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Treating those **with** autism like **[competent and worthy human beings]** shouldn't be a radical notion
by Carol Cujec

photo illustrations by Suda Lazzara-House

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Imagine being trapped in a body that does not cooperate with your mind: craving the touch of your mother as a child yet stiffening in terror at being held by her; wanting to smile at friends but instead averting the eyes on your expressionless face; yearning to blend in with typical people yet being mortified by your own erratic shaking and running; being unable to dependably form words with your mouth or even perform simple sign language. How would the world view you? How would it treat you?

Peyton Goddard, 32, knows just how it feels. For the first two decades of her life, she had no dependable form of communication. She was placed in segregated special education classes, where teachers assumed that she and other autistic children could learn to control their behavior. What they perceived as willful disobedience led to punishment and minimal opportunity for real learning. Eventually, she was labeled severely mentally retarded. Depression revealed itself in withdrawal, inability to participate in therapy sessions, unpredictable movement (what she calls "motor madness"), hysterical laughter, severe insomnia and complete loss of her limited language skills. In those dark days, her only means of control was to refuse food as she contemplated suicide. She vowed to stay alive, however, with the small hope of one day helping other children. Peyton was finally thrown a lifeline at age 22 by a woman she calls her savior, Anne Donnellan.

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Professor Anne Donnellan and adjunct professor Jodi Robledo of USD's Autism Institute have helped the Goddard family and countless others see autism from a new perspective and devise accommodations to help people regain control of their movement and language skills. As members of a small but vocal group of autism researchers, they have rocked the field with a radical notion: Treat all people as competent and worthy human beings.

"We're trying to change the world, is what we're doing," says Donnellan, smiling, her rosy cheeks glowing. "You'd think I was old enough to know better." Donnellan, a professor in USD's School of Leadership and Education Sciences, has been a leader in developing and promoting positive approaches to support and understand individuals with the autism label. In 1970 she founded the first preschool in the United States for children with autism in San Diego. She has served on scores of state and national committees and foundations, including the Department of Education's Autism Task Force, and has been interviewed on such programs as "Oprah" and "Nightline."

Donnellan describes autism as a pervasive developmental disorder affecting movement, communication and behavior that is generally diagnosed by age 3. Though each person has unique symptoms, the Autism Society of America (ASA) says that these may include language delays, repetition of words or phrases, difficulty interacting with others, self-injurious behavior, little eye contact, obsessive attachment to objects, uneven motor skills and unresponsiveness to sounds.

Not so long ago, the blame for autism

was ascribed to cold mothers (dubbed "refrigerator mothers") who did not nurture their children properly. Donnellan tells of one mother from Colorado who, 30 years ago, was taking her son to weekly therapy sessions at a major hospital, which refused to reveal her son's diagnosis. One day the mother hid in a supply closet to see where they filed his chart. When she pulled it out, she saw the word "autism" and demanded to know more. However, the hospital wouldn't tell her because they considered her to be the cause of the problem. "At the time, she had a newborn child, and she pleaded, "Please tell me what I did. I don't want to do it again!" Donnellan says. When she went to the second-ever ASA meeting in 1970, Donnellan says parents were still fighting this misconception, which had no data to support it.

The causes of autism are still unknown today, and the number of affected children seems to be skyrocketing. The ASA calls autism the fastest-growing developmental disability, with 1 in 150 births affected, an estimate of up to 1.5 million Americans. While some genetic basis seems likely, researchers say that environment also plays a role, since identical twins do not always share the diagnosis of autism. The ASA lists problems in pregnancy, viral infections, exposure to environmental chemicals and even common childhood inoculations as potential causes being investigated.

After seeing more and more children with symptoms of autism, 10 years ago Donnellan rallied for the government to study the numbers. Nonetheless, she cautions that the results of such studies can be misleading. "In 1991 federal education law changed and made autism a separate category, so of course there would be more kids in that category because it didn't exist before." Though she resists calling it an epidemic, as some advocates do, she admits she is worried.

But what bothers her even more is how people with the autism label are treated. A hundred years ago, those with symptoms of autism would be locked up with other so-called deviants. "People used to go to visit those places like they would go to the zoo," she says. She says that today, many people are still being institutionalized and medicated unnecessarily. Worse yet are the severe and bizarre aversives, or punishments, that people suffer in the name of behavior modification, which include shocking children with cattle prods, putting them in full body restraints for hours at a time, shooting ammonia sprays in their faces and making loud noises in their ears. "You would go to jail if you did these things to a dog," she says passionately. As a result, many of these kids develop symptoms of post-traumatic stress disorder. The theory behind these "treatments" is that the child's behavior is bad and must be punished in order to diminish it. Donnellan firmly disagrees: "There is no condition that anybody has ever used aversives on that we can't do just as efficiently and effectively without punishment."

