early diagnosis of autism. At the same time, NBC aired a weeklong special report, "Autism: The Hidden Epidemic," with stories about autism featured on the network's news shows. National foundations such as National Alliance for Autism Research, Cure Autism Now, and the Autism Society of America have raised millions of dollars to inform parents and health care providers about autism. Celebrities like Anthony Edwards and sport stars like Doug Flutie and Dan Marino have helped focus media attention on critical issues surrounding autism.

Expanding Diagnostic Criteria

There are no blood tests or other biological markers for autism; diagnosis is based on meeting certain behavioral criteria, typically those found in the Diagnostic and Statistical Manual of the Mental Disorders (DSM). Individuals diagnosed with autism can have very different symptoms from others with the same label, but still meet the DSM criteria for autism.

Regularly updated by experts in the field, the DSM represents current thinking and changes greatly over time. Prior to 1980, the DSM described "infantile autism," but included no mention of PDD. In 1980, the DSM-III introduced PDD and thus broadened the category. The 1987 DSM-III-R (R stands for revised) further expanded the definition of PDD, and blurred the lines between typical development and autism. In 1994, DSM-IV introduced the categories of Asperger Syndrome, Rett Syndrome, and childhood disintegrative disorder as subcategories of PDD. Since 1980, the broadening of the PDD category has coincided with a rising prevalence of children diagnosed with these labels. A newer version of the DSM is in development and likely will bring additional changes. As research studies generally define participants who have autism according to the most current version of the DSM, the changes in prevalence that have been reported in research in part may reflect the changing diagnostic criteria.

Services Linked to Diagnoses

A diagnosis of autism may provide individuals and their families access to a network of supports and services. These may include developmental evaluation, speech-language therapy, occupational therapy, physical therapy, respite care, coordination of medical services, behavioral consultation, and an Individualized Education Plan (IEP). In 1992, the US Department of Special Education added autism as a disability category under the Individual with Disabilities Education Act (IDEA). Rates have steadily increased in this category since its inception. The increase in identified children may be attributed in part to the changing IDEA categorization, as well as the need for a diagnosis in order to access services.

Genetics and Autism

Research studies of families with one or more members with autism have provided evidence that autism is highly heritable. Studies of twins suggest that if one identical twin has autism, the other twin is 60-90% likely also to have autism. For fraternal twins and siblings, this figure is 5-15%; still, a much higher risk than in the general population. Many genetics studies have identified differences in specific chromosomes, including chromosomes 7 and 15. Some portion of the rise in diagnoses of autism may be attributed to these "family trees" where successive generations have the potential for increasingly more members with autism.

Exposure to Environmental Toxins

Certainly the explanation for the increase in autism that has received the most publicity is exposure to environmental toxins, in particular mercury in the form of the thimerosal preservative in the measles-mumps-rubella (MMR) vaccine. Five major studies have failed to find a link between thimerosal and autism. The Centers for Disease Control and Prevention, the Food and Drug Administration, the World Health Organization, and the American Academy of Pediatrics all have issued position papers stating that there is no convincing scientific evidence linking MMR vaccines to autism. At the same time, many parents and a substantial number of those in the medical community cite studies to support their view that such a link does exist.

A number of researchers believe that the rise in autism may be at least partially attributable to exposure to a range of environmental toxins, including mercury and other heavy metals. University of Texas researchers recently found a possible link between autism and exposure to mercury from coal plant emissions. Researchers at the University of California, Davis recently announced preliminary results that individuals with autism may have an altered immune response that make them more susceptible to a variety of environmental contaminants. No firm conclusions can be drawn yet about the relationship between specific toxins and the rise in the diagnosis of autism.

At this time, the question of why we are seeing such a rise in the prevalence of autism in our children has not been satisfactorily answered. Many possible explanations exist and it is likely that more than one factor is contributing to this increase.

THE THIMEROSAL DEBATE

*For more information concerning the controversy surrounding thimerosal, read Robert F. Kennedy, Jr.'s article, "Deadly Immunity," in the June 2005 **Rolling Stone Magazine**. Available on line at www.rollingstone.com/politics/story/_/id/7395411*

To look at the other side of the debate, see the Center for Disease Control's recent and well organized update at www.cdc.gov/nip/vacsafe/concerns/autism/default.htm

Evidence of Harm, Mercury in Vaccines and the Autism Epidemic: A Medical Controversy by David Kirby (St. Martin's Press, 2005) follows the thimerosal debate through the eyes of several parents. Although his bias is clear, Kirby is even-handed in reviewing the shortcomings of each of the major scientific studies presented to date, regardless of which side of the controversy they support. He also unpacks the complex political maneuvers that have already greatly reduced the liability of pharmaceutical companies should a causal link between autism and thimerosal be established.

(This first appeared in the July-August 2005 ARCH of the Upper Valley Newsletter)

Making Learning a Priority

Julia Freeman-Woolpert, Disabilities Rights Center

Jimmy Caster is happiest when he is simultaneously using two laptop computers, listening to the radio, and watching TV, preferably while bouncing on a ball. Jimmy's mother, Kristine, says her son's active mind begs for lots of stimulation. Jimmy's fascination with computers began in preschool. Now, at age seven, he has a wireless Internet connection and plays educational computer games both online and off.

