New Hampshire

RAP Sheet

The Latest in Disability Research, Advocacy, Policy, and Practice

Winter/Spring Issue 2011

RISING TO THE CHALLENGE – ASD IN NH

THE WORLD MAY CHANGE

Tamara Le, Graduate New Hampshire Leadership Series, Class of 2010

I laughed. I really, really laughed.

My husband, my daughters, and the band of little boys chasing them around a bulbous, orange, plastic octopus, laughed. And, then they screamed. And, laughed some more.

Peaceful, simple joy had captured us.

Out of the corner of my eye I saw her - a crisp, fashion-magazine mother. She gave me the look. I noted her child's whispering inquiry, "What's wrong with her?"

"She's learning how to play, sweetheart," I said from our bench. This wasn't my first encounter with a curious child and an embarrassed parent.

"She's learning how to talk, too," I continued. Before fashion-mag-mom could apologize, I said, "You play very well young lady. I bet you would be a good play teacher for them."

She smiled and ran off to join the other children.

Two years ago my daughter (who carries a diagnosis of PDD-NOS, an autistic spectrum disorder) wouldn't have been able to come to the playground. Just getting out of the car at a new location could prompt a day-long tantrum.

PICTURE PEOPLE

Tamara Le's Daugthers Making Silly Faces.

Competing noises, smells, an inability to process simple verbal interactions like "Hi," or "What's your name?" Even the capacity to recognize social interactions, just wasn't in the cards.

Play was a long time coming.

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Welcome to the Winter/Spring Issue of the Rap Sheet on Autism Spectrum Disorders (ASD). This is the second Rap Sheet devoted to this topic. When we covered ASD in the fall of 2005, the prevalence rate of autism was one in 166 children; today it is one in 110. In this issue New Hampshire families, educators, policy makers, and advocates talk about how they are meeting the challenges posed by this complex disorder.

Susan Covert, Editor

A collaborative effort by the

Disabilities Rights Center, Institute on Disability, and NH Council on Developmental Disabilities

(Cover story continued)

Disabilities are not for the faint of heart. ASD hit our family like a freight train.

From theatre to television to writing, my career and capacity to communicate had taken me around the word. My husband, a bona fide rocket scientist who as a child survived war in Vietnam, speaks three languages and dabbles in two more.

Who were we if we couldn't communicate with our child?

Our choice was to arm ourselves with the tools we knew how to use: love, wisdom and warrior-like determination. We dove headfirst into the ASD treatment maze.

Speech, occupational, and physical therapies. Early intervention, special education, mountains of documentation. Insurance claim rejections, private school rejections, and of course, fashion-mag-mom playgroup rejections.

It was apparent early on that without supports, without a community, we would all drown in the ASD hurricane.

Enter the Institute on Disability's New Hampshire Leadership Series (NHLS).

I'd served on boards before, chaired committees, held workplace leadership positions, but nothing I'd experienced in life taught me more about effective and impact-driven leadership than NHLS.

In less than a year I connected to an entire statewide community of amazing, resilient, intelligent people. People who taught me how to create, effect, and change legislation. People who understood the disability rights movement is indeed, a battle for civil rights. People who led me to a parent-rep position with New Hampshire pediatricians working to build early diagnostic criteria for autism.

NHLS led me to a position as a parent support group facilitator at the University of New Hampshire. It led to a job funded by the New Hampshire Department of Education that focuses on supporting Special Education Directors in their efforts to create parent leaders in their schools. It led to a position as a Legislative Advocate for Area 8/One Sky.

I was creating change.

Yet, deeper and more profound, was the way in which NHLS empowered all of the 30-some members of my class of 2010. To work alongside those who laid the groundwork for inclusive schools and communities in New Hampshire 30 years ago was a gift and an honor.

A teacher. A hairdresser. A nurse's assistant. Clinicians. Parents. People with disabilities. People without. NHLS is a movement that eventually, touches everyone.

So, as I stop to listen and cherish the sweet laughter of my child playing with other children, I realize how important love and wisdom and warrior-like determination are. Who knows, the world may change.

New Hampshire has.

CLYDE E. TERRY, NOMINEE FOR MEMBER, NATIONAL COUNCIL ON DISABILITY

Congratulations to Clyde E. Terry who has been nominated by President Obama to serve on the National Council on Disability, an independent federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities.

Mr. Terry is Chief Executive Officer of Granite State Independent Living and is the past Executive Director of the New Hampshire Developmental Disabilities Council. Mr. Terry has spearheaded a national coalition of disability organizations on election reform and election accessibility for persons with disabilities and co-authored the 2001 publication "Voters Denied Equal Access at the Polls; A Status Report of the Accessibility of Polling Places in the United States."

Mr. Terry received his B.S. from Emerson College and his J.D. from the Franklin Pierce Law Center, now the University Of New Hampshire School Of Law.

Photographer - © Ed Karjala Photography

Clyde Terry to serve on the National Council on Disability

COUNCIL ON ASD SEES SUCCESS, NOTES CHALLENGES AHEAD

By Kirsten Murphy, Administrative Director for the NH Council on ASD

When the New Hampshire Commission on Autism Spectrum Disorders (ASD) published its 2008 report for improving autism-related services and supports, Commission members knew that continued leadership would be crucial if their 43 recommendations were going to move off the page and become a reality.

The State legislature agreed and in the 2008 session enacted RSA 171(A)32 establishing the New Hampshire Council on ASD to provide coordinated leadership in addressing the healthcare, education, and service needs of individuals who experience autism or a related disability. Council membership includes representatives from key public and private agencies, Governor appointees, family members, and a self-advocate.

Looking back on the Council's first two years, Council's Chair, Michelle Jarvis, who is the mother of a son with autism and the President of the Autism Society of New Hampshire, cited a number of Council achievements:

- Passage of Connor's Law in the 2010 session of the State Legislature. This law requires state-regulated health insurance policies to cover the evidence-based treatment of ASD. (For more information see article on page 5).
- Development of training standards for direct support professionals who work one-on-one with individuals who have a diagnosis on the autism spectrum.
- Fostering the creation of regional teams of professionals and parents that provide a crucial link between the Council and New Hampshire communities.
- Oversight of the New Hampshire Registry for ASD to track public health data about the incidence of ASD and its early identification
- Insuring that primary care physicians in New Hampshire screen young children for ASD in a manner consistent with American Academy of Pediatrics guidelines.
- In partnership with Easter Seals New Hampshire, establishing a training unit about ASDs for all law enforcement officials who attend the New Hampshire Police Academy.

"Because we are essentially an advisory board and have very limited funding, we work closely with public and private agencies in everything that we do," explained Jarvis. "Credit for our accomplishments should go to these partners as much, if not more, than to the Council."

Council Vice-Chair Brian Huckins, also a parent, noted that along with implementing recommended changes in service delivery, Council leadership has insured that the needs of individuals with ASD "stay on the radar screen" when important decisions are made. "As more and more individuals with ASD receive services, it's important that parents and self-advocates have an established way to participate in any changes in the service system that will affect their lives," said Huckins.

As an example of a system change that is currently underway, Huckins cited the Bureau of Developmental Services' initiative to improve the assessment of adult service needs through the use of a tool called the Supports Intensity Scale (SIS). "We are raising some good questions about how this tool can be used most effectively with individuals whose primary challenges are social, not intellectual," said Huckins.

CHALLENGES AHEAD

"While we are seeing measurable improvement in the early screening and diagnosis of children," said Jarvis," there is still a great deal of work to be done." She predicts that the Council will continue to focus on health insurance issues, including addressing a bill recently filed in the State legislature that would repeal Connor's Law.

According to Jarvis, federal stimulus funding has spurred a number of promising pilot projects in Early Supports and Services for children with ASD under the age of three, including parent training and technology supported behavioral therapy. "I would like to see the Council participate in assessing that work, helping to sustain what has been most successful and making those practices consistently available to families regardless of where they live," said Jarvis. She also added that more attention should be given to addressing the needs of teens and adults with ASD.

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BELONGING

CarolAnn Edscorn, Autism Ability

Watching and listening, I linger beneath the maple tree. There is movement and color flashing. Loud cries and shouts of laughter assault me, making it impossible to listen to the birds or the soft breeze playing with the red and orange leaves. I stand on the edge of the schoolyard. It is recess and the children are playing. I am avoiding them and enjoying the sunlight dappling the leaves. The children barely tug at my curiosity. I am beyond shy and beyond their interest.