While Peyton was spared most of these

techniques in her school years (her individualized education plans, or IEPs, specified that no aversives be used), she suffered nonetheless. She was forced into segregated classrooms where educators focused solely on behavior control. Peyton might sit on the ground at recess and not be able to respond to the repeated commands of her teacher: "Get up. Get up. Get up..." Without offering assistance, they would leave her in the same spot for more than an hour at a time. As a consequence for what teachers viewed as disobedience, she might be locked away in what the school called a shutdown room. For more than 15 years on Peyton's IEPs, the math goal was to count verbally from one to 20.

"I'm not sure if that's even a measure of math skills," says her mother, Dianne Goddard, herself a former educator, "but that is all that was expected of her, and it was never achieved because more and more she lost her verbal ability." Peyton's early gains in literacy and even speech (at age 9 she was able to put five or six words together and make spontaneous language) disappeared as she lost all interest in school and even in life itself.

In December 1990, Donnellan experienced what she calls an upending experience — an event that forced her to question everything she thought she knew about autism. A woman named Rosemary Crossley came from Australia to demonstrate a new strategy to help people with autism communicate. It was called facilitated communication (FC), and the idea behind it was quite simply to have a facilitator support someone's arm so that person could type on a keyboard. For people whose movement is difficult to control, having someone steady their arm and provide some resistance seemed to allow them enough control to type out words with one finger. Early criticism of this method, including a searing assessment of it on an episode of the PBS series "Frontline," suggested that the facilitators were actually controlling the user's typing, either consciously or unconsciously. How could people who had been presumed mentally retarded suddenly type clear, even powerful messages?

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Donnellan first witnessed FC with a young man that she knew well who was severely mute. "We all cared a lot about him, and generally it was very hard to keep him still and on task. Yet he was able to work for an hour and 45 minutes with this woman. She was assessing his abilities, and he was willing to keep working and type out a message to his mom. Everybody who knew him knew that the words were coming from him. The experience shook her to the foundation, and forced her to admit that a big part of the story had been missed. "By that time I had spent already 20 years in the field. I was an expert, an international speaker, and for another year and a half I just said 'I don't know. I don't understand it.'"

Donnellan, along with other researchers, including her colleague Martha Leary, a speech and language pathologist specializing in autism, concluded that autism involved sensory and movement disorders similar to those found in Parkinson's or Tourette's syndrome. This meant that people with autism were not always in control of their movements, and this prevented many of them from creating speech.

"As I've looked back on it, we clearly, as a field, were missing the point from day one," she says. "We had all assumed that this boy was mute, but that's not the natural state of things. It doesn't automatically come with retardation or autism, but nobody looked at it because we had this convenient category to put him in. There was never any claim that people with the autism label were missing the linguistic part of the brain. Unless there is some huge physical impairment involved, if you're in a linguistic environment, you're going to create language. Anyone who has children knows that they have a lot of language before they can speak. My granddaughter is 14 months old. She's got a new word every day."

It was Donnellan who arranged for the

then 22-year-old Peyton Goddard to try facilitated communication after meeting the family at a USD autism conference in 1997. Since there were no resources in San Diego at the time, Donnellan arranged a session at the Whittier school district near Los Angeles. "I just went alone with Peyton because I wasn't really expecting anything," recalls her mother Dianne. When asked to type her name, she typed "PYEYTKON." Having never done this before, her hand lacked precision, but like many people who are able to type for the first time, she wanted people to know that she was smart: "I... INTLGENT ... I TYPE TO TELL ... PEOPOPL ... I THINK ... MOM THINK I... SMRT." Dianne was overwhelmed. "I went to the bathroom and wept," she recalls.

Before that moment, Peyton's parents had dreaded the day Peyton would finish school, as empty as it had become for her. "For years she went to school programs that were nothingness. Now taking care of the nothingness was going to be our responsibility. "What they had envisioned was a job for Peyton at her father's restaurant filling salt and pepper shakers. Facilitated communication opened up a whole new world for her. One of the first things Peyton asked was to attend college. Cuyamaca College in El Cajon, Calif., helped accommodate Peyton's special needs, including providing proctors for her essay exams, which would take her six hours to type. Peyton discovered that she could control her motor problems during lectures by doing puzzles. "She needed to engage her hands so that she could engage her mind," explains Dianne. She could complete a 200-piece puzzle in a 50-minute class. She listened so well, in fact, that she never even had to read the notes written by her aide.

Not only did Peyton earn her degree, she graduated valedictorian with a 4.0 average.

