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The Board of Directors  
The Asperger's Society of Ontario

Dear Directors:

**Re: the removal of Asperger's Syndrome as separate from Autism in DSM V**

On CBC radio one morning recently, a member of the Asperger's Society of Ontario was being interviewed. The interview was with regard to news that the term "Asperger's Syndrome" was to be dropped from the forthcoming DSM V. Everyone would be covered under the heading of ASD [Autistic Spectrum Disorder], rather than making the distinction of that part of the spectrum now referred to as Asperger's Syndrome. I want to add my support to her campaign to retain that label in DSM!

Who am I? In short, I have been a professional engineer at AVRO aircraft, an Anglican parish priest, and the head of a mathematics department and senior physics teacher at a High School. Now, at seventy-nine years of age, I believe that I am a 'mild Asperger'. I was probably much less 'mild' when I was younger!

How did I come to self diagnose as an Asperger? I have a 'step' grandson, Bryce, who is 'forty plus' years younger than myself. About fifteen years or so ago, Bryce remarked that we had a lot in common, and he was self diagnosed as having Asperger's syndrome. We have grown to be very close. He pointed me to Simon Baron-Cohen's book, "The Essential Difference" which in multiple readings I found indeed a lot of traits that truly fitted. Then I acquired Temple Grandin's books "Unwritten Rules of Social Relationships" and 'Thinking in Pictures'. Again, many similar points became obvious. The final touch was Tony Attwood's book 'The Complete Guide to Asperger's Syndrome'. When Bryce said "We are birds of a feather", he was right. We have many interests in common and mutual affection. Bryce has both lent his support to my writing this letter, suggested changes that I have made, and enthusiastically endorses the letter. One day I mentioned to my wife Doreen that when an Asperger is asked a question, he or she often looks aside from the face of the questioner in order to concentrate on his thinking. She said that I do that regularly, sometimes puzzling the questioner. Should you want more of my background, please read the addenda. I will not bore you with a list of symptoms!

**Our message:**

**Labels:** I am concerned by putting a 'label' on a person or categorizing someone without great care. On the one hand it affects the person so labelled when they are aware of it; on the other hand it affects those who so label the subject, When a teacher applies a mental label to a pupil, the teacher will probably unconsciously treat the student differently than the others, and that in turn will affect the performance and the demeanour of the student. Conversely, a student who knows that a label has been applied to him will be affected.

And what could happen if the label is changed from Asperger's to Autism? A more frightening label by far! This not meant to say that Asperger's Syndrome is *not* a subset of the ASD, but that the differentiation is of importance!

For example, I was given a class with a poor self image in my first year of teaching, and they had been responsible for the departure of the previous math and physics teacher! Fortunately, I treated them with respect. They in turn showed respect for me, and so affected my image in the school very positively, including students, teachers and the principal. Some of the students saw me as something of Mr. Spock, my favourite character in Star Trek. I became the head of mathematics and the senior physics teacher. The students knew that I cared about them, even if I did not display emotion or raise my voice.

**What's in a name?** Again, a name or label such as Asperger's Syndrome [AS] given by a clinician to a person is bound to affect him both in his own eyes and in the eyes of those around him, whether students, teachers, psychologists, psychiatrists, etc. Even those who would use DSM V may be unknowingly affected, but those being treated, their families, and the general public, will, I believe, be much more affected, and affected negatively!

The label of Asperger's Syndrome or AS may actually be a relief to some, particularly if they have talents that can be encouraged. People who understand the nature of AS may assist 'Aspies' in social relationships, employment, working with their teachers, and so on. On the other hand, as Temple Grandin points out, sometimes labelling backfires. An official diagnosis may result in attempts to convert the AS person into a reasonable facsimile of an NT or 'neurotypical', at the same time reducing opportunities for that person to grow in those sectors where he is good, excellent or even brilliant! Some teachers and school systems may hold him back; other may indeed help him towards a good future.

The 'Aspie', perhaps undiagnosed, may become close to a mental breakdown because of the energy expended to live and work with NT's; people would come in bad shape to Simon Baron-Cohen because every day meant a tremendous amount of emotional 'work' trying to 'fit in' with others as far as possible. A secondary problem is that the label can become a confining 'shell'. A shell can give some sense of security, but on the other hand even a tortoise has to stick his head out to go anywhere, and if he sticks it out at the wrong time he may get stepped on, so to speak. A good mentor can be invaluable. Personally, I knew that I was to some extent different, but there was no knowledge of AS when I was growing up. Consider the 'bumble bee'; it was said that the bumble bee theoretically cannot fly, but, not knowing that fact, it flies happily along. I was a bit like that, and with God's help mediated by friends and my wonderful wife, I just kept moving on, even if it was rough at times.