Another state, another school, another recess with louder children. In fifth grade I am the tallest student. I am beneath a large elm tree, caressing the rough bark, gazing at the bright green leaves. The warm spring sunshine softens the schoolyard chaos. Suddenly he leaps into view. "You are so stupid." He punches me in the stomach. I am wordless, stunned. Students gather around and the teacher approaches. "What did you do to him?" It is decades before I have an answer; I thought that it was me who was hurt.

Trust is the absolute basic struggle for everyone and incredibly so for people on the autism spectrum. My vestibular discernment means I cannot even trust the ground I walk on. Not knowing where I fit in my surrounding environment interferes with my relationship to the physical world. I also see better peripherally which makes it harder to interpret my surroundings and read the facial expressions of those around me. My different ways of being in the world seem to be very large triggers for people who then decide that I am not—sigh—normal.

Trusting one's self is the worst. I know how smart I am - yet I make social errors that do not make sense. I joke, "Oh dear, I put BOTH feet in my mouth! Please pass the ketchup." or apologize, desperate to reconcile my literal reaction to a word or situation. The emotion-packed response of others makes me feels like I am being shot with a cannonball. The politics of the workplace are the most difficult. I am embarrassed by how many jobs I have had. "We all like you. You just are not a team player. You criticized the department head. Please pack up your desk."

I literally will chase after a person I think of as a friend. Her red face and stomping footsteps sends a pretty clear signal. I wish her original signal had been as clear. "What did I do? What social rule did I break this time?" The retort is typical. "You're so smart. You figure it out." It is overwhelmingly hard to summon the courage to keep going into social environments and to risk developing relationships knowing that at any moment a person might lash out or I might inadvertently hurt someone. I blame myself, though I often do not know what I've done. Our emotional filters are so different.

I desperately wish to fit in. I know to wait my turn in conversation. Then I blurt what I need to communicate, smile, and move along. I know if I turn about, I will see raised eyebrows, pursed lips, and wrinkled brows. I followed the rules! I waited. I spoke clearly and slowly. I smiled. I did not waste anyone's time. But it was not—quite—right.

There is so much stress on acquiring skills and realizing potential—get, get, get. But we also need to learn to let go, to be trusting. For me, and my friends in autism, this is a critical skill and one that can be taught directly, explicitly. The first step is learning to trust yourself, then those closest to you. It is mutual trust – not shared interests or similar beliefs - that form the basis for real friendships. My true friends allow my nature to reveal itself. They wait, or ask questions. They don't presume to know. We accept one another. We forgive. We have learned we can trust each other.


Photo Courtesy of CarolAnn Edscorn

CarolAnn Edscorn

Are you willing to be my friend? I would like that. I might say or write something awkward. Are you willing to laugh at those with me? I might be clumsy ("Call me Gracie") and my brain may be literal ("Who's on first?"). But, if we are friends we both feel that we belong and that is the best thing EVER.

CarolAnn Edscorn lives in Jaffrey, New Hampshire, with her husband and children. She does workshops at schools and conferences around the state and the country. Her blog is **www.auticat.com/**

CONNOR'S LAW: INSURANCE COVERAGE FOR TREATMENT OF AUTISM SPECTRUM DISORDERS

By Julia Freeman-Woolpert, Disabilities Rights Center

In the summer of 2010, Governor Lynch signed into law House Bill 569, more commonly known as Connor's Law. The new law requires that private health insurance plans in New Hampshire cover prescribed treatments for autism spectrum disorders, including speech, occupational, and physical therapies, and Applied Behavioral Analysis.*

"The enactment of Connor's Law is a tribute to the determination and persistence of parents and other advocates in their tireless efforts to obtain equal health benefits for their children", said Richard Cohen, Executive Director of the Disabilities Rights Center. "It also shows the sensitivity of state law makers when presented with the facts and benefits of insurance coverage for needed services, not only for the direct beneficiaries - children with autism - but for families and society as well."

Kirsten Murphy, Director of the New Hampshire Council on Autism Spectrum Disorders, predicts that the implementation of Connor's Law will bring with it a new set of challenges. Murphy anticipates some growing pains as insurers add behavioral therapy to their list of covered services and foresees some wrangling over reasonable rates for coverage. The law caps coverage for Applied Behavioral Analysis at $36,000 annually for children ages 0 to 12, and $27,000 for those ages 13-21.

Private insurers will be required to cover these treatments in policies issued or renewed on or after January 1, 2011. Note: if the policy renews in December 2010 or earlier, the new policy does not have to provide the coverage until the next time it is renewed. This may mean for some that the coverage doesn't go into effect until close to a year after the law takes effect.

Early and intensive treatment for autism can improve the outcomes enormously for these children, much as insulin does for children with diabetes and heart surgery does for children with a heart condition.

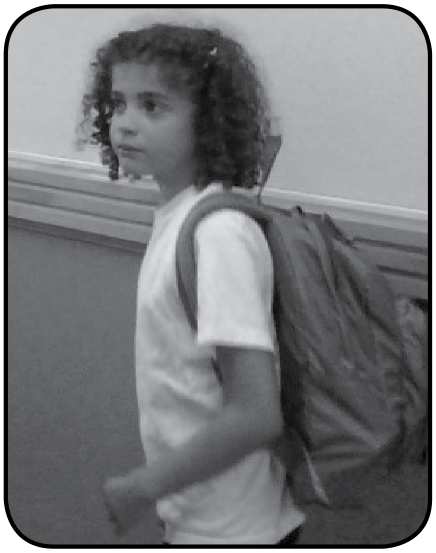
According to Murphy, Connor's Law also corrects the problem of insurance companies that refused to pay for services that were considered "habilitative," rather than "rehabilitative". "Now, carriers cannot refuse coverage solely because the services are habilitative," she said.

Connor's Law does not change benefits under Medicaid's Healthy Kids Gold and Silver plans or those of private self-insured employer plans. Murphy sees this issue as something for future advocacy efforts.

*Applied Behavioral Analysis is defined as the science in which the principles of the analysis of behavior are applied systematically to improve socially significant behavior, and in which experimentation is used to identify the variables responsible for change in behavior. It is a time intensive, structured approach that utilizes a variety of interventions.

INCLUDED FROM THE BEGINNING

Linda Quintanilha



Photographer - Linda Quintanilha

Mary Quintanilha

My daughter Mary was diagnosed with autism in 2005. Prior to her diagnosis, I never thought much about special education. I grew up in a segregated world where children with disabilities were taught in different classes and often went to different schools or institutions. I missed the opportunity to have friends who had disabilities, something that would have provided me with a richer and more diverse educational experience.

Thankfully this is changing. More and more children with disabilities are included in regular classrooms. Mary goes to public kindergarten in Hancock; she spends

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NUTRITION AND AUTISM

Patricia Murray, RD, MED. LD

Do you think my child will benefit from a gluten free diet? If my son takes vitamin B6 every day will it help him learn to talk? My child won't eat anything but MacDonald's French fries and chicken nuggets; can you help me? These are questions I regularly hear from parents who have a child with autism.

Many dieticians who work with children on the spectrum often refer to nutrition as the missing link. We learned in our biology and biochemistry courses how important vitamins, minerals, amino acids, and essential fatty acids are to a child's developing brain. We know that the fats from milk, fish, and breast milk are important for brain development and necessary for insulation on the neuron axon - the myelin sheaf. Vitamins and minerals act as catalysts to produce neurotransmitters and iron and vitamins B and C are critical to optimum brain function. As most children with autism do not have problems with growth failure, attention to nutrition is often overlooked. While children can have an adequate caloric intake for growth, if they are not getting the right nutrients they may still be malnourished. In fact, there are several nutrition problems that are common in children with autism. These include nutritional deficiencies, food allergies, feeding problems, food intolerances, frequent illnesses and infections, constipation, diarrhea, reflux, and drug-nutrient interactions.

While proper nutrition is not a cure for autism, it can help children to improve normal functioning. The goals for nutrition intervention are to provide the proper nutrients to support and maximize the function of the brain and the body and to help the child better respond to other interventions and therapies. Nutrition therapy begins with a thorough nutrition assessment that includes screening for anemia, mercury or lead toxicity, and deficiencies in protein or other nutrients. An effective nutrition intervention addresses feeding difficulties, recommends dietary changes, treats dietary deficiencies, and helps to resolve problems with constipation, diarrhea, reflux, and food allergies or intolerances. Most importantly, a nutrition intervention provides information and support to families.

