



An Interview with Ruth Sullivan, Matriarch of the Autism Community

By Paul Rothbein

Ruth Christ Sullivan, Ph.D., has long been active in the autism community, as both the parent of a son with autism and a professional. She was the first President of the Autism Society of America in 1965, and has worked tirelessly throughout her life to improve understanding of, and services for, individuals on the autism spectrum.

Dr. Sullivan, you have been an expert on autism and active in the autism community for close to 50 years now. Is there a difference in the autism community's integration in society today than in the 1960s?

There's an immense difference. In the early days, 1964-1965, most people had never heard of autism, including people in the behavioral health professions. We had to start by spelling it - AUTISM. It was a really rare disorder then, with very few psychiatrists or psychologists seeing such a case. And if they had, most would not have recognized it, nor known how to treat it because there was almost nothing in literature about the disorder. And most had not heard of it, even in medical school.

Do you think autism was more rare in the 1960s or is the explosion in autism today just the result of better diagnosis?

I think increased awareness is part of it, yet I think there were people on the spectrum in our society all along. In fact, as we began to know more about autism and more reports and useful information appeared in the literature, people would come forth and say "so and so must of been autistic." The symptoms started making sense as indications of autism. One of America's best known short stories, "Bartleby, The Scrivener" by Herman Melville (1853) is about a relatively high functioning man with autism, though, of course, there was yet no name for it then. In the last three decades several published papers have agreed the man probably had autism. So it's been around for a while. It just wasn't labeled as such.

Autism is definitely a very popular subject today. Celebrities like Jenny McCarthy have written bestseller books about raising a child with autism, the movie Rain Man won many academy awards, and HBO has an upcoming movie, Temple Grandin, releasing in early February. Has Hollywood and the media been influential in advancing understanding of autism and people with autism?

I would say their influence has been good, without a doubt. The media was really able to do on a larger scale what we were trying to do on a much smaller level. *Rain Man* (1988) did more for advancing public awareness of autism in one year than all of us at ASA, as a small parent-run organization, had done in the 25 years before the movie release. It set off an explosion of information about autism. I am deeply grateful to Dustin Hoffman, who portrayed a very believable Raymond, as well as to Barry Levinson, Director, and Mark Johnson, producer of the film. They were courageous to have taken on this highly unusual story. The first public showing was held in Huntington, WV as a benefit for Autism Services Center, the agency I founded in 1979. The movie definitely had a huge impact on autism awareness - around the world.

How important do you feel it is to use people first language? Is it overemphasized or underemphasized?

I don't think it's overemphasized. When you want to get the attention of the masses it sometimes takes certain language. People first language (i.e., "person with autism" vs. "autistic") might strike some people as a little dramatic. Certainly it's good manners; it's a loving thing to do, it's a respectful thing to do. And I think it is certainly good for raising awareness about disabilities or any other thing that sets people apart as being of less value.

Do you feel that sometimes the use of people first language is more about being politically correct than recognizing individuals as people first?

Exactly. But it's not a bad thing when people do it to be politically correct. However, they don't get the point – acknowledging the individual rather than defining the individual by his or her disability.

Most media attention gravitates towards children with autism. How do you feel – being the mother of an adult with autism - about the inequity in information, programs and services for adults with autism? Why do you think children with autism receive more attention than do adults with autism?

I think there are two reasons behind this. First, children have more appeal in a poster. When we created the Autism Society of America in the mid-1960s we were all parents of young children. The organization was originally named the National Society for Autistic Children. Within a few years we realized these children were going to be adults in the not too distant future, so we amended the name to the National Society for Adults and Children with Autism, and then later to the Autism Society of America. And, we all worked very, very hard to advocate for services for younger children, because that was our own personal focus at the time.