Jimmy and his four year-old brother Timothy keep their mother extraordinarily busy. Having two sons with autism is not for the faint of heart, but Kristine Caster, is one determined lady. "I believe in hard work and perseverance," says this mother who has made it her full time job to help her boys grow and develop. Kristine works closely with the elementary school and notes that, "Communication between home and school is essential." She describes herself as the "CEO" of her sons' educational programs, coordinating all the various aspects of their learning. At home she continues the boys' education, teaching communication and social skills during most of their waking hours.

Neither Jimmy nor his brother speaks. Instead, both boys are learning to communicate using the Picture Exchange Communication System* (PECS). Kristine spends a lot of time finding and laminating pictures for their picture communication boards. Recently Jimmy has started supplementing his communication with sign language, which is becoming faster and easier for him to use than the communication board.



Jimmy Caster, the master of multi-tasking

Tony Barry – A Man of Many Interests

Julia Freeman-Woolpert, Disabilities Rights Center

Every morning at 5:30 AM, Tony Barry rolls out of bed and goes for his morning jog. After breakfast, he takes the bus to work, an hour and a half ride with a couple of changes. Most days after work, Tony stops off at the YMCA to swim laps – always 40. He likes things to be just so.

A man of many interests, music is his favorite. Tony reports, "I like Brahms and Chopin and Grieg and Mozart. I like Broadway music too. I like My Fair Lady, Mary Poppins, and The Sound of Music." He enjoys playing basketball, bowling, and doing yard work around the house where he lives with his mother, Margaret. He also loves traveling and for his upcoming 50th birthday his brother and sister-in-law are taking him to his favorite destination, Manhattan. "I like the skyscrapers and the tall buildings and the bridges and the tunnels."

When Tony was a child, autism was a rare and little understood disorder. Tony started talking at an early age, but by the age of four had stopped talking and withdrew into his own world. He developed repetitive movements. When the doctors couldn't come up with a diagnosis, it was his mother who did the research. The first time she suggested autism to the family's pediatrician, he asked, "What's that?" The family was on its own when it came to figuring out how to teach Tony or how to help him cope with his autism. His mother remembers, "There was no guidance of any kind."

In the beginning, Kristine was at a loss as to how to help her children learn. When Jimmy was four he was placed in an out of district program in Bedford. Kristine was amazed that after only a week in the program, Jimmy was potty trained and was beginning to communicate using his first picture system. When Jimmy came back to school in Hooksett, his educational plan came with him. Today Jimmy is included in the regular classroom, where he takes his turn as the Pledge Leader and Office Assistant. "I don't like pullouts," says Kristine. When the class is engaged in an activity that isn't appropriate for Jimmy, he has a space in the back of the classroom where he works with his teaching assistant on individual skills. There are times Jimmy does need time away from the class. To help him get focused for the day, Jimmy arrives at school a half an hour early to work with his teaching assistant on sensory integration.

While Kristine would like to see the school provide more of technology for her sons, she is not one to wait around for this to happen. "Time is precious," she explains. To ensure that their sons have the tools they need to learn, the family has purchased laptop computers, cameras, copiers, scanners, educational games, and a laminator – to name but a few items. These additional expenses, along with Kristine quitting her job to stay home and work with her sons, have put a strain on the family's budget. Until only recently, Kristine's husband Steven worked two jobs in order for their family to afford the equipment and supplies the boys use to learn and communicate.

For the Casters, their sacrifice and hard work is paying off. Jimmy has made steady gains with communication and other skills; he is making more eye contact and now uses utensils at mealtime. Jimmy's computer literacy continues to expand, and it won't be long before he'll be providing his teachers with computer tips – perhaps he already is!

- ◆ For more information about the Picture Exchange Communication System (PECS), go to the website of Pyramid Educational consultants at <http://www.pecs.com/>
- ◆ For an explanation of sensory integration, see this article by an Occupational Therapist on the website of the Center for the Study of Autism: <http://www.autism.org/si.html>

This was a time before children with significant disabilities had a right to a public education. The local mental health center suggested that the family place Tony in an institution. The family considered the Philbrook Center, but couldn't afford it. For three years, Tony was taught by the nuns at Holy Cross and eventually enrolled in Miss Jacques' School, a private school within walking distance of his home.

At the age of seven, Tony's only spontaneous speech was talking on the phone with his grandmother. This gave Tony's mother an idea; she installed upstairs and downstairs telephones and made a phone call



Tony Barry, right, and a co-worker greet each other at Moore-Wallace

when she wanted to have a conversation with her son. Whenever Tony showed a spark of interest in something his mother ran with it. When he seemed intrigued by typing, she bought him a typewriter. Tony taught himself to type and spent hours copying composers' biographies off record jackets. Later, Tony used the typewriter to communicate. When his doctor had questions for him, Tony would type the answers. For some reason Tony can't explain, it was just easier for him to communicate this way.

As a young boy, Tony memorized his father's college yearbook; he knew everyone in it all, their addresses, and the

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Recent changes to Special Education Law: What do they mean for you and your child?

Julia Freeman-Woolpert, M.Ed., and Ronald Lospennato, Esq. Disabilities Rights Center

By now, if you have a child who receives special education, you know there have been significant changes to the Individuals with Disabilities Education Act (IDEA). Most of these changes went into effect on July 1, though state and federal regulations have not yet been updated. Many school districts are still familiarizing themselves with the new IDEA and have not yet implemented it. Some changes in IDEA will have a big effect on your child's educational planning, others you may not even notice.