Basic nutrition therapy includes eliminating all artificial colors, dyes, preservatives, sweeteners, trans fats, and highly processed foods from the child's diet. It should be noted that in Europe foods that contain Yellow 5, Red 40, and other dyes must carry the warning - *May Have an Adverse Effect on Activity and Attention in Children*. (I recommend that parents request that their child's teachers or therapists not use food as a reward. The M&Ms or other candy typically doled out have no nutritional value and are loaded with artificial additives, including food dyes.) Many children will benefit from a basic multivitamin and mineral supplement (free from artificial additives) and increased omega-3 fatty acid intake. Treatment of constipation, diarrhea, and/or reflux is also critical. In children with autism, these issues are more common due to their lower muscle tone, low fiber diets, and increased food allergies and intolerances. Treating these problems helps to heal and improve the function of the gut.

IS YOUR CHILD A PICKY EATER OR A PROBLEM EATER?

Picky Eater	Problem Eater
• Child eats less than 30 foods	• Child eats less than 10 foods
• Child eats at least one food from most textures and food groups	• Child refuses to eat foods from entire food groups
• Child eats their favorite food every day becomes tired of it, stops eating it but will eat their favorite food again in 2-3 weeks	• Child drops food from their diet, will not put the food back in their diet and eventually have only 5 or fewer foods in their diet. • Child eats the same favorite food every day, eventually tires of the food and stops eating it but will not substitute another food or eat the favorite food again. • Child is rigid about types food will eat and become very brand specific (will only eat McDonald's fries)
• Child is willing to touch, taste, or at least have a new food on their plate	• Child will not have a new food on their plate, touch, taste or smell it and will cry and have a tantrum if a new food is introduced.
• Child is willing to try a new food after the food has been introduced 10-12 times	• Child is not willing to try the food after being introduced 10-12 times • Child cannot accept changes and cannot break from mealtime rituals.

Many children with autism cannot speak and may have a high threshold for pain making it difficult to diagnosis reflux and other gastrointestinal disorders. An excellent article on this topic, Evaluation, Diagnosis and Treatment of Gastrointestinal Disorders in Individuals with ASDs: A Consensus Report and Recommendations for Evaluation and Treatment of Common Gastrointestinal Problems in Children with ASDs, by Dr. Timothy Buie, a pediatric gastroenterologist at Massachusetts General Hospital, and his colleagues appeared in the January 2010 issue of Pediatrics. I recommend parents go online (*see the link below*) and download this article to share with their pediatrician. **http://pediatrics.aappublications.org/cgi/search?sortspec=relevance&fulltext=Evaluation%2C+Diagnosis+and+Treatment+of+Gastrointestinal+Disorders+in+Individuals+with+ASDs**

Some children may benefit from advanced nutrition therapy; this may include a trial on gluten, casein, and/or soy-free diet(s) and the prescription of specific vitamins and minerals. As with any intervention, it is important that all caregivers are aware of the intervention and that during the trial period there is careful documentation to assess whether or not the intervention was beneficial. It is especially important that elimination diets are conducted under the supervision of a pediatric dietitian, as taking foods out of the diet may result in the loss of vital nutrients, placing the child at an even greater nutritional risk. For additional information, Elizabeth Strickland's book, *Eating for Autism: The 10-step Nutrition Plan to help treat your child's autism, Asperger's, or ADHD*, is an excellent resource for families.

When I receive a referral for a "picky eater" I want to know what other struggles with food this child may have. Is the child merely a picky eater or a problem eater? If the child has a sensory-based feeding disorder I will make a referral to a feeding specialist. Together we will work as a team with the parents and caregivers to address the problem. The ultimate goal is for eating to become a pleasurable and sociable experience. This may seem nearly impossible for a child who has trouble touching food, smelling food, tasting food, or even watching people eat. While the process will take time, with the right feeding team this goal can be attainable.

A child with autism may have many nutritional challenges, but with support and proper nutrition interventions these problems can be resolved.

SAVE THE DATE

13TH ANNUAL

autism summer institute

EVERYBODY READS, EVERYBODY WRITES, EVERYBODY HAS SOMETHING TO SAY

AUGUST 8-10, 2011 | CROWNE PLAZA, NASHUA, NH

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Ellen Boudreau chairs the Council's Work Group on Independent Living and Employment. Boudreau, a parent of a young adult with autism, pointed out that, "our kids are growing up and their needs are changing." In contrast to early childhood intervention, Boudreau noted that the guidelines for best practice supports are not as clearly defined for adults.

"Job supports, post-secondary education, life coaching, and ongoing behavioral healthcare are all part of the equation," said Boudreau, "but what that looks like and how individuals on the spectrum access those supports and opportunities, is still a work in progress." Boudreau and her group are developing a proposal for a statewide conference in late 2011 to help build a stronger consensus as to the best practices that New Hampshire should be striving for as it works to improve services for adults with ASD.

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her time with the rest of her classmates and is presented with the same curriculum. Accommodations are made in order for this to happen. It isn't easy. Teachers have all kinds of learners in their classroom and are expected to present differentiated lessons for children with a wide variety of abilities. Doing this successfully takes time, training, and understanding of different learning styles.

Classrooms have changed since the days when children sat quietly at their desks practicing their penmanship in unison. If you walk into a successful inclusive class today, you might find three kids who are not in chairs at all; two constantly moving up and down on a bouncy ball and a third under his desk. While this may seem like chaos, all these children are engaged in the class. The reality is when students have the opportunity to learn in their own way, they are able to focus and learn better.

The kindergarten room in Hancock is a wonderful place. At first, the children had lots of questions. Why doesn't Mary talk? What is autism? Why does Mary have her own teacher? Why does Mary flap her hands like that? The questions lasted about a week. The students have grown accustomed to having a child in their room who learns very differently.

All kids have difficulty with change, and for Mary, transitions are especially hard. The world that is not designed for the way her brain is wired. She's highly intelligent, but we haven't yet found a way to give her a voice. Mary uses a picture board, but her ability to communicate with it is very limited. This is extremely frustrating for her; often crying or having a tantrum is her only form of communication. At first, the children were distracted by Mary's obvious differences and some were nervous around her. I'm sure there were times when some of the staff wondered if this was going to work. It took about a month to get Mary settled into her new environment. There was support for her and for the other children in the class.

It was extremely hard work, but has paid off for everyone. The classroom has become a community that cares for each other. Mary has friends that are amazed by her abilities. She can put a puzzle together quicker than most of the other students. She knows her alphabet and numbers and loves to work along side of the other kids. She loves being outside on the playground. The other children are impressed that she can do all this without speaking.

The same children who were nervous in the beginning of the year have become her friends. Now at school, my daughter hears - Mary I've saved your swing. Mary I'm only going to your birthday party if you come to mine! I love you Mary. In spite of Mary not speaking, these amazing little people communicate. Their friendship is one of respect, not benevolence.

I expect of Mary what I expect of all my children. I expect her to do her chores, to work hard in school, and to grow into a responsible adult who contributes to her community and to society. I want for her what every parent wants for their children. I want her to be happy, to have friends to find love and companionship, and to have the freedom to live as she chooses. I believe that only through full inclusion will this be possible.

All of us - including Mary - need supportive friends and lifelong companions. Through inclusion and the friendships that develop as a result, the support that Mary needs may very well happen as naturally for her as it does for any of us. The inclusive setting in Hancock has given me great hope. I have a vision of my beautiful daughter finding her rightful place in her community and with a family of her own to support her.

Life, Liberty, and the Pursuit of Happiness - these rights haven't always been extended to those in our country who have disabilities. Until recently I had not considered the civil rights implications of special education. I am amazed that it has taken so long for me to appreciate this connection. Fortunately, the Special Education Team leaders in the ConVal School District are paving the way for Mary and other students with disabilities to enjoy the rights the rest of us take for granted.

A REMINDER ABOUT DIGNITY OF RISK

By Julia Freeman-Woolpert, Disabilities Rights Center

The world in which we live is not always safe, secure and predictable... Every day that we wake up and live in the hours of that day, there is a possibility of being thrown up against a situation where we may have to risk everything, even our lives. This is the way the real world is. We must work to develop every human resource within us in order to prepare for these days. To deny any person their fair share of risk experiences is to further cripple them for healthy living. - Robert Perske

At the bedrock of New Hampshire's developmental service system is a commitment to protecting the rights of individuals to exercise personal choice and self-determination and receive services in the least restrictive environment. Those served by Area Agencies have the right, for the most part, to pursue the friendships, interests, jobs, and lifestyles that they want. In practice, however, things don't always work this way.

