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## ... But With a Ways to Go

Bill Buese

*Johnson County Community College*, [bbuese@jccc.edu](mailto:bbuese@jccc.edu)

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## ...BUT WITH A WAYS TO GO

by Bill Buese, Professor, Head Trainer HPER and Athletics



When I heard that the first diversity event to be sponsored by JCCC's newly created office of Diversity, Equity and Inclusion was going to address autism, I was both thrilled and pleasantly surprised. Diversity truly does reach well beyond the familiar set of "isms" we commonly think of when we hear the word "diversity." I am glad that our new ODEI appreciates the true breadth of diversity and is prepared to broaden our horizons on a variety of fronts. For the past 17 years, I have had my own adventure with autism, through my son, Brian.

Brian was diagnosed with Asperger's syndrome when he was 14. He's now a senior in high school. Very smart, nonetheless he faces problems that are common to those with Asperger's autism. The "executive" functions of short-term memory and organizational ability continue to hamper him in school. Sometimes my wife, Lisa, and I worry that when he goes out into the world, Brian may have difficulty maintaining a job or remembering to take his very important "vital to his well-being" medications. It is sometimes more difficult for us than it is for him. However, last year, the

persistent drumbeat at school to perform and to be prepared to go out into the "real world" drove him into a state of emotional turmoil. I responded twice to meltdowns at school. To finally convince him that he was going to be fine took plenty of reassurance from us, his psychologist and his excellent group of supporters at Olathe North. Autism, regardless of the level of severity, is best faced with support.

At the JCCC autism conference, I gained insight into the diversity found in the autistic population. There are significant variations along the autism spectrum, but no two autistic people are alike. The running joke is, "if you've met one autistic person, you've met ONE autistic person!" There are strong differences of opinion about the cause of autism. Some people believe that they have found the cause in sensitivity to various nutrients. Still others attribute it to vaccinations or the preservatives that were at one time used in them. Most authorities simply assert that we really don't know the root cause, or causes, of autism.

Autistic children, in particular, are treated much differently than they were between the 1950s and 1970s. Once viewed as a form of psychosis, we know now that autism spectrum disorders are the result of a wiring variation within the brain. There seems to be a degree of heritability, primarily through



*Brian and Bill Buese*



the male line. Treatment once included electroshock therapy, institutionalization and isolation from parents. Adult autistics often languished in institutions, lived at the margins of society, or found themselves in prison. Humane and effective methods continue to be developed to help people with autism reach their personal potentials. Accommodations at work or school help ameliorate an autistic person's hyper-sensitivities to environmental stimuli and so improve concentration and optimize learning. Autistic people are often visual learners, so visual teaching methods are used. Social skills are modeled for autistic people by their teachers, therapists, age peers and parents. Some nonverbal autists are able to use keyboards to communicate. Others are affected so severely that their ability to communicate is significantly and permanently hampered. Social interaction can be difficult for all people with autism, but the depth and severity of the condition in some may seriously limit their ability to become independent adults. Others, less affected, integrate well into most social and work environments. These folks live independent, productive and fulfilling lives. The condition can, to varying degrees, change over time as the person matures and continues to gain experience. But autism never goes away. Autism is managed by the person himself, often with the assistance of a support network.

There are strong opinions held by members of various autism advocacy groups. For instance, the Autism and Asperger's Self-Advocacy Network, whose motto is "Nothing about Us, Without Us," encourages autistic people to advocate for themselves in schools and workplaces. AASAN also combats negative attitudes and stereotypes about autism. Another prominent organization, Autism Speaks,

assists parents and educators of people with autism, offering a constellation of supports and resources. Accurate, scientifically sound information about autism is a major emphasis, along with facilitation of research efforts around the world. Autism Speaks works to encourage close cooperation among all autism advocacy groups. Both organizations advocate societal and political action for the betterment and understanding of people with autism spectrum disorders.

As with other so-called minority groups, autistic people (and those close to them) are not monolithic in their outlooks. Some believe "people first" language is appropriate and state "I am a person with autism." Others feel that the label has saved them when they were properly identified, finally, and subsequently received appropriate assistance. These folks usually prefer to say "I'm an autistic person." A few like the term "autist." Some believe that communication is the primary problem with being autistic. Their goal is to create a communication environment so autism-friendly that all autistic people may participate more freely in society. Still, some have grown-up autistic children who will never be able to function well in the wider society in spite of their ability to communicate fairly well. One parent at the JCCC conference lamented that "My kid can't talk, and I don't read minds. So how am I supposed to teach our child to speak up for herself?" For her, a cure might be the foremost advocacy goal.

Autism manifests itself along a broad spectrum. Like any group of people, sometimes their commonalities define them. At other times, it is their differences. For autistic people, their journey into inclusion is well underway, but with a ways to go.