Attorneys at the Disabilities Rights Center (DRC) think the following changes are ones that are most likely to affect you or that you need to know about. These are by no means all of the changes; visit the DRC website at www.drcnh.org/IDEA_reauth.htm for more complete information.

Short-term objectives

For most children, short-term objectives are no longer required under federal law. Benchmarks, or short-term objectives, are only required for those children, estimated to be less than 1% of students with disabilities, who take "alternate assessments aligned to alternate achievement standards." The DRC is concerned that this change may mean parents have no way of measuring progress toward their child's annual goals, especially given the changes to the requirements for reevaluations. In practice, the DRC has found that most school districts are still using short-term objectives. Indeed, the current rules require the use of short-term objectives, although it is unclear if these rules are enforceable. On a positive note, education and related services are to be based "on peer-reviewed research to the extent practicable." This means the school should be using educational methods and services that have been shown to work.

Evaluations

Reevaluations will now occur no more than once a year, unless the parents and the school district agree otherwise. More significantly, while reevaluations every three years had been mandatory, under the new IDEA they will occur "at least once every 3 years, unless the parent and the local educational agency agree that a reevaluation is unnecessary."

Specific Learning Disabilities

School districts are no longer required to find a severe discrepancy between achievement and intellectual ability in order to determine that a child has a specific learning disability and therefore needs special education. This means there is one less hurdle to jump in order for the team to determine that a child has a learning disability.

Transition

The age at which transition services must be considered under the Individual Education Plan (IEP) has changed from 14 to 16 and is to include "appropriate measurable postsecondary goals" and "the transition services (including courses of study) needed to assist the child in reaching those goals."

Team meeting participation

Members of the IEP team are not required to attend an IEP meeting if the parent and the school district agree that attendance is not necessary "because the member's area of the curriculum or related services is not being modified or discussed in the meeting." By mutual agreement, a member of the team can be excused from the meeting if the member submits input in writing prior to the meeting. In both of these circumstances, the parents' agreement to waive a team member's attendance must be in writing.

Attorney fees

Parents may now be responsible for paying for the school district's attorney fees if the cause of action is found to be "frivolous, unreasonable, or without foundation," or if the purpose was "improper, such as to harass, to cause unnecessary delay, or to needlessly increase the cost of litigation."

Many of the changes to the process – waiver of team meeting attendance, three-year evaluations – require parental consent. The DRC and other advocacy organizations are concerned that parents may find themselves under pressure from the school to consent to these changes.

If you need more information about changes to the IDEA, visit the DRC website at www.drcnh.org/IDEAauth.htm or call DRC at 228-0432 or 1-800-834-721, voice or TTY.

Adolescence Meets Autism Spectrum Disorders: Two Essential Challenges and How to Master Them

Teresa Bolick, Ph.D., Licensed Psychologist

FIRST...

Don't forget that one of the tasks of adolescence is to learn to be as independent as possible. Make sure that you and the adolescent have a mutual understanding of the goals and how to try to reach them.

CHALLENGE # 1: ADAPTIVE SELF-REGULATION

Adaptive self-regulation is the ability to regulate thoughts, feelings, and behavior efficiently enough to participate in everyday life. Many adolescents with ASD spend most of their lives with stress levels "up to their eyebrows." They try hard to manage their sensations, thoughts, and feelings through repetitive behaviors, routine, and single-minded focus on special interests. The problem is that their self-regulatory strategies are frequently inefficient or inappropriate to the situation.

It's impossible to eliminate all of the stress in life. And everyone has trouble coping with the last straw when already "up to here." The key to self-regulation is to reduce stress and strain before it accumulates to unmanageable levels or "overload."

Strategies to prevent overload

- ✓ Create a "home base" to support the adolescent's sensory needs. For example, a student with hypersensitive hearing is likely to need a quiet space at school and at home for study or for regrouping.
- ✓ Allow music, snacks, and other sensory tools that improve concentration and reduce stress.
- ✓ Experiment with clothing and hygiene routines that reduce irritation but without creating socially penalizing situations.

Strategies that manage stress

- ✓ Teach relaxation strategies, ideally in a group with other adolescents.
- ✓ Develop a regular exercise routine, adapted to the student's sensory and motor profile.

- ✓ Encourage the adolescent to get involved with music, drama, or art, as a participant or as a spectator.
- ✓ Help the adolescent learn to use special talents and interests as stress management strategies (such as drawing or "blogging" when overwhelmed).

CHALLENGE #2: PORTABLE COMMUNICATION

Portable communication means that the adolescent is able to express needs, desires, thoughts, and feelings to anyone anywhere. All too often, we hear from parents or professionals, "But I know what he means." That's terrific, but it doesn't do much good if you're not around. Even adolescents with Asperger Syndrome or PDD-NOS typically need help to develop portable social communication skills.