Service systems have a way of taking control of peoples' lives. Often it is program availability, service policies, and agency interests - not individual choice - that determine where people live and work, who they associate with, and how their days are spent. This is especially the case when an Area Agency decides that an individual's interests and choices pose some risk. While, in theory, all Area Agencies recognize the concept of "Dignity of Risk," liability and other concerns tend to override an individual's right to make choices that entail a certain degree of risk.

Most of us have accumulated over our lifetime a list of regrettable incidents we'd like to forget and put behind us. Some of these are harmless youthful indiscretions, while others are more serious and may have resulted in significant consequences. Occasionally, one of these events will continue to haunt us, but mostly we can move on. For people who rely on social services, the ability to move on is rarely an option. With the monitoring and lack of privacy inherent in the service system these individuals are more likely to get caught if they do commit an offense and because of a desire to please or lack of comprehension about the charges are more likely to confess to something they didn't do. Any indiscretion or questionable behavior is recorded in detail in the person's permanent record. And once in the record, the incident - whether it actually happened or not - is never forgotten and rarely forgiven. Future evaluations and reports on the individual typically carry this information forward, noting that the person "has a history of…" or "was reportedly involved in..."

The records for children in the juvenile justice system are sealed when they reach adulthood and criminal records can be expunged, but human services records never die. Even when a client or guardian discovers an error or false statement in the personal record, there is no requirement that this information be removed. Under existing service regulations, agencies must include in the client's record "clarifying or rebutting information deemed by the individual to be inaccurate," however, these regulations do NOT require that inaccurate information or even outright lies be removed. Consequently, every incident, rumor, misunderstanding, mistake, subjective opinion, and falsehood that gets written down is there to stay and to be considered by service providers when they are making decisions that will affect the person's services and quality of life.

The Disabilities Rights Center has had cases where an Area Agency or service provider acted overzealously limiting the person's freedom and independence with the intention of protecting the client or the agency from potential risk. Risk aversion and the need for agency control is especially pronounced when there are incidents involving sexual behavior. The public's fear of sex offenders is often fueled by misperceptions and is disproportionate to the actual level of danger. In service systems, even the slightest hint of sexual inappropriateness, is enough to create a flurry of meetings, evaluations, and restrictions that in some cases go well beyond common sense.

In a recent case, DRC represented a woman whose Area Agency refused to let her spend time alone because of an inappropriate note that she wrote when she was in her early 20's to a teenager. On the basis of one note written eight years ago, this client has spent years receiving counseling on boundaries and appropriate behavior. Even though there has never been any other incident of inappropriate behavior

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LEADERSHIP EDUCATION IN AUTISM SPECTRUM DISORDERS

Ann Dillon, M.Ed, OTR/L, Institute on Disabilities

Professional leadership training has had an enormous impact on the quality of supports and services available to New Hampshire children who have disabilities and their families. For 17 years, the Institute on Disability at the University of New Hampshire, in collaboration with Dartmouth Hitchcock Medical Center, has operated the Leadership in Education in Neuro-Developmental Disabilities (LEND) Program. With a mission to improve the health of infants, children, and adolescents who have disabilities, the LEND Program has provided high quality interdisciplinary education and clinical training that promotes culturally competent, family-centered partnerships. New Hampshire's program is part of a national effort; 39 LEND programs across the United States and in the District of Columbia have provided essential training for many state and national leaders in the disability field.

In 2008, the New Hampshire LEND Program received supplemental funding from the 2006 Combating Autism Act to add the Leadership Education in Autism Spectrum Disorders Program (LEASD). Funding from this 3-year expansion grant has been used for the following three initiatives:

- Creation of a 1-year fellowship for professionals wanting to develop their leadership skills in the field of autism.
- Formation of Learning Collaboratives to provide support to New Hampshire medical home practices on implementing autism screenings in primary care offices.
- Creation of a Family Coordinator position and additional training opportunities in the Autism/Genetics Clinic at CHaD, Wentworth-Douglass Hospital in Dover.

The LEASD Program's initiatives have produced impressive results.

Those participating in Leadership Training have include:

Four fellows graduating in the LEASD Class of 2010

- Kate Borelli, M.Ed., special education, autism consultant in Governor Wentworth District
- Melissa Breen, M.Ed., special education, Barrington School District
- Jen Doris, special education, M.Ed, Director of Lakes Region Early Supports and Services
- Lora James, M.Ed., special education, ESS Community Partners.

Four new fellows enrolled in the LEASD Class of 2010

- Maureen Dow, BS, autism consultant
- Joy Kiely, M.Ed, autism consultant
- Lorene Reagan, RN, Administrator, New Hampshire Bureau of Developmental Services
- Martha Toy Fountain, MD, Exeter Pediatrics

The New Hampshire Leadership Education in Neurodevelopmental Disabilities (LEND) program provides graduate level interdisciplinary training at the University of New Hampshire, and interdisciplinary services and care in collaboration with Dartmouth Hitchcock Medical Center through the Seacoast Child Development Clinic. The New Hampshire LEND program is currently funded and administered by the Health Resources and Service's Administration's (HRSA) Maternal and Child Health Bureau (MCHB). For more information about the LEND or LEASD programs please contact Betsy Humphreys at Elizabeth.Humphreys@unh.edu or Ann Dillon at Ann.Dillon@unh.edu

The Learning Collaboratives established by the LEND program and the Center for Medical Home Improvement of the Crotched Mountain Foundation (**www.medicalhomeimprovement.org**) have supported medical practices to implement screenings using the Modified Checklist for Autism in Toddlers (M-CHAT™). Children are screened at 18 and 24 months as part of their well-child check-ups in accordance with the American Academy of Pediatrics guidelines. Participants in the two year-long Learning Collaboratives have included doctors, a dentist, nurse practitioners, care coordinators, nurses, LPN's, and parents. The Learning Collaboratives have resulted in the following outcomes:

- Eighteen practices (17 medical practices and one pediatric dental practice) have participated in a Learning Collaborative.
- A total of 3,316 New Hampshire children in participating practices have been screened using the M-CHAT.
- Sixty-five children have screened positive for ASD and have been referred for follow-up services.

The LEASD Autism/Genetics Clinic has supported 35 children and their families in learning about and/or pursuing genetics testing for their children who have been diagnosed with an Autism Spectrum Disorder.

The New Hampshire LEASD Program is helping to develop leaders who are in the forefront of ASD training and screenings. The program is increasing the knowledge, skills, and leadership abilities of health-care and education professionals and supporting the provision of evidenced-based services for children with ASD and their families. Most importantly, the LEASD initiatives have helped ensure that New Hampshire children who have an autism spectrum disorder and their families are receiving needed services and interventions as early as possible.

If you have questions about getting very young children screened, you can contact your local health care provider and ask for an M-CHAT or speak with your Area Agency about your concerns. This link connects you with a free downloadable version of the M-CHAT - http://www.firstsigns.org/downloads/m-chat.PDF


Photographer – Matt Gianino

LEND and LEASD Fellows and Faculty, September 2010.

INELIGIBLE FOR ADULT SERVICES?

By Julia Freeman-Woolpert, Disabilities Rights Center

James (*not his real name*), who turned 21 in May, is a man of many interests. An avid reader, he enjoys science fiction, history, fantasy novels and as he explained, "anything that's not a self help book." He loves video games and surfing the Net. He is taking an online course in computer repair, working on his GED, and learning Japanese. He's a chess player and a photographer.

Yet, despite all his interests and talents, James is unemployed, has no social life, and rarely leaves home. James has high functioning autism and an extreme social phobia that severely impairs his ability to function. As is typical of people with autism, he also has a great deal of difficulty with social interactions.

James needs supports in order to work and learn how to live independently, however, his intelligence has made it difficult for him to qualify for services. When his application for Area Agency services was denied, the intake worker said she thought he should have been found eligible and would talk to her supervisor about this. It's been months and James is still waiting to hear back from her.

James has plenty of evidence to support his application. He has a well-documented developmental disability and received special education throughout his school years. His difficulties in developing social skills and managing his behavior even led the school district to recommend to his mother that he drop out. (Note to parents: *this is illegal.*) While his mother refused to let him drop out, James decided on his own to stop going to school. In fact, for two years he stopped leaving the house altogether. Eventually, with the help of an advocate, his mother was able to negotiate with the school district to pay for an out of district day program. The program gradually introduced James to social situations and with support he began leaving the house, got a part time job at a store, and was making good progress.

Then he turned 21.

With no school funding, James supports ended. He no longer is able to go to his job or access the community. His mother, who has tried to get him involved in activities, said, "He's only left the house five or six times in the past six months. It's not like I can really force him."

