

CJ Foundation Gala Speech

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I would like to thank the CJ foundation and Dr. Jill Kelderman, for inviting me to speak tonight at your annual gala. I hope you are all having a wonderful evening so far.

Right before coming here tonight I was helping my 18 year old daughter, Sarah, who has Autism get ready for her prom. That in itself, is a perfect introduction to my remarks this evening, about living with and understanding the Autism Spectrum.

The autism spectrum is a huge part of my life both as a developmental and behavioral pediatrician and as a parent of a child with autism. In my medical practice over half of the families I see have a child or teenager with some variety of autism. Despite my professional status, years of training, and expertise with Autism, I continue to learn something new every single day.

There is a saying amongst many professionals who are experts in treating and diagnosing Autism that goes: “When you have seen one child with autism, you have seen one child with autism”.

Regardless of the terminology we use – Aspergers, PDD-NOS, Autism, ASD, there are specific characteristics all individuals with these labels share – difficulties with communication and social skills, restricted interests and repetitive behaviors. However, the ways these behaviors and difficulties manifest themselves varies widely among individuals. This is the “uniqueness of autism”.

So the great irony is that as professionals, we must try to understand what is the same about autism, keeping in mind that neat categories and defining characteristics become a challenge with so much diversity.

With this understanding of “the uniqueness of autism” the diversity can be truly mind boggling. (For example -some individual have genius level IQs, others do not, some children are non-verbal, others can't stop talking, some individuals are sensitive to sound, others won't react to a fire alarm, some are food restricted, others eat everything in sight including objects, some

children and adults don't like to be touched, others hug everyone they see, one child can't remember her name, yet she knows the birth dates of every president). All of these behaviors I have seen, and all of these children share an ASD diagnosis. This diversity is also a challenge for families. Understanding that abilities are not evenly distributed within or amongst individuals with ASD, and that progress varies too, can be hard to accept. Why some children do so well and other fail to make significant gains remains a mystery.

I marvel at the families and children I see every day. For some progress comes quickly, others painstakingly slow. Yet, regardless of the pace of progress- each of these families strives to provide their children with all of the therapies, treatments, and love humanly possible. In fact, the families of children on the spectrum are special in their unwavering persistence and resilience. We all know (myself included), this is not an easy path and not without a human toll. These families are deserving of respite, support, and inspiration, and as we all know by our presence here tonight, the CJ foundation is trying very hard to meet the needs and challenges these families face.

I would like to spend a few moments on one of my favorite topics which is the upside of Autism, which views ASD in a more positive light. This perspective is an attempt to see beyond the defining ASD from the perspective only of deficits and a disorder.

If you do an internet search on the definition of autism these are some of the answers you will find: Autism is...

“A mental condition, present from early childhood, characterized by great difficulty in communicating and forming relationships with other people

A lack of empathy ...

An inability to relate to others....

An abnormal absorption with the self....

An inability to treat others as people...

Autistic is a person who suffers from autism.”

Some of these phrases can be offensive to those of us who know and love individuals with ASD and to individuals with ASD themselves. I do not want to minimize that **WITHOUT A DOUBT AUTISM CAN BE VERY HARD** to live with, and there are millions of adults and children with behavioral and language difficulties so severe they have very restricted lives. However, even individuals with severe problems we are finding, remarkably, many can learn to communicate and find more adaptive behavioral responses when given the opportunity with technology and other supports. I would highly recommend all of you in the audience today take the time to see the award winning documentary Wretches and Jabberers. This a movie about the lives of Larry Bissonette and Tracy Thresher, two adult men nearly cast aside by society whose lives change when they are given a way to communicate with the world through typing. One of the many profound realizations of this movie is that what matters the most to Tracy and Larry is to have a life with meaning, and the acceptance that they are more like the people around them than different. Also that in spite of their outbursts, and at times erratic behaviors, and limited speech, they are as human as we are. It's a beautiful and moving portrait of what can lie beneath the exterior of a person if we take the time to look deeper.

WHAT IS STRIKING ABOUT all of the definitions of Autism is that the upside of autism is missing. Autism is only seen as severe, debilitating, and pervasively impairing a person's life. Yet what about attention to detail, remarkable memory, creativity, and tenacity ...these characteristics can be in the mix as well. For some individuals a "narrow area of interest" or obsession, becomes a passion which can lead to important discoveries and inventions, social change, great works of art and music, and even new technologies.

To many of you the inventions and discoveries by individuals with ASD are well known, but perhaps not to all of you here tonight so let me give you a few real world examples.

For my older daughter Sarah, after attending a school with several children in wheelchairs, she became obsessed with the fact that they could not join in the playground with everyone else. She began doing her own research and found the organization boundless playgrounds which helps adapt playgrounds for children of all abilities. Sarah went to the city commission with her idea and began raising money. Out of this the Coral Springs

Boundless Playground Project was formed. This was entirely the passion and dedication of a 15 year old – now nearly 19 year old, teenage girl on the spectrum whose inability to let something go became a positive contribution to society. Sarah continues with her efforts and the accolades and awards she has received for her work on the playground are vitally important to her. The project, as she tells me, gives her value and validation, critically important in the identity of a young teen. (Now it still can be hard to live with at times, you could ask her typically developing sister Emily....but I think everyone in our family would rather deal with an obsession to build a playground than many other problems a teenager could have.)

There are individuals on the autism spectrum whose unique ability to sift through vast amounts of information leads to important observations vital in science, economics and other fields. Many of you are familiar with the examples of proven and suspected famous people on the spectrum from Darwin to Gates, Zuckerberg to Einstein. One case you may not be familiar with is the story of Dr. Michael Burry. Noted author, Michael Lewis, in his book *The Big Short*, details the fascinating stories of the people involved in Wall Street's economic collapse due to subprime mortgages. Dr. Michael Burry is a key figure. Dr. Burry left his residency at Stanford University Hospital in the middle of his training as a neurologist to pursue a career in investing. He formed a company called Scion Capital and during this time he started reading the prospectuses of subprime mortgage bond offerings. Michael Burry, with his penchant for detail and ability to sift through large volumes of technical financial information, foresaw the future disaster of the subprime mortgages several years before the crisis became public. Dr Burry was not psychic, he has Aspergers. His ability to hyper focus on details of interest to him, and his phenomenal ability to analyze financial data, meant he could actually take the time to read the technical prospectuses of Wall Street firms, in doing so he realized something wasn't right, the numbers did not compute. Michael Lewis commented "The one guy that I could trust in the middle of this crisis was this fellow with Aspergers", he says "He became the moral center of this market for me because he was the most honest and moral character".

We are learning that there are certain settings where people with autism are particularly well suited and can display their strengths. Young adults with ASD are still remarkably under-employed, but I hope we are learning,

through stories like these, to teach young adults with ASD to find where their strengths are and use them. Our job as caring parents, professionals, and supporters of individuals with disabilities is to teach the world to be more accepting of idiosyncrasies and less judgmental, this will allow individuals with ASD who may not fit with social norms to work and live among us.

We are living in a time where autism is starting to be viewed as a different way of being, not simply a disorder. Of course there are still many challenges for individuals with autism and their families no matter where they are on the spectrum. There are obstacles with language, sensory processing, independent functioning, and maintaining relationships. Yet thankfully doors are being opened and foundations such as CJ are a critical part of this process.

What makes the CJ foundation special is that every dollar donated goes to efforts that directly help children and families coping with the challenges of autism, other special needs and cancer. It is foundations such as CJ's with their vision of doing "a world of good wherever it is needed" that are paving the way for a world of change

To all you mothers out there tonight happy mothers day...

Thank you and have a wonderful night!