Strategies that support communication

- ✓ Talk with the adolescent about what to tell others about his/her communication. For example, one young man wrote to his teachers asking them to give him plenty of time to answer and to please ask him to repeat if they didn't understand him the first time.
- ✓ Always give the adolescent time to understand what you say and to compose an answer.
- ✓ Respect the adolescent's ability to communicate. Don't look to someone else for an answer unless the adolescent cues you to do so.
- ✓ Ask for clarification when you don't understand what the adolescent means.
- ✓ If the adolescent uses an augmentative communication system, ensure that he/she always has it nearby. (This is the adolescent's voice.)

- ✓ Use visual AND verbal cues. Visual cues can take many forms – photos, picture symbols, lists, or gestures. These help the adolescent understand and remember important information or steps in a process.
- ✓ Coach peers regarding ways to support the adolescent's communication.

Direct teaching of skills

- ✓ Always start with the skills that the adolescent needs or wants most.
- ✓ Teach skills within meaningful context, whenever possible.
- ✓ When necessary, teach scripts for specific social situations.

- ✓ Be sure to teach slang, including when to and when not to use it.
- ✓ Teach the unwritten rules about which topics, words, and tone of voice can be used in different situations.

ONE LAST "TAKE HOME" MESSAGE

We often worry about what will happen to our children when they grow up, especially when the child has a disability. As we look to the future of our children, though, we must remember the words of Ralph Waldo Emerson (1878), "What is a weed? A plant whose virtues have not yet been discovered." I wish you the best in discovering your adolescent's virtues.

The Friendship Experience

Ben Carozza, Concord High School Class of 2006

I cannot possibly explain my high school experience without giving you some background information. When I was ten years old and a fourth grader, I was having trouble in my classroom. I constantly worried that I did not have enough friends, or as many friends as my peers. Worrying about friendships was a major distraction. It got in the way of my education and made me very anxious. I was frustrated that it was so much harder for me to make friends than it was for everyone else. I obsessed over this so much that I behaved in an odd manner. To help figure out what was going on, my parents took me to a developmental pediatrician. I was given a diagnosis of Asperger Syndrome.

Over the following years, I became better at building friendships. However, my opportunities for meeting other kids were limited by living in a small community. Throughout my elementary and middle school years, I never had more than sixty students in my grade. It was time for a change. Luckily, I would be going to a high school that had nearly five hundred students in my class.

I realized I might have some difficulty making friends in a new school. But from the very start, I found a place where I could succeed. I joined the school band. This was actually the suggestion of my therapist, but I liked the idea. I am a good musician and playing in the band I could meet people who share some of the same interests that I do.

Before school even started, I spent a week at "band camp." At camp I met a whole bunch of new people and by the time school started I already had some friends. With band classes, after school rehearsals, football games, and parades, I've had lots more opportunities to make friends. I've taken advantage of these opportunities.

These friendships didn't just come to me. I worked to build friendships. I acted very friendly and happy around the other band students. I started basic conversations and asked them about their interests and

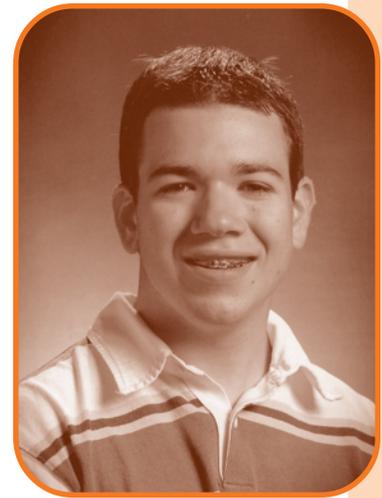
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not just mine. To people without Asperger Syndrome, this may seem like a simple thing, something many people do without even thinking. But because I have Asperger Syndrome, I had to teach myself how to make friends. I did this with some help from my therapists. I consider myself lucky since many people with Asperger Syndrome have a hard time learning this.

High school was becoming a world I could not have imagined five years earlier. It has been an oasis filled with happiness. I didn't have to try hard to make friends, and it appeared that everyone loved me. It's not like I am the most popular kid out there and it's not like I spend every weekend hanging out with friends. But the quantity of my friendships is better than I have ever known.

In the end, I am just one of many people with Asperger Syndrome who has struggled making friends. Now as a senior, I look back and realize that my high school years have been a life lesson. High school has taught me that all things are possible, and if you really try hard at something, you can succeed. It is my goal to teach other people with Asperger Syndrome that just because you may have difficulty in some areas, like social relationships, it doesn't mean you can't succeed in those areas. You may have to work harder at it than other people, but you can do it. This is a message that I hope to share throughout my life. As I look back, my high school experiences will serve as my inspiration for teaching the world what I have learned.



*Ben Carozza,
Concord High Class of 2006*

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degrees they received. Tony can still recite this information. His capacity for remembering names comes in handy for his friends and family. If anyone has trouble recalling a name, they just ask Tony.

Eventually, Tony started speaking and interacting with people. A medication prescribed when he was a teenager seemed to help a lot. Jogging and swimming took the place of his other repetitive movements. Today Tony has a job; he's talkative and sociable. All those things he wasn't ever going to be able to do – well, he's doing them.

For the last eight years Tony has worked at Moore Wallace, a Manchester printing company. He's part of an "enclave," a type of supported employment where a small group of people with disabilities works within a larger business, receiving training and supervision from a job coach. Tony reports, "I like my job. I like my job coach and my coworkers." A walk through the plant with Tony is quite a social event as he greets everyone he passes by name. In fact, it seems Tony knows most everyone in the city. His friendly, gentlemanly manners have made him a familiar Manchester figure.