Dr. Teresa Bolick, a psychologist who specializes in high functioning autism and Asperger's, is all too familiar with what happens when her clients turn 21. "We're now at a place where we can do a great job with youngsters in school," she said. "And then they fall off a cliff if good adult services are not in place."

While some people with high functioning autism or Asperger's are able to create a life for themselves without supportive services, most are not. Some develop co-morbid disorders such as depression and qualify for mental health services. Others end up in the criminal justice system, often

"Developmental disability" under state law means a disability:

(a) Which is attributable to an intellectual disability, cerebral palsy, epilepsy, autism, or a specific learning disability, or any other condition of an individual found to be closely related to an intellectual disability as it refers to general intellectual functioning or impairment in adaptive behavior or requires treatment similar to that required for persons with an intellectual disability; and

(b) Which originates before such individual attains age 22, has continued or can be expected to continue indefinitely, and constitutes a severe disability to such individual's ability to function normally in society.

due to a misunderstanding of social rules. Most individuals, like James, do not get the supports that they need and remain at home, dependent on their families.

The unemployment rate for adults on the autism spectrum is very high. Dr. Bolick has a dozen young adult clients (22-35 years of age) that she has followed from childhood. Only one is fully employed, another works in a family business, and a few have part time fast food or retail jobs that are well below their skill levels. Aside from volunteer work, most have not found any employment. For these individuals the issue is not their ability to do the work, but rather a lack of the social and communication skills that are critical to finding and keeping a job. The short-term assistance available through Vocational Rehabilitation does not provide the ongoing supports that many people with autism need in order to be successfully employed.

Even people who have a critical need for ongoing supports may find it difficult to qualify for Area Agency services. An estimated 25-30% of all applicants are found ineligible. For some, their functional deficits are severe, but not severe enough. For others, there may not be enough information to determine the degree of their disability. Applicants, like James, have average or above average intelligence that mask their severe functional limitations. At times, Area Agencies have been overly restrictive in determining eligibility or have erroneously disqualified someone because of a co-occurring disability such as mental illness. Being determined eligible for services is especially problematic for those with pervasive developmental disorder not otherwise specified (PDD-NOS) or Asperger's disorder whose disability was not identified until after they had left school.

Persistent advocacy on the part of parents can make the difference in obtaining appropriate services. Dr. Bolick recommends that parents keep detailed documentation, beginning as early as middle school, of the challenges their child has and services needed. Her advice to families is, "Advocate, advocate, advocate, advocate. If you need to get an additional evaluation, then get one. If you're turned down, then appeal."

James plans to reapply for Area Agency services. Until then he'll remain isolated at home without the supports he needs.

For more information about accessing Area Agency and other services, contact the Disabilities Rights Center at 1-800-834-1721 or visit the website at **www.drcnh.org**.

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and her therapist has found her to be a low risk, the Area Agency still refused to let this woman spend time by herself. It took a hearing officer's order for her to reclaim the right to experience the dignity of risk.

Allowing for the dignity of risk does not mean that Area Agencies or providers abandon their commitment to ensure that the individuals they serve are safe. People with cognitive and intellectual impairments are more than twice as likely to be victims of crime than are people without disabilities and too often service providers are the ones responsible for this abuse and exploitation. However, there is also a real cost to being over protective. The consequences of not allowing the person to stretch and grow include low self-esteem, unrealized potential, and a severely diminished life. New Hampshire's rules for developmental services require that services "provide opportunities for the individual to exercise personal choice, independence and autonomy within the bounds of reasonable risks." So let's be reasonable and reconsider how we are defining the dignity of risk.

WHAT WILL I DO AFTER HIGH SCHOOL?

Caroline Arakelian, David Hagner. Heidi Cloutier, and Amy Frechette; Institute on Disability

All teenagers worry about what life will hold after high school, however, for students with an autism spectrum disorder (ASD) thinking about the future can be especially intimidating. Whether the goal is employment, college, or a combination of the two, thoughtful planning can make a significant difference. The Family-Centered Transition Project, a two-year collaborative project of the Institute on Disability and our sister Institute at the University of Maine, assists students with ASD and their families to work towards their postsecondary goals, include finding a job, getting a driver's license, improving social relationships, and attending college.

Families participating in the project begin the process by attending a series of training sessions that cover a variety of postsecondary issues. Most importantly, this introductory series helps to empower families to take a leading role in planning for the future. Once training has been completed, the student and family work with a project facilitator who conducts person-centered planning sessions to help the student develop a personal vision and create a plan of action. Over a period of 5 to 8 months, the student, family, and invited guests meet monthly. These planning meetings include brainstorming possibilities for the student, organizing ideas, identifying resources, and developing strategies for moving forward. In order to gather more information and to draw upon community resources, the student may invite school personnel, neighbors, friends of the family, and extended family members to attend one or more planning meetings. Project facilitators use graphic facilitation to record ideas and keep the group moving forward. The project also provides mentoring and advice from an adult with ASD who has been to college, lives independently, and serves on the project team. In New Hampshire, Amy Frechette has helped students and their families access services and plan for jobs and college. Amy has recently been appointed to the faculty at the University of New Hampshire.

In its first year, 24 transitioning students and families worked with the project. Of the six students who have graduated from high school, one is employed full time, one is attending a full-time vocational training program, and four are enrolled in college. Examples of college placements include a participant from Newington, New

State Champion robotics team

WANT TO KNOW MORE

For those interested in learning more about person-centered planning and transition services, the following training and resources are recommended.

The Institute on Disability course "Methods, Models and Tools for Person-Centered Planning" is held every January and spring at the University of New Hampshire campus in Durham. Patty Cotton's book Elements of Design: Frameworks for Facilitating Person-Centered Planning is an excellent resource and the basis for the Method, Models, and Tools course. David Hagner's book, Career Advancement Strategies and Tools, provides information about employment and career planning. Both books are available through the IOD Bookstore at www.iodbookstore.org/

The website www.ilr.cornell.edu/edi/pcp is a good resource for information on person-centered planning and www.thinkcollege.net has valuable information about postsecondary options.

Hampshire who is pursuing a degree in computer engineering at the University of New Hampshire and another who is enrolled in the marine science program at a community college in Maine. Fifteen participants are building their resumes with summer jobs and community work and volunteer experiences during the school year. Six have found paid employment and are working in a variety of settings including libraries, computer labs, and an amusement park. There have been other important successes as well. One project participant was inducted into the National Honor Society and another was a member of his school's state championship robotics team. One student who hopes to have a career as a photographer had his photographs exhibited in a local art gallery. Students in the project are demonstrating to themselves and to everyone else what can be achieved with careful planning, high expectations, and the right supports. In the words of one student, "When it comes to my future, the sky is the limit."

The project is currently in its second year and serving a second group of students and families. The project is employing rigorous evaluation methods to document the effectiveness of using person-centered planning and supports to help students with ASD make successful transitions. While grant funding for the project ends in August of 2011, findings from the project will be widely disseminated and hopefully schools and other programs supporting students with ASD will replicate this model when assisting students and families plan the transition from high school.

ANTIOCH UNIVERSITY NEW ENGLAND

– LEADING THE WAY IN ASD TRAINING –

By Shelley Viles, MS, Director, Center for Autism Spectrum Disorders Training, Antioch University New England

Soon after the birth of our son, my husband and I began to notice things. He was obviously very bright and inquisitive, but he showed sensitivity to sound, had difficulty interacting with others, and demonstrated a lack of eye contact. As new parents, we had no idea what this meant. Thus began a long journey of specialists, contradictory and missed diagnoses, and a search for schools and providers who understood our son and knew how to help. After years of struggle, we finally discovered that our son has Asperger's syndrome.

Through my personal journey I saw the need for more professionals with specialized knowledge and experience in working with individuals with autism spectrum disorders (ASD). This need is especially acute in rural areas such as northern New England. As the Continuing Education Director for the Department of Applied Psychology at Antioch University New England (AUNE), I sought to remedy this and in 2003 founded AUNE's Center for Autism Spectrum Disorders Training with a focus on providing autism-related workshops and conferences.

In 2005, I founded the Autism Spectrum Disorders Certificate Program at AUNE. This graduate certificate program provides professionals with training in working with individuals with Asperger's Syndrome, Pervasive Developmental Disorder (PDD-NOS) and High Functioning Autism. Classes are taught by leaders in the field, including such nationally

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Photographer - Sean Wiley

Antioch University faculty member, John Moran, Ed.D., BCBA, working with a young child.