Which leads into reason number two. When parents are young they have a huge amount of energy. The diagnosis is a shock and many respond with funneling all that energy into their child, finding (or creating) appropriate programs, advocating for services, setting up

home programs, etc. They work very hard for many years doing this and as they get older they get very tired. They've neglected themselves all those years to give everything they have to their child, and they get ill, they get feeble. Their child grows into adulthood, still needing **appropriate** programs and services that are virtually nonexistent, and these parents just can't work as hard anymore.

When you go to ASA conferences now you don't see a lot of older parents. You see parents in their 20s to 40s, individuals still fighting for the same reasons we did – for appropriate programs and services for their child with autism or Asperger's. And just as we did, they embrace this fight. But as their child learns and grows, they begin to burn out, age out, and eventually find themselves unable to continue the battle. I've had parents tell me, "I'm afraid to die. Who will take care of my child?"

Yet, all these children grow into adults. As a society, we are pitifully unprepared to handle the wave of adults with autism that continues to mushroom day by day. The estimated cost to society for programs and services for individuals on the autism spectrum is now estimated at \$60 billion a year. In the next decade it is estimated to balloon to \$200-400 billion per year! (Source: Autism Society of America website, www.autism-society.org) That's *billions* of dollars. This is – and should be – a pressing public concern. Every 1 in 58 boys is now diagnosed on the autism spectrum. (Source: Autism Speaks website, www.autismspeaks.org.) And, all these children become adults, most of whom will continue to need at least some level of service throughout their lifetime.

Currently there are very few services provided for adults on the spectrum, in this country and abroad. (See the ASA position paper by Dr. Sullivan, "National Crisis in Adult Services for Individuals with Autism," revised 2007. www.autismservicescenter.org/position.pdf.) And there are even fewer good or appropriate services for this population, especially in the area of residential services. In our agency in Huntington, WV we have services for people from diagnosis to death. We have group homes where adults can live – with 24/7 staffing - and services for individuals living in their own apartment. We provide job coaches to help them gain marketable skills, find and keep a job. We help them with their social life. We help them participate in life to the fullest and be contributing members of society. Most of the 265 or so people we serve still live with their families, in their own homes. But there are very few communities like ours.

How did you feel when your son was first diagnosed with autism?

At the time he was diagnosed there were only a few articles besides Dr. Leo Kanner's trail blazing report, "Autistic Disturbance of Affective Contact" (1943). He gave the syndrome its name: Autism. There was not even a basic understanding within the overall medical community about autism. A psychologist told me there was nothing wrong with my handsome little boy. "You're just an overanxious mother." This was during the Freudian era; the medical establishment called us "refrigerator mothers." The prevailing thought was that autism resulted from mothers who were cold, unfeeling, unloving and didn't know how to raise their children. That theory, cited as fact, appeared in the medical and mental health literature as well as in the public media, including television.

You can't imagine how devastating and difficult this time was, to battle such ignorance about autism. That attitude was one of the first things we had to fight. I met parents and a few helpful professionals, including some fine psychiatrists and psychologists, who shared the idea that the characteristics of autism were based more on neurology than learned behavior. Dr. Bernard Rimland, himself a psychologist, and a parent, wrote a groundbreaking book on autism that shook the medical community and started the shift in our understanding on autism. (*Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, 1964.) He was instrumental in getting us together, in November 1965, and we started ASA. I was the first president.

We began to write our own literature; we created our own definitions. We met with public officials on local and state levels; we went to Congress. I was the first autism lobbyist in Congress. There was much excitement when in 1975 the landmark Education for All Handicap Act (EHA) was passed by Congress, but the only categories specified were mental retardation, cerebral palsy and epilepsy. However, the definition of "disability" was broad enough to qualify for funding autism education services **if** the school personnel approved it. Few did, legitimately citing lack of funds and untrained teachers. Finally, in 1990, autism was solidly included in the revamped EHA as a separate category in the new Individuals with Disabilities Education Act (IDEA).