Peyton is tall and thin with curly brown hair, expressive brown eyes, and prominent dimples, which appear when she smiles or laughs, a skill she has only regained in the past six months. As she types, her body struggles to cooperate with her mind as her tongue restlessly darts out the corner of her mouth; she lies down when she wants to be sitting, sometimes getting up even though she may not want to go. As she types, her eyes struggle to focus on the keyboard. When she looks away, her parents supportively call her back to task: "Keep going ...What's next?... Is that what you wanted to type?" Her mother holds her hand with a slight backward resistance in order to give her enough support to accurately type the next letter. It takes her perhaps six or seven minutes to type a sentence, including going back for corrections. As she types, her parents offer emotional support. Patiently, they never finish a word or a thought for her, as many might be tempted to do. This is fortunate because her words are often surprising, and few could guess what she intended to say next.

Facilitated communication allowed Peyton to finally reveal to her parents at age 24 what she called the great secrets of her life — the primary source of her depression in the dark years. She had been the victim of sexual abuse at age 9 by a distant relative and then later by a teacher at her school, a teacher who by this time was in prison on the testimony of other students. Sadly, says Jodi Robledo, statistics suggest that perhaps 70 percent of children with disabilities are abused in some way. Peyton's goal in telling her parents was not revenge but healing. This is also why she asked to go off all her medications, a process that took three years. Her mother recalls, "She told us, 'I want to feel, so I can deal, so I can heal, so I can help. 'By "help" she means advocating for children, which she now does through her presentations for conferences and community groups and through her writing.

"What's been such a blessing for us is seeing how Peyton's advocacy is keeping kids out of institutions," says her father, Pat. "Our family has moved from anger to advocacy because that's what Anne Donnellan and the Autism Institute are all about. Peyton has taught us that leadership for change does not come from anger; it comes from a peaceful heart."

People like Peyton offer researchers the opportunity to understand autism from the insider's perspective. "Peyton is really our teacher," Robledo insists. "We've met so many people with autism in the last 10 or 15 years who have shared what autism is to them, and it's a very different picture from what we see in the textbooks."

Understanding movement in particular has helped people accommodate differences, says Donnellan. Peyton's mother agrees that this was the key to her daughter's success: "If we had understood movement differences when Peyton was young, we would have been able to accommodate her and avoid what she calls her wasted youth. "With this knowledge, they can now offer Peyton emotional and physical support to help her build new motor patterns and move toward independence in daily activities like typing, brushing her teeth and putting on her jeans.

Housed in just one small office on campus, USD's Autism Institute is committed to spreading the word because, as Donnellan says, "so much of the information out there about autism is just awful." Donnellan and Robledo get the word out by publishing, speaking at national conferences, making presentations in local school districts and hosting their winter and summer conference series at USD, which bring together educators, parents and researchers from throughout the world. The institute's Web site, which is in the process of being updated, will soon become a resource for parents and educators on movement differences and relationship-based support.

"Of course, we are so excited to be moving into the beautiful new SOLES building," Donnellan says. "It will be terrific to hold institute seminars and conferences in a state of the art facility. From what I hear, we will have not only an auditorium but seminar space as well."

Currently the Autism Institute is supported solely by its conference series and the high-powered dedication of its principals, but Donnellan is hoping to find funding for additional clerical support so that they can do even more.

"We're really trying to change the way people think about autism," she explains. "We need to stop thinking about it in terms of the deficits, but to think about how hard these people are trying to be in the world with us. We need to change to support them, because it's easier for us to change — we're the ones with the flexibility. Most of the social skills programs assume that all the changing has to be from the side of the person with autism. That's not a very realistic idea."

Before Peyton's graduation, her mother recalls a visit from Donnellan. "Peyton typed to her, 'I owe you priceless. I can never repay you,'" recalls Dianne. "Dr. Donnellan replied, 'Okay, let's say you owe me, but when you graduate, it's paid in full. "Working with a therapist, Peyton has created phrases to define her new self-concept, replacing the way she was defined by others throughout her life. Her mother has written her words on a calendar so that Peyton can see them each day: penny shining, present opening, uppity not, umbrella jollity, pore out peacing love. When asked about her future plans, she types in her characteristic poetic style: "I PLOT LOVING PEACEFREED BOOK."

To Donnellan and Robledo, their work is simply an extension of USD's commitment to social justice and human rights: "All human beings deserve to be treated as respected members of the community — respected for their abilities and disabilities," says Donnellan. "I'm not a Pollyanna. I know I'm not going to see it all happen, but we should presume competence in people, and then we will look for competence. If we presume incompetence, that's what we'll find."

Peyton's advocacy keeps kids out of institutions. Change doesn't come from anger, but from a peaceful heart.

For more information about USD's Autism Institute, including its summer conference July 9-11, 2007 go to www.sandiego.edu/autisminstitute or e-mail autisminstitute@sandiego.edu.