NEW HAMPSHIRE STATE DIRECT SUPPORT PROFESSIONAL COMPETENCIES:

WORKING WITH CHILDREN AND YOUTH WITH AUTISM SPECTRUM DISORDERS

Adopted by the NH Council on Autism Spectrum Disorder, November 5, 2010

The following competencies are guidelines for the knowledge and skills that Direct Support Professionals should demonstrate in order to work effectively with children and youth with Autism Spectrum Disorders (ASD). Direct Support Professionals (DSP) include, but are not be limited to: paraeducators, paraprofessionals, 1:1 assistants, and aides.

These guidelines are intended for use by a variety of groups and can be used to:

- Assist providers in identifying areas of need for professional development
- Guide the creation of programs or courses to meet the training needs of DSPs
- Provide parents, educators, and case managers with a basis for assessing applicants for direct support positions in home and community settings.

This list focuses on competencies that are specific, unique, and critical to successfully supporting a child, teen, or young adult who experiences autism or a related disability. The emphasis is on elements of high quality instruction beyond basic compliance standards. No competency is deemed more important than another, and the list should be considered as a whole. Each skill or area of knowledge could – and should – be developed in much greater detail by practitioners seeking to chart a comprehensive course of study for Direct Support Professionals.

To work in education or therapeutic programs for children and youth with Austism Spectrum Disorders, Direct Support Professionals will demonstrate the following core competencies:

1. Understand the value of providing instructional support and other direct services to children and youth with ASD

   Awareness of the history of how ASD has been understood and addressed

   Awareness of the benefit of supporting students with ASD in typical school, home, and community settings

   Ability to use a broad variety of instructional strategies including use of visual supports, PECS, discrete trial, incidental teaching, floor-time, and sensory diets

   Understanding and ability to apply a philosophy that values all student learning and the principles of least dangerous assumption

2. Knowledge of the legal issues related to the education and treatment of children and youth with disabilities and their families

   Knowledge of IDEA, Section 504, the ADA, and NH Rules and RSAs

   Knowledge of written plans and their implications for DSPs in relation to legal requirements and district or agency policies and procedures

3. Awareness of diversity among the children, youth, families, and colleagues with whom they work

   Awareness of how different aspects of diversity enhance opportunities for learning

   Awareness of cultural biases and personal differences that affect working with students, families, and other team members

4. Understand the roles and responsibilities of certified or licensed staff and DSPs

   Knowledge of staff roles and responsibilities for program development, evaluation, and instructional supervision of DSPs, including legal requirements and district or agency policies and procedures

   Understand the value of DSPs in instructional support and other direct services to children and youth with ASD

   Understand shared roles and responsibilities including teaming and collaboration

5. Knowledge of patterns of human development and milestones typically achieved at different ages, as well as risk factors that may prohibit or impede typical development

   Awareness of learning theory and different approaches that may be implemented by certified or licensed staff

   Awareness and respect for the impact on families who have children with ASD

Knowledge of development from birth to 21 in the following areas: communication, self-help, physical development, cognitive development, and social/emotional development

6. Ability to practice ethical and professional standards of conduct, including the requirement for confidentiality

Maintains confidentiality

Follows district and agency policies and procedures

Follows directions of teachers and other supervisors

Participates in on-going training

7. Ability to communicate effectively with students, colleagues, and families; follow instructions; and use problem-solving and other skills to work as an effective member of the team

Ability to use effective communication to increase understanding

Ability to use strategies for problem solving and negotiation

Ability to use self-evaluation and reflection as it pertains to working as an effective member of the instructional team

8. Knowledge and application of elements of Positive Behavior Support

Understand the key core principles of Positive Behavior Support

Ability to apply core principles of Positive Behavior Support and consistently follow-though with positive behavior support plans

Ability to understand and use reinforcement, redirection, and intervention strategies

Ability to use crisis prevention and crisis intervention strategies as outlined by district or agency policies and procedures

Ability to use data collection and observation techniques

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known presenters as Elsa Abele, a specialist in pragmatic language; psychologist and author, Dr. Teresa Bolick; and Dr. Fred Volkmar of the Yale Child Study Center.

Students in the program include educators, psychologists, speech-language pathologists, advocates, and parents of children with ASD. Many alumni have gone on to positions of leadership or become entrepreneurs. Judy DeNault, who started her own business summed up her experience, "The Autism Spectrum Disorders Certificate Program at Antioch University, truly gave me the tools and resources, interactive learning and the confidence to develop and open a communication center and social/sensory gym dedicated to children, teens, and adults with a large variety of social-communication abilities. Instructors brought "real world" issues, strategies, materials, and challenges to each class which made for functional learning opportunities."

In June 2010 AUNE expanded its offerings to include the Applied Behavior Analysis Certificate Program, a four-semester program for those interested in becoming a Board Certified Behavior Analyst or Board Certified Assistant Behavior Analyst. Behavioral therapies are recognized as an effective evidence-based treatment for individuals with an autism spectrum disorder. With insurance reform having recently gone into effect in New Hampshire and legislation enacted or pending in 45 other states, it is anticipated that the demand for behavior specialists will grow rapidly.

Shelley Viles

Another recent AUNE initiative is the creation of the Friends and Family of Individuals with Autism and Asperger's support group. Participants explore such topics as family dynamics and stress, parental guilt, and stress management and coping. The group has proved so popular that a second session has been added. Group meetings are free and open to the public by reservation. For more information please call 603-283-2156.

Now, twenty-three years after my son was born, he is a successful college senior. He has assisted with AUNE class demonstrations and attended AUNE conferences and events. Little did I realize back when we were struggling for a diagnosis and information to help our son that our family's journey would lead me to help other parents through this process and ultimately to a career in the field of autism.

As recognition for her achievements in the field of autism spectrum disorders, Shelley Viles was honored to receive the Doug Flutie Jr. Award for Autism in 2009.

For more information on Antioch University's Autism Spectrum Disorders or Applied Behavior Analysis Certificate Programs please see: **http://www.antiochne.edu/ap/asd/** or call 800-552-8380.

WHAT IF...? A NEW VIEW OF PEOPLE WITH AUTISM*

Cheryl M. Jorgensen, Ph.D., Institute on Disability/UCED, University of New Hampshire

"All he talks about is train schedules." "She can never be in a regular class with her sensory issues?" "He can't hold a real job because of his behavior." These statements, used to describe individuals who have autism, reflect a belief that people with autism are abnormal and that autism is a disorder that must be cured, and ultimately, eradicated.

What if we the fundamentally changed the way that we think about autism and instead of seeing it as the problem, accepted it as a natural part of human diversity? What if, instead of trying to make people with autism normal, we saw their challenges as problems with their environment? What if we valued their unique talents and recognized their potential to contribute to our schools and communities?

Let's consider a new view – one that would radically change how medicine, human services, education, and the media regard autism - autism is a natural part of the human experience and that having autism should not diminish a person's ability to live a full life in the community. (Ironically, this language is found in both the Americans with Disabilities Act and the federal Combating Autism Act.)

Founder of the Autism Self-Advocacy Network (ASAN), Ari Ne'eman, believes that inclusion of people with autism in the mainstream of community life is a civil rights issue. "The goal of autism advocacy should not be a world without Autistic people. Instead, it should be a world in which Autistic people enjoy the same access, rights and opportunities as all other citizens" (**http://autisticadvocacy.org**)

What would change if we truly valued diversity? Parents would not have to fight for their children to be included in regular classes in neighborhood schools. Curriculum and instruction would be designed to accommodate the learning needs of *all* students, including those with autism. Adults with autism would be included in all conversations about autism - in communities, in the State house, in research centers, and even in the U.S. Congress - and decisions affecting their lives would not be made without their leadership and full participation. Instead of being considered the "experts", professionals would work collaboratively with individuals who have autism and with their families. They would ask about individual preferences, life goals, and what supports are needed in order for the individual to fully participate in family, school, and community life.

A traditional view holds that the characteristics associated with autism - perseveration, sensory sensitivities, and difficulty understanding social cues - are predominately negative. What if we stopped thinking about these characteristics as deficits and instead adopted a new view that every person has strengths and that all behavior has meaning? What if perseveration was seen instead as an intensive focus? What if sensory sensitivity was an indicator of artistic talent? What if challenging behavior was recognized as the way the person communicates fear, pain, or loneliness?

What if we adopted the viewpoint that every person has strengths, that their fascinations offer a view into their world, and that their challenges are signs that they need better supports? When someone with autism experiences a challenge, we would first look at what in the environment (including our attitudes) needs to be changed and ask ourselves how we can better support the individual.

