

1[Remarks given Friday, July 11, 2008, by Lois J. Blackwell, Founder --Judevine Center for Autism upon receiving the Founders Award from the Autism Society of America at their 2008 Annual Convention held in Orlando, Florida]

Friday, July 11, 2008 – Evening of Champions

I am deeply honored to be here today. Thank you Lee Grossman, Dr. Cathy Pratt, Liz Roth, and all of the members of the ASA Board of Directors for this great honor. And thank you Ruth Sullivan for your friendship and support of my work over the years.

In the late 1960's I was Assistant Director of the Social Exchange Laboratory at Washington University in St. Louis working with Martin Kozloff helping to design environments that would not support deviant behaviors. Children who had unusual behavior patterns were being referred to the Social Exchange Lab. No one knew what to do with them and there was nowhere to send them for help. We were the referral of last resort. Remember-- at that time autism was not recognized as a medical diagnosis. Many children were labeled emotionally disturbed, borderline personality disorder, mentally retarded, severely behavior disordered...or any of a wide variety of other diagnoses. The advice to parents who were seeking help was often to "...just put the child 'away' and forget about him — there's no hope and no help. You're young! Go home and have another baby!"

When the grant money ran out for the project, and the research was concluded, these families who were seeing their children beginning to learn and make progress...had nowhere to go with their child. This was 1970. There were no treatment programs for autism – no websites and no resources. Information on autism was sketchy, to say the least. The parents were desperate. What could be done?

....We had a meeting!!!

And that's where it all began. Together with the families of these first 14 children, we raised \$9,000 collecting change on the street corners of St. Louis. We leased an old parochial grade school and the parents worked evenings and weekends getting the building ready. The Judevine Center for Autism was founded and formally incorporated on November 9, 1970 and opened its doors to its first group of children in October 1971.

Judevine evolved from an unwavering belief that the abilities of people with autism of every age and every level can be released through our outcome-based, results-oriented Judevine method. This method is rooted in behavioral laws...which are like the laws of gravity. You don't have to believe in gravity in order to feel its effect. One behavioral principle that underlies all successful approaches to the treatment of autism is that positive reinforcement of the behavior you are seeking to develop works.

A central belief at Judevine, and one of its guiding principles, was said best by Johann Wolfgang von Goethe, "If you treat an individual as he is, he will stay as he is; but if you treat him as if he were what he ought to be and could be, he will become what he ought to be and could be." It's all about framing expectations and goals. It is the belief that the person is more normal than abnormal, and not just a skin-bounded bundle of behaviors.

Our data showed that the children were making significant progress. Parents and professionals from across the country came to see what we were doing and asked for help. What could we do?

...We had a meeting!!!

Our first concern was how will we get our teaching staff prepared to work with autistic children – teaching children with autism was not part of the college curriculum, no matter where the teachers had received their training! How could we keep the thinking set and teaching strategies we had developed consistent from one generation of teachers to the next? We needed to develop

a replicable system for training staff. And that is what we did.

First we started with professional training – to meet our internal needs. We developed an intensive, competency-based professional training program. Then, recognizing how important parents are in the progress of their child, and that the children would spend most of their waking time with their parents, and that positive behaviors can be reinforced across environments, we developed a specialized competency-based parent training program—intensive, but very effective.

This is the program Judevine has used to train and continue to train families from all over the country, and internationally. They learn about autism, techniques and strategies to reach their child with autism, but, most importantly, a framework on how to think about the challenges as they present themselves — a thinking set. At Judevine, we refer to this as “A THINKING SET THAT WORKS”.

The mission of Judevine is what drives the organization. “The mission of Judevine is to make a real difference in the quality of life of children and adults with autism and their families, wherever they may live.” My advice to service providers in the audience is the importance of developing a good vision...and then to make your decisions based on staying true to that mission. That is not easy!

There is so much I could talk about tonight...the lessons we have learned at Judevine through the ups and downs and evolution of an organization, and the changes in the field of autism. Thank you to the many children, families, staff, and professionals from whom I have learned so much on this journey and without whom, Judevine would not be.

There remains another challenge for us to think about and address –Research. I am very excited about the incredible research opportunities that are available today, and the great increase in funding resources being directed toward autism. While the research is exciting and speaks to the

future needs of these children, remember there are children and adults along the way who cannot wait for perfect answers.....they need help today! They need services TODAY! And, each family is faced with deciding which service will help their child the most. This is the quagmire of today.

It makes me think about going to a grocery store in 1970...and going in 2008. In 1970, a trip to the grocery store was much different from what it is today. Now, our product choices are endless; so many brands and flavors. How do you know what to buy? The once family-owned corner grocery store that served as the main resource is now replaced by an abundance of commodity-driven corporate companies.

Autism services today are no different. With funding resources at the highest levels ever and continuing to rise, families and people suffering with autism will have the help they need. Or will they? What distinguishes the services available to them? What flavor do they buy? What brand do they trust?

As we focus on particular areas within the field of autism, we must take great care to not lose sight of the child. While there are great needs to be met in many areas, many questions which must be answered, and many puzzles to solve, we must not lose sight of the person. The person is not a collection of diagnoses, symptoms and behaviors. The person is so much more than that.

Sometimes, when pursuing research, people only look at one aspect, i.e. they are looking micro instead of macro. This would be like looking only at Bangladesh, for example, when they are trying to research the global economy. Autism is complex and multifaceted and must be viewed as such. Otherwise, we're like the blind men and the elephant. Some people are always looking for a "magic bullet". There is no magic bullet. It's not that simple.

Another concern I have about autism research is that we must be wary of hubris—of self-aggrandizement. We all must keep within our own selves, the desire to care for others. I want you to know, that as touched as I am about the recognition that I have been blessed to

receive, it has never been about me.

It is about the people we serve, the people whose lives are affected by autism. As great discoveries and developments are made through autism research, we must remember that. It's not about the person who does the discovery or development...it is about the person who will be helped...whose life will be forever changed for the better.

All that being said, I could not be happier about the level of public interest and research in autism that is happening. I'm excited about seeing the developments and discoveries as they occur. We have learned so much about autism in the last 37 years. There is so much we still must learn and discover. But there remains a formidable challenge. And that challenge is to remember why we are here and not to forget how we got here.

As parents, M.D. doctors, teachers, therapists, behaviorists, DAN! practitioners, trainers, funders, researchers, and everyone in the autism community, we must be vigilant to work together and collaborate...and not to work against each other. As Abraham Lincoln said in a speech delivered at the close of the Republican Convention on June 16, 1858, "A house divided against itself cannot stand."

We must work together. We must do the right thing for those we serve. We know what we need to do. And as he said four years later in his Annual Message to Congress on December 1, 1862, "The way is plain, peaceful, generous, just -- a way which, if followed, the world will applaud and God must forever bless."

Thank you.