There are still times when it is difficult for Tony to connect with other people. On those days, he speaks mechanically, in short phrases, and only when he has to. At times he reverts to his repetitive movements. Tony never will like too much noise or change and his mannerisms always will be a bit eccentric. There is no doubt that Tony will continue to need supportive services. But if you ask him, he will tell you he is enjoying his life. He has things he loves to do and he's doing them. Clearly, his friends, family, and coworkers enjoy being with Tony and appreciate those things that are unique and interesting about him. But if you live in Manchester, you probably already know Tony and what a nice man he is.

The Autism Network: We're Building It Because You Asked For It

Christine McMahon, COO Easter Seals, NH

"HELP!" That's what Easter Seals, NH hears from frustrated families. Parenting a child with a disability is extraordinarily hard work, but parents of children with autism spectrum disorders (ASD) are forced to do much more. They research treatments and therapies and spend hours on the phone, often in vain, trying to find services for their children. They drive hundreds of miles zigzagging across NH and into neighboring states getting their children to appointments with therapists and specialists. To pay for these services, parents have to negotiate different service systems and funding streams. Parents are exhausted! They want to be parents, not case managers.

NH's current service delivery system is not organized to meet the diagnosis, treatment, and support needs of the growing number of children with ASD and their families. Vital services are not adequately available or locally accessible. There is insufficient funding for many of the services families most need. Resources for emergency interventions, family support services, and care coordination are woefully limited. Disconnectedness between services, specialists, and funding streams makes it nearly impossible to carry out a cohesive treatment plan. Schools, area agencies, providers, and other organizations working in isolation lack the capacity, expertise, and authority to meet the complex treatment and service needs of individuals with ASD and families. The result is a disjointed, overtaxed, piecemeal system that exacts an enormous price both for individuals and society. Parents caring for a child in crisis lose their jobs because of missed work. Young adults with ASD never receive the services and the support they need to reach their full potential. Children are inadequately served and families become more and more isolated.

The problem is complex and growing. After years of struggling to serve the increasing number of people with ASD and their families, Easter Seals realized a long-term solution was needed. We brought parents, people with ASD, the State, the medical community, schools, area agencies, mental health centers, and other providers together to analyze the problem. We held public forums and conducted surveys. We asked, "What do you need?"

And we got answers. Families want what's best for their children and they also want to live normal lives. Families want information at their fingertips. They want access to the very best diagnostic services and treatment options and help in making sense of it all. They want ample respite. They want after school programs and integrated social

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and recreational opportunities. They want ONE treatment team that works as a team. They want local services in a community that welcomes their children. In a crisis they want a number they can call – day or night.

Easter Seals, NH assembled a Steering Committee to further explore this issue. It soon became clear to both service providers and the State that no single entity can solve this problem. We needed to make a shared commitment and pool our energy and resources. This was the beginning of the **Autism Network for Diagnostic, Treatment and Family Support**.

The Autism Network is working to combine local resources with mobile statewide resources to give families increased local service options along with a centralized source for information, care coordination, family support, and diagnostic and treatment services. The result hopefully will be more cohesive, accessible, and effective services.

Almost immediately the Network has been able to make improvements to the service system. With help from foundations and other philanthropists two new Sensory Integration labs have opened in Southern NH. By pooling financial resources, Easter Seals, Manchester Schools, area agencies in Manchester and Nashua, and the Mental Health system hired a highly skilled Care Coordinator and a Family Support Coordinator who already are serving hundreds of families. A toll-free number, **1-877-6AUTISM** was established to give families and providers someone to call for information, support, or services. The Network has begun to increase NH's capacity for emergency intervention, family support services, and other critical services.

It is hard work to retool a deeply entrenched system, especially when funding is limited; it requires creativity and commitment from providers *and* funders. The success in getting the Network going would not have been possible without flexibility from the state's Department of Health and Human Services. NH DHHS has encouraged providers to be creative and has assured us that they understand that rules may need to change with the times. While the Department's Commissioner John Stephen has made it clear that there are no new monies, he has also promised to fund *what's best*, not simply *what's easiest*.

The Autism Network is new and much still needs to be done. But as a growing Network of consumers, families, medical providers, social services, schools, philanthropists, and State government, we are committed to sharing our expertise, creativity, and resources. The value of the Autism Network is far greater than the sum of its parts. We promise to never lose sight of our purpose and to never stop listening. When people ask for help the Autism Network will rise to the challenge.

"With this ring, I thee wed."

Julia Freeman-Woolpert, Disabilities Rights Center

A love of country music brought them together. A love of each other keeps them together. Cory and Lana Collier met in February, and after a whirlwind courtship, married twice: once in her hometown and once in his. They're young and they don't have much money, but they do have each other. Cory's advice to those thinking about marriage, "Listen to your heart. Your heart will tell you."

Cory wrote this poem to Lana for his wedding vows:

*Lana, You've always been there when I needed you.
You were the sunshine that broke through the clouds on the darkest of days,
You were the warmth that I needed on those cold days,
You were the strength I needed when I was weak,
Lana, I'll be there for you when you need me.
I'll be the sunshine that will break through the clouds on the darkest of days,
I'll be the warmth that you need on those cold days,
I'll be the strength you need when you are weak,
Lana, without you, my life would not complete.
You have filled the void that was in my heart
That is why, Lana Elizabeth Syrie, with this ring I thee wed.*



Congratulations to Cory and Lana Collier on their recent marriage.