Paula Kluth, a researcher, trainer, and writer about inclusive education and children with autism, said, "I have worked with students interested in Korea, vacuum cleaners, screwdrivers, dogs, stop signs, churches, weathervanes, triangles, The Wizard of Oz, Scooby Doo, and basketball. Any of these interests might be used as part of a classroom curriculum. A student who loves trains might be asked to write a story about riding on a caboose, encouraged to research different railroads on the internet, or directed to do an independent research project on ground transportation in America." (**http://paulakluth.com**).

Changing our mindset about autism and about people with autism is a radical departure from the status quo. How do we decide if these new views are right, if they have validity, and if they will help, not hurt, children and adults with autism?

In considering these questions, I would recommend that we be guided by principle of making the "least dangerous assumption," a concept first coined by researcher Anne Donnellan. As laid out by Donnellan in 1984, "The criterion of the least dangerous assumption says that in the absence of conclusive data, we should make decisions based on assumptions that will have the *least dangerous consequences* to our students, if we are wrong about those assumptions." So how might we use the least this principle to figure out whether traditional views on autism have merit or whether new views ought to guide our thinking, our practices, and our policies?

Let us consider what happens when we view autism as a disease to be eradicated. What are the consequences of sorting people with autism into "low functioning" and "high functioning" categories and segregating them in special schools, self-contained classrooms, sheltered work settings, and residential institutions? What if it turns out that we are wrong? Most people would recognize that in accepting these traditional assumptions we, in fact, have done *great* harm to individuals with autism.

In contrast, what if we presume the following - Autism is a natural part of the human experience. All children and adults are competent. We should value and build upon people's unique talents. All people with autism should be fully included in their schools and communities. Now, what if someday we found out that we were wrong? Would we have caused any harm? I believe that the answer would be a resounding "No!" Far from causing harm, having high expectations, treating people with respect, honoring their unique talents, and including them, will have enriched not only their lives, but ours as well.

(This article is based on a keynote presentation given at the Institute on Disability's Autism Summer Institute on August 9, 2010.)

(Continued from page 17)

9. Knowledge and application of elements of effective instructional supports for children and youth with ASD to assist with teaching and learning

Knowledge of research-based educational and therapeutic programs for students with ASD including ABA Methodologies, Discrete Trial Training, Incidental Teaching, and use of visual supports

Ability to implement small group instructional techniques

Ability to apply specific individualized instructional programs in academic areas including programming that includes: sensory diets, behavior plans, self-help skills, toileting, nutritional needs, ABA methodologies, discrete trials, and reinforcement systems

Ability to consistently use reinforcement strategies

Ability to use data collection and observation techniques

10. Ability to motivate and assist children and youth with ASD to actively and successfully engage in classroom, community, and home based learning and activities

Ability to use chronologically age appropriate interest and ability-level material

Ability to implement recommendations to modify and accommodate materials as necessary

Ability to use chronologically age appropriate reinforcement strategies

11. Ability to support active engagement with peers

Ability to facilitate and support the development of social skills and social competences

Ability to facilitate and support the development of friendships and meaningful connections to peers

12. Awareness of the ways in which technology can assist in teaching and learning

Awareness of assistive/augmentative communication systems

Ability to effectively use a broad variety of technology for instructional support and communication

If you have questions regarding these guidelines contact Kirsten Murphy, Director, New Hampshire Council on Autism Spectrum Disorders at Kirsten.Murphy23@gmail.com.

ASD Resources

NEW HAMPSHIRE RESOURCES

AANE- Asperger's Association of New England

Provides a supportive, understanding community for individuals, families, and professionals throughout New England. Services include phone consultation; social, activity, and supports groups; training; and legislative advocacy.

617-393-3824 (New Hampshire AANE Chapter)
http://www.aane.org. rg/

Antioch College Center for ASD Training

ASD and Applied Behavior Analysis certificate programs, workshops.

http://www.antiochne.edu/ap/ce/asdworkshops.cfm

Autism Society of New Hampshire

A volunteer, parent driven organization dedicated to those living with ASD. Resources include a getting started packet, statewide training calendar, message board, and support groups.

603-679-2424 www.nhautism.com

Concord Area REACH Team

A multi-disciplinary team of parents and professionals in the greater Merrimack County area seeking to improve the quality of services and supports through regional collaboration

www.ConcordREACH.info/home.html

Connor's Law

New Hampshire law ensures insurance coverage for treatment of ASD.

http://www.connorslaw.info/

Easter Seals Autism Network

Family support, trainings, and direct services

1-877-6AUTISM http://nh.easterseals.com/site/PageServer?pagename=NHDR_Autism_Servicesen

Institute on Disability at the University of New Hampshire

The IOD advances policies and systems changes, promising practices, education, and research that strengthen communities and ensure full access, equal opportunities, and participation for all persons. www.iod.unh.edu

New Hampshire Resource Center on Autism Spectrum Disorders

Graduate certificate in ASD, NH Leadership Education in ASD (LEASD), Summer Autism Institute.

http://www.iod.unh.edu/PriorityAreas/autism/mission.aspx

National Center on Inclusive Education

Promotes the inclusion of all students within general education classrooms and school communities.

http://iod.unh.edu/PriorityAreas/inclusive-education/about_NCIE.aspx

Seacoast Child Development Clinic

Interdisciplinary evaluation for children through age five who have developmental challenges. The Clinic assists families to make informed decisions for medical, developmental, and educational needs.

(603) 862-0561
http://www.seacoastclinic.unh.edu/index.html

New Hampshire Autism Council

Legislated body established in 2008, to address the healthcare, education, and service needs of individuals with ASD and their families.

http://nhcouncilonasd.org/

New Hampshire Department of Health and Human Services

Special Medical Services

NH Title V program that funds services for individuals birth to 21, who have or are at risk for a chronic medical condition, disability, or special health care need. Includes diagnostic evaluations for children ages 0-6 with developmental concerns, including ASD.

1-800-852-3345, ext. 4488 or 603-271-4488
http://www.dhhs.state.nh.us/DHHS/SPECIALMEDSRVCS/default.htm

Division of Family Assistance

Assures access to adequate and quality health care for adults and children, including those with disabilities. Programs include: Medicaid, New Hampshire Healthy Kids, Katie Beckett, and in home support for families with disabled children.

877- 464-2447
http://www.dhhs.nh.gov/dfa/medical/index.htm

New Hampshire Bureau of Developmental Services

Administers the state's Area Agency network serving individuals with developmental disabilities and their families. Services include: family support, early supports and services and autism services for children under age 3, and adult developmental services.

1-800-852-3345, ext. 5034
http://www.dhhs.nh.gov/dcbcs/bds/index.htm

New Hampshire Family Voices

Resources and support for families who have children with health conditions and disabilities. Lending library- books and videos about ASD are mailed postage paid.

1-800-852-3345 Ext 4525
http://www.nhfv.org

SERESC

Educational supports, technical assistance, trainings

http://www.seresc.net/ed_autism.php

NATIONAL & INTERNET RESOURCES

Autism Acceptance Project

http://taap.org

ASAN- Autistic Self Advocacy Network

Seeks to advance the principles of the disability rights movement in the world of autism.

http://www.autisticadvocacy.org/

AIM- Autism Internet Modules

Over 30 training modules on numerous ASD topics.

http://www.autisminternetmodules.org/

AUTCOM - The Autism National Committee

National autism advocacy organization.

http://www.autcom.org/about.html

Autism Society of America

Works to increase public awareness, advocates for appropriate services for all, and provides the latest information on ASD. Down loadable pamphlet series Living with Autism.

http://www.autism-society.org

Autism Speaks

Advocacy organization funds research for the causes, prevention, treatments for autism. Increases public awareness of ASD and advocates for individuals with autism and their families.

www.autismspeaks.org

First Signs

First concerns about ASD and diagnosis. Video Glossary demonstrates the early red flags and diagnosis of ASD.

http://www.firstsigns.org/

ICAN - Interactive Collaborative Autism Network

Online training modules including assessment, approaches, communication.

http://www.autismnetwork.org/

IRCA-Indiana Resource Center on Autism

Articles, List of video trainings, internet modules.

http://www.iidc.indiana.edu/index.php?pageId=32

Learn the Signs-Act Early-CDC (Center for Disease Control and Prevention)

Screening and Diagnosis, facts about ASD, Spanish translation.