Many people with autism/Asperger's are gifted in the arts and sciences. Beethoven, Isaac Newton, Albert Einstein, Thomas Jefferson, and Mark Twain are now thought to have been on the autism spectrum. Some individuals suspect that Bill Gates has Asperger's Syndrome. Do you think teaching this to children in elementary school will help improve their interpretations of autism as they grow up?

Yes, I do. When I first learned about autism, all that was written described classic autism – the child who had significant behavior problems, perseveration of sameness, few social skills, no or delayed speech, with severe anxiety. None of us had ever seen an adult with autism. We didn't know such a vast spectrum of impairment existed, that some individuals could be severely affected and others only mildly so.

As our numbers grew we started noticing individuals whose symptoms seemed milder. Then, in 1981 an academic paper written by British researcher, Dr. Lorna Wing (a psychiatrist and parent of a son with autism) referenced a 1944 landmark paper by Austrian pediatrician Dr. Hans Asperger, who published the first definition of Asperger's Syndrome (in German). He did not give the set of behaviors a name. We learned about individuals who were on the milder end of the autism spectrum. It helped us understand the diversity of autism spectrum disorders.

As a parent, it does help to know that many people with high functioning autism or Asperger's can exist independently and function within society. Like Bill Gates, they have some social skills; they are often very smart – even brilliant. They are more likely to have had parents who raised them in a way that enhanced their innate skills and helped them overcome their challenges (especially in social and relationship skills). These

parents prepared their children to function in society. They are more likely to have good manners, self-discipline, know how to dress appropriately for the situation, and think and reason for themselves. It is a wonderful thing – for both a parent and an individual with autism or Asperger’s - to know one can be on the spectrum and still do well in society.

One of the most famous and inspiring people with autism is Dr. Temple Grandin, a highly accomplished professional, a prolific author, a dedicated autism advocate for over 30 years now. The label of Asperger’s has been attached to Bill Gates only more recently.

Is there better information available today for parents raising a child with an autism spectrum disorder?

Most definitely! There are literally thousands of books now, with new ones releasing almost weekly. There is no shortage of literature on autism today, in print and on the Internet. In fact, for parents new to autism the amount of information can be overwhelming.

It helps to connect and join with trusted sources, like the Autism Society of America, and find other parents who can share information about good agencies, professionals and other resources. ASA has reliable information, and ASA chapters exist in every state. Chapters are made up of parents who are typically very well informed about autism, and especially about services in their own communities. I would urge parents to contact their local society and get active. These parents know where to find the good doctors, the good pediatricians who are knowledgeable about autism and the best to go to for a diagnosis or evaluation.

Better information exists now than it did even 10 years ago. We have medical and service professionals who have made autism their career and have 30 or more years of knowledge and experience under their belt. Parents and schools, community programs and private providers serving people with autism, after several decades of experience, have a wealth of sound, reliable information and literature at their disposal now.

Many people view individuals with autism with pity. Is that productive for the advancement of people with autism?

Well, pity is better than hate and destruction, but what we need is understanding. Pity can be useful, in that as an emotion it can spur individuals to want to help people who have any kind of disability. Pity can be a bridge to true awareness and understanding, where people treat others with dignity and work to bring about needed programs and services for individuals with autism and Asperger’s. I would prefer a person feeling pity than having a mental or emotional block towards autism, where “out of sight, out of mind” is their attitude towards this population of individuals.

Good things can start from pity. Pity can be transformed into understanding, and is likely to result in respect, acceptance, appropriate programs, and hope for people on the spectrum and their families. I think all the laws we have today started with a dose of pity.

When approached in the right manner, most people, including legislators, want to help. I have found that there is a goodness about people you can tap into. I've learned that sharing information is one of the most important and powerful things you can do. We can all bring about important changes, one individual at a time.

BIO

Paul Rothbein, an internet marketing consultant from Dallas, Texas, is a part-time journalist specializing in personal interviews with interesting people. He is active in both the autism and epilepsy communities.

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