Cory Collier is a Second Lieutenant in the Civil Air Patrol and working towards promotion to First Lieutenant. He also has his own business, Collier Web Design. On his website Cory notes that he was diagnosed with Asperger's and Tourette's in the late 1990's.

AVAILABLE RESOURCES RELATED TO AUTISM SPECTRUM DISORDER

Compiled by Kirsten Murphy, Director, ARCH of the Upper Valley

On-line Resources for the ASD Community

www.autism-society.org Website for the American Autism Society

www.nhautism.com Website for the Autism Society of NH

www.cureautismnow.org Website for the national organization, Cure Autism Now

www.ddpi@flash.net Dennis Debbaudt's Autism Risk & Safety Newsletter

Debbadt is a nationally recognized authority on autism-related safety issues. His newsletter, which is published as he has time, is a good way to stay on top of new safety products and recommended emergency protocols.

www.home.sprynet.com/~schafer/ Although it helps to become familiar with the editor's bias, the Schafer Autism Report offers reliable and current summaries of articles from numerous scientific journals and newspapers across the country

www.wrongplanet.net Put together by a young man from White River Junction, VT, this is an excellent and inspiring resource, especially for teens with ASD.

www.aspergerteens.com This website is designed by a NH teenager with Asperger Syndrome to help other teens with Asperger Syndrome deal with adolescent life.

www.autismsociety-nc.org The Autism Society of NC maintains an excellent bookstore with over 400 titles related to ASD. Profits go to assist the NC Autism Society.

AVAILABLE RESOURCES, CONTINUED

www.autismspeaks.org Developed following NBC's media campaign for autism awareness last spring, this is one of the best websites for tracking progress on the Combating Autism Act of 2005.

The ARCH (Autism Resources for Community and Home) Electronic Newsletter is published every other month; the editor culls numerous websites and emails to offer information and resources that can be accessed in the VT-NH upper valley region of Northern New England. To subscribe send an email to ARCH@valley.net.

Books and Other Materials

I strongly urge parents – especially those who have only recently received a diagnosis of ASD for their child – to read any of several excellent first-person narratives that illustrate the differences in sensory perception and social cognition that an individual with ASD experiences. These include:

The Curious Incident of the Dog in the Night-time, by Mark Haddon (Doubleday, 2003). *Although fiction, Mark Haddon provides a readable novel that proves invaluable in helping readers to understand that dysfunctional behaviors associated with ASD are rooted in anxiety, not defiance.*

The Mind Tree, by Tito Rajarshi Mukhopadhyay (2003). *Poetic and miraculous, this book flies in the face of the popular notion that individuals with classic autism do not have the capacity for self-reflection or abstract thought.*

Songs of the Gorilla Nation, by Dawn Prince-Hughes, Ph.D. (Harmony Books, 2004). *Although Prince-Hughes gritty account may offend some, she breaks all stereotypes of individuals with ASD as withdrawn and risk-averse.*

There's a Boy in Here, by Judy Barron and Sean Barron (Simon & Schuster, 1992). *A classic that every one who loves someone with ASD should read.*

Women from another Planet, edited by Jean Kearns Miller (2003). *Powerful and a challenge to the common notion that only males have ASD.*

The Autism Perspective (TAP) is new magazine whose mission is to become an unbiased com-

prehensive resource for information, service options, and treatments. To subscribe visit their website www.theautismperspective.org/

The Autism Sourcebook: Everything You Need to Know About Diagnosis, Treatment, Coping, and Healing, by Karen Siff Exkorn (ReganBooks, 2005). The Autism Sourcebook was recently featured on Good Morning America, it can be ordered through the Autism Speaks website www.autismspeaks.org/autism/index.asp

A percentage of the proceeds from the book sales will be donated to Autism Speaks.

Guides Specific to New Hampshire

The New Hampshire Task Force on Autism, Assessment & Interventions, (2001-2003). *An excellent review of the advantages and concerns that come with each of the major treatment modalities for autism. This guide can be obtained free of charge by contacting the Autism Society of NH at 603-679-2424 or by emailing nhautism@yahoo.com.*

Maneuvering Through the Maze, A Family Resource Guide to NH Services for Families who have Children with Disabilities or Special Health Care Needs, 2nd Edition, (NH Family Voices, 2005)

NH Agencies and Organizations

ARCH of the Upper Valley, located just over the border in Norwich, VT, ARCH serves families in lower Grafton and Sullivan Counties. Their on-line newsletter and telephone consultation is open to anyone. Contact: ARCH@valley.net or 802-649-2720

Autism Network for Diagnostic, Treatment and Family Support.

Operated by Easter Seals, NH, individuals, families, and service providers can call the Network toll-free, 1-877-6AUTISM for information, support, and services.