www.cdc.gov/actearly

National Professional Development Center on Autism Spectrum Disorders

Multi-university center promotes the use of evidence-based practice for children and adolescents with autism spectrum disorders.

http://autismpdc.fpg.unc.edu/

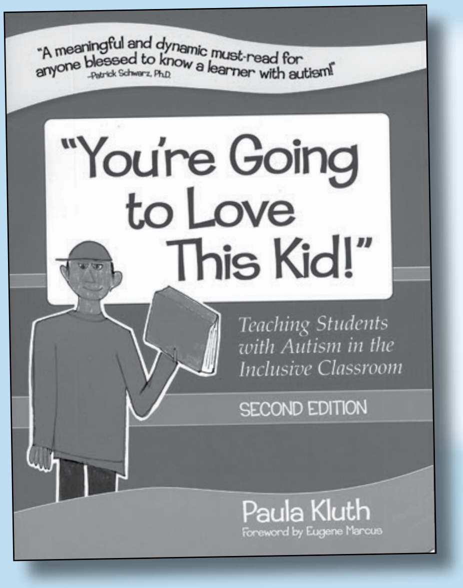
Paula Kluth

Inclusion, learning, positive supports. Online articles.

http://www.paulakluth.com/index.html

Social Thinking-Michelle Garcia Winner

http://www.socialthinking.com



These and Other Great Titles Available Through the Institute on Disability Bookstore at

http://www.iodbookstore.org

INSTITUTE ON DISABILITY / UCED
A University Center for Excellence on Disability

IOD TRAINING

Inclusive Practices in Action: Writing Standards-Based Individual Education Plans (IEPs) with Measurable Objectives

Learn how to write IEPs that connect students with disabilities to the general education curriculum, while using measurable goals that meet identified needs.

Date: March 8, 2011 Time: 4:00–7:00
Location: IOD Professional Development Center, Concord, NH | Cost: $35
Presenter: Laurie Lambert, M.Ed.

AT for All

Hands-on, interactive assistive technology workshops featuring solutions for home, school, work, and play.

Remaining Sessions:

March 9, 2011 – Beyond Duct Tape and Velcro: 101 AT Solutions YOU Can Make Using Everyday Materials | Cost: $175

April 7, 2011 – Universally Designed Technology to Support Reading, Writing, and Communication in the General Education Classroom | Cost: $35

May 4, 2011 – Natural Support Strategies and Assistive Technology Solutions in the Workplace Cost: $95

Time: 9:00–3:00 - except April 7 (4:00–6:00)
Locations: Holiday Inn, Concord, NH (October 8 & May 13 only)
IOD Professional Development Center, Concord, NH
Presenters: David Hagner, Ph.D., Dan Herlihy, and Therese Willkomm, Ph.D.

Going for Guardianship

Information and tools to guide families through the entire process of obtaining guardianship of older adults

Dates: March 16, 2011 – Common Man Inn & Restaurant, Claremont, NH
May 11, 2011 – Best Western Hotel and Suites, Portsmouth, NH
July 14, 2011 – Highlander Inn & Conference Center, Manchester, NH
Time: 9:00–3:00 | Cost: $30
Presenter: Mary McGuire, Esq.

Foundations in Transition

Practices to improve the self-determination skills of youth and to provide educators, community providers, and family members with tools to help young people succeed

Remaining Sessions:

March 9, 2011 – Think Outside the Box: Student-Centered Educational and Employment Options

April 13, 2011 – Resource Development: Who Needs to Come to the Table?

Location: Holiday Inn, Concord, NH
Time: 8:00–2:30 | Cost: $95 each
Presenters: Dawn Breault, Heidi Cloutier, Donna Couture, Jennifer Cunha, Jonathon Drake, David Hagner, Amy Jenks, JoAnne Malloy, Therese Willkomm, and Heidi Wyman

Home Solutions for Independent Living: The Dementia-Friendly Home

Learn to conduct home assessments and to make the home environment as "dementia-friendly" as possible.

Date: March 11, 2011 Time: 9am–4:30pm
Location: IOD Professional Development Center, Concord, NH | Cost: $75
Presenters: Cathy Creapaux, Janet Dineen, and Therese Willkomm

Facilitating Friendships in the Inclusive Classroom

Identify strategies for facilitating friendships in the inclusive classroom.

Date: March 22, 2011 – Time: 9:00–3:00
Location: IOD Professional Development Center, Concord, NH | Cost: $85
Presenter: Susan Shapiro, M.Ed.

Supporting Friendships! Facilitating Social Networks for Young Adults with Disabilities

Learn about social networks and the role that a facilitator can play in supporting friendships.

Date: March 23, 2011 – Time: 9:00–3:00
Location: IOD Professional Development Center, Concord, NH | Cost: $85
Presenter: Lisa Hasler

& EVENTS

Developing and Supporting Meaningful Careers for Individuals with Disabilities

Critical information and tools for assisting individuals to achieve high quality employment outcomes

Sessions:

March 24, 2011 – Career Planning and Job Search Methods
April 7, 2011 – Job Development, Customized Job Proposals, and Customized Job Support
May 4, 2011 – Natural Supports Strategies and Assistive Technology Solutions in the Workplace

Time: 9:00–3:30
Location: IOD Professional Development Center, Concord, NH | Cost: $95 each
Presenters: David Hagner, Heidi Cloutier, and Therese Willkomm

Emergent Literacy Assessments for Young Children: Using the Individual Growth Development Indicators (IGDIs)

Training on IGDI -learn to administer the IGDI measures and to use the online data collection tool.

Dates: April 5 & 19, 2011
Time: 8:30–2:30
Location: IOD Professional Development Center, Concord, NH | Cost: $250
Presenter: Leigh Rohde, M.Ed.

4 EASY WAYS TO REGISTER!

online
WWW.IOD.UNH.EDU

call to register or to request a registration form
603.228.2084

mail a completed registration form
Institute on Disability
56 Old Suncook Road, Suite 2
Concord, NH 03301

fax a completed registration form
603.228.3270

2010-2011 Research to Practice Series: Implementation and Sustainability of Inclusive Education - A Series for School & District Administrators

Nationally-recognized experts discuss the research-to-implementation-to-sustainability gap in inclusive education and strategies for closing this gap. Presented by the National Center on Inclusive Education.

Remaining Sessions:

March 31, 2011 – Special Education Finance: The Costs and Benefits of Inclusive Education
May 5, 2011 – Wrap-Up and Presentation of Outcomes

Time: 9:00–3:00, except March 31 (11:00–5:00)
Locations: IOD Professional Development Center, Concord, NH
Grappone Conference Center, Concord, NH (3/31/11 only)
Cost: $75 each
Facilitators: Cheryl M. Jorgensen, Ph.D. and Mary C. Schuh, Ph.D.

Save these Dates!

JUNE 27-30, 2011

5TH ANNUAL ASSISTIVE TECHNOLOGY SUMMER INSTITUTE

IOD Professional Development Center,
Concord, NH

AUGUST 8-10, 2011

13TH ANNUAL AUTISM SUMMER INSTITUTE

Everybody Reads, Everybody Writes, Everybody Has Something to Say

Crowne Plaza, Nashua, NH

New Hampshire

RAP Sheet

The Latest in Disability Research, Advocacy, Policy, and Practice

Winter/Spring Issue 2011

NH Council on Developmental Disabilities
21 South Fruit Street, Suite 22, Room 290
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TDD access also through NH Relay Service: 1-800-735-2964 (Voice and TDD)
E-mail: advocacy@drcnh.org ✦ Website: www.drcnh.org
"Protection and Advocacy System for New Hampshire"

The Disabilities Rights Center is dedicated to eliminating barriers to the full and equal enjoyment of civil and other legal rights for people with disabilities.

INSTITUTE ON DISABILITY/UCED – UNIVERSITY OF NH
10 West Edge Drive, Suite 101, Durham, NH 03824-3522
Phone (Tel/TTY): (603) 862-4320 ✦ Fax: (603) 862-0555 ✦ Website: www.iod.unh.edu

Institute on Disability/UNH – Concord
56 Old Suncook Road, Suite 2
Concord, NH 03301
Phone (Tel/TTY): (603) 228-2084

The Institute on Disability advances policies and systems changes, promising practices, education and research that strengthen communities and ensure full access, equal opportunities, and participation for all persons.

NH COUNCIL ON DEVELOPMENTAL DISABILITIES
21 South Fruit Street, Suite 22, Room 290
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Phone: (603) 271-3236 ✦ TTY/TDD: 1-800-735-2964 ✦ Website: www.nhddc.org

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

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