Autism Society of New Hampshire, P.O. Box 68, Concord, NH 03302-0068. Contact: info@nhautism.com or 603-679-2424. *A volunteer, parent-driven organization dedicated to those living and dealing with ASD in NH through education, awareness and advocacy.*

Crotched Mountain TRUST Center, Carter Hall, One Verney Drive, Greenfield, NH 03047. Contact: Mike Shields at mike.shields@crotched-mountain.org or 603-547-3311. *Sponsors numerous workshops and trainings, including Dan Hobbs "Gentle Teaching."*

Dartmouth Center for Child Development, Children's Hospital at Dartmouth, One Medical Center Drive, Lebanon, NH 03756. Contact: 603-650-7884. *Evaluation and professional consultation.*

Institute of Professional Practice, Inc. Contact: Le'Ann Millinder, PhD., NH Clinical Director, or Matt Cioria, MS, BCBA, Clinical Coordinator, 6 Chenell Drive, Suite 100, P.O. Box 2168, Concord, NH 03302-2168, phone 603-224-8085 Or 1-800-750-8085. *ABA consultation and training for school and home programs. IPP also maintains field offices in Nashua, Lee, and the Lebanon area (White River Junction, VT).*

Jacob's Bridge Through Autism, Box 234, Plymouth, NH 03264. Contact: Susan and John Scheinman, Co-Founders and Parents, 603-536-2767.

Parent-to-Parent New Hampshire, Contact: Phil Eller at p2pnh@valley.net or 603-448-6311. *Connecting with parents state-wide who have "been there."*

Resource Center for Autism, Institute on Disability/UCED, University of NH, Durham, NH. Contact: Mary Schuh 603-228-2084. *The Center comprises professional development and technical assistance, evaluation and diagnosis, and academic and research initiatives, including one of the nation's few Ph.D. programs in the study of ASD.*

Seacoast Child Development Clinic, Institute on Disability/UCED, University of NH, Durham, NH. Contact: 603-862-0561 or Seacoast.Clinic@unh.edu. *Evaluation and professional consultation.*

SERESC, 29 Commerce Drive, Bedford, NH 03110-6835. Contact: Robin Knight, 603-206-6816 or knight@seresc.net. *Frequently sponsors conferences, especially those featuring Theresa Bolick, Ph.D.*

Studies to Advance Autism Research and Treatment (STAART), Dartmouth Hitchcock Psychiatric Associates, Section of Child and Adoles-

cent Psychiatry, Lebanon, NH 03756. Contact: Rosemary Affeldt, LICSW at 603-650-0854 or Rosemary.Affeldt@Dartmouth.edu. *Currently sponsoring an NIH study for children and teens with ASD and high levels of repetitive behaviors.*

Upper Valley Support Group, Lebanon, NH. (603) 448-6311 (general number) or (603) 448-1268 (respite). *Services include: consultation, PIC trained special education advocates, parent-to-parent support, and a respite care program that has Flutie Foundation funds earmarked for families who have a child with ASD.*

Other Organizations

Asperger's Association of New England, 182 Main Street, Watertown, MA 02472. Phone: 617-393-3824. *AANE provides an excellent packet to new members that includes papers ranging from information for the newly diagnosed to resources for individuals with Asperger's who are interested in attending college. Their annual conference is also excellent.*

Autism Society of Vermont / University of Vermont Department of Communications Summer Institute on Autism Spectrum Disorders, Contact: 1-800-559-7328. *One of the very best regional conferences, sponsored annually in June.*

Ladders, Massachusetts General Hospital, 65 Walnut Street, Wellsley, MA 02481. Contact: 781-449-6074. *The nearest available medical center with expertise in metabolic and gastro-intestinal disorders in relation to ASD. Their annual fall conference for parents, "Current Trends in Autism," provides the most scientifically up-to-date information available to parents in our region.*

The Maple Leaf Center, Olde Pine Lane, Wallingford, VT 05773. Contact: 802-446-3601. *Operates both a clinic with expertise in NLD and numerous regional conferences, including those by Carol Grey and Tony Attwood.*

U·P·C·O·M·I·N·G E·V·E·N·T·S

Institute on Disability Research-to-Practice Series Understanding and Supporting Individuals with Autism and their Families

LIFE AS A PARAPROFESSIONAL: STRATEGIES FOR WORKING WITH STUDENTS WITH CHALLENGING BEHAVIORS – Cathy Apfel, IOD, UNH A highly interactive session to help paraprofessionals develop approaches to support students with a wide range of behaviors. This seminar is offered at the Highlander Inn Hotel, Manchester NH on September 28, 2005; November 16, 2005; January 19, 2006; February 16, 2006; March 16, 2006; April 13, 2006.

– *All Sessions Below will take place at the Grappone Conference Center in Concord* –

Supporting Young Children with Autism and their Families – Ann Dillon, M.Ed., OTR, Project Coordinator IOD, UNH and Michelle Sullivan, PhD, Research Assistant Professor, IOD, UNH. This session will discuss issues around early identification of autism spectrum disorders (ASD) in children under the age of three as well as early supports and services for families who have a child diagnosed with ASD, or have concerns that their child may be on the spectrum. *December 6, 2005.*

Autism and the Myth of the Person Alone – Lessons from First Hand Accounts – Douglas Biklen, PhD, Syracuse University, Cultural Foundations of Education, Teaching and Leadership. This presentation will challenge prevailing views of autism and disability and force participants to rethink assumptions about people who are diagnosed as having social and intellectual disabilities. *January 11, 2006.*

Understanding Autism and Challenging Behaviors – Ruth Ryan, MD, Neuropsychiatrist, Chief Clinical Officer Grafton, VA. Understanding a person with challenging behaviors involves obtaining information from the individual and the people who know the person best. As we sharpen our listening we can avoid the destructive "quick fixes" of sedating medication and coercive behavioral procedures. *January 30, 2006.*

Balancing ABA and Inclusive Education – Ilene Schwartz, Professor of Special Education at the University of WA. Applied Behavior Analysis (ABA) is one of the most effective instructional approaches for working with people with autism. This workshop presents the basics of ABA and how ABA can be a cornerstone for effective inclusion for people with ASD and other disabilities. *March 13, 2006.*

Potential Causes of Autism – The Relationship Between Autism and the Environment – Martha Herbert, M.D., Ph.D.; Harvard University. In the afternoon the Autism Society of NH will present a panel on alternative approaches to supporting individuals with autism. *March 28, 2006.*

Evidence Based Practices in Educating Students with Autism in Inclusive Classrooms – Michael McSheehan, Clinical Faculty, Institute on Disability, UNH. This session will translate the most recent advances in inclusive education research for students with ASD into practical application. Examples will emphasize students with who qualify for Alternate Assessment. *April 20, 2006.*

*All Sessions in this Series are \$90 – save \$10 by registering online at www.iod.unh.edu
This Series is cosponsored by the Autism Society of NH*

SERESC Workshops

*All Workshops will be held at Southeastern Regional Education Service Center (SERESC) 29 Commerce Drive, Bedford, NH.
To register contact Robin Knight, at (603) 206-6816 or rknight@seresc.net.*

From IEP to Classroom and Community: Using Modifications, Accommodations and Direct Intervention to Maximize Strength and Minimize Challenges – Teresa Bolick, Ph.D. This will be an interactive workshop, with a continued listserv support. This is for **Middle/High School** grades.

October 20, 2005, 8:30 - 3:30. Registration deadline: October 6, 2005. Cost \$105.00, after deadline \$130.00.

Sensory Diets – Traci Gilman, OTR/L. This workshop will remove the mystery of sensory diets and includes strategies to help children with sensory processing challenges get through their day.

November 15, 2005, 9 - 2:30. Registration deadline November 1, 2005. Cost \$95.00, after deadline \$120.00.

Asperger Syndrome and Related Challenges in Young Children: A Common Sense Approach – Teresa Bolick, Ph.D. This one-day conference focuses on understanding of how Asperger Syndrome affects young children and offers strategies for support and intervention.

November 16, 2005 Registration deadline November 3, 2005. Cost \$130.00; \$115.00 for parents or paraprofessionals, after deadline \$155.00.

Applied Behavior Analysis in Educational Settings - Using Direct Instruction and Discrete Trial Methods for Children with ASD – Thomas Benjamin, M.S., BCBA, Behavior Analyst. Designed for educators and parents; participants will become familiar with basic concepts and theories of Applied Behavior Analysis.

December 9, 2005. Registration deadline November 28, 2005. Cost \$120.00, after deadline \$150.00

Advanced Clinical Issues in Childhood Autism and Related Disorders – Teresa Bolick, Ph.D. This one day workshop will explore "ABA" vs. "developmental pragmatic approaches."

January 11, 2006; Snow date of January 18, 2006. Registration deadline December 27, 2005. Cost \$135.00; \$115.00 for parents and paraprofessionals, after deadline \$160.00.

Advanced Sensory Diets – Traci Gilman, OTR/L. This workshop will provide information about sensory processing disorders and will address direct treatment options, sensory diet ideas, and methods for documenting progress.

January 19, 2006, 9:00 - 2:45. Registration Deadline January 6, 2006. Cost is \$95.00.

Visual Supports: Strategies to Support and Maintain Active Participation in School, Home, and Community – Teresa Bolick, Ph.D.; Donna Bever, M.A., CCC/SLP, Judy Enos, B.S.; Kristine Caster; Robin Knight, B.S. A conference with one-day instruction and one-day make it and take it for parents and teachers, who live and work with children with communication challenges. Offers examples of how to encourage choice making, following directions, and smooth daily transitions using visual supports.

January 30-31, 2006, 8:30 -3:30. Registration deadline January 16, 2006. Cost \$200.00 for both days; \$175.00 for parents and paraprofessionals; \$105 for one-day, after deadline \$250 for both days.

Asperger Syndrome: Getting Ready for the Real World – Teresa Bolick, Ph.D. and Traci Gilman, OTR/L. This conference which will discuss Asperger Syndrome and how it relates and impacts with adolescence and adulthood.

March 23-24, 2006 8:30-3:30. Registration deadline March 12, 2006. Cost \$250.00; \$200.00 for parents, after deadline \$ 275.00.

SERESC would like to thank the Autism Society of New Hampshire for its collaboration and support through reduced fees and scholarships for parents for their support for education of those who live and work with young children with autism spectrum disorders.

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INSTITUTE ON DISABILITY/UCED – UNIVERSITY OF NH

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NH DEVELOPMENTAL DISABILITIES COUNCIL

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Dignity, full rights of citizenship, equal opportunity, and full participation for all New Hampshire citizens with developmental disabilities.

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