Now, in my opinion, the removal of the term Asperger's Syndrome and simply referring to different positions on the Autistic Spectrum Disorders could be disastrous! The public, and, unconsciously, many clinicians and counsellors, will have an image of autism that would be damage many AS individuals.

Members of the public who are informed of both the negative aspects and the positive aspects of AS may be very helpful. As they learn of the sometimes great potential of an individual 'Aspie', they may help that individual to reach his potential. Similarly, the AS person [an 'Aspie'] may be emboldened to move ahead towards a satisfying life and

make a real contribution to the community. But referring to him as being autistic and it may well be damaging and limiting!

The effect, even if unrecognised, on TV depictions also vary greatly in their depiction of people who have Autism or Asperger's Syndrome. The other night I saw a person labelled as an Asperger in a weekly crime programme. He was considered very intelligent but very dangerous. Many people might then **tend** to view all reference to Asperger's in a negative manner, without a clue to the great achievements of many with AS.

*Change the label to Autistic, and you add confusion to ignorance* when you are dealing with that part of the spectrum which includes Aspies. The effect on the Asperger himself is equally problematical. Coping with the label of Asperger's may create problems, but reference to 'high functioning autistic' is likely to make it much harder to be accepted and to accept one's position, without leaving as much hope for a fulfilling life as the label 'Asperger's' does!

What's in a label? A tremendous amount! The future can depend on it.... Bryce and I certainly hope that the term Asperger's Syndrome remains as a subdivision on the spectrum when DSM V is published. This may not seem much to a non 'Aspie', but does to those who are Aspies and to those who are relatives, teachers, clinicians, and so on.

#### **In closing:**

Having listened to the broadcast, and being of a varied background and having a degree of understanding what it means to be somewhere on the spectrum, even 'mildly', I feel that it is incumbent on me to add even this small amount of support. Bryce echoes my sentiment. We do hope that our effort to support you in this will be of some value. Copies of this letter are being sent to Autism Ontario and to the Autism Society of Canada.

With best wishes,  
Sincerely

Don Wilson

#### **Addenda**

##### **Who am I to comment on this matter?**

Why should my opinion carry the slightest bit of weight? Born in 1931, I lived with relatives most of the time until my mother recovered sufficiently from depression to come home. I was five and a half at that time. Starting at kindergarten, where I was almost a year older than most, was undersized and had no experience of children of my own age, I was bullied after being paraded to read in front of other classes by the principal. I made one school friend in the K-Grade 4 years, and I became an aircraft/aviation addict. From grade 5 to 8, I was in another school, where I made one 'life long' friend who entered the field of aviation thanks to my enthusiasm. I couldn't play sports, because of asthma and an inability to cope with multiple input and noisy instructions. I had, I believe, the top marks in some subjects at graduation. I avoided sports and girls. Essentially, I was a 'loner'.

At High School, grades 9-13, while derided by some teachers, I was greatly encouraged by the chemistry teacher, and graduated from Grade 13 with the General Proficiency Award [minus the course in physical education]. I only know one nickname that I acquired during that time: I was called 'Prof' after starting to explain the compressibility effect in a grade ten science class. A student asked the lady teacher to explain what was meant by the sound barrier, and I put up my hand when she said that she couldn't, and she let me speak. She soon stopped me and told the class not to ask me about it, since she didn't understand what I said and therefore they would not understand either. When travelling home on a bus from university, I heard a loud "Prof!" from behind; it was a former fellow classmate.

A model aircraft shop opened up a block from home, and introduced me to other modellers. The hobby shop owner treated me like a nephew and took me under his wing. After a few years he even asked me to manage his shop on Saturdays! Years later, as an Anglican priest, I buried him, stating that he had taught me "morality without pomposity".

Encouraged by the chemistry teacher and my father, I worked a year to gain funds, applied to McGill in Engineering, was accepted and was given a scholarship after the first year. I graduated near the top of my class. Then I went to work as a professional engineer at AVRO Aircraft, working on the Arrow jet fighter and learning to fly a small aircraft. Most of my friends were by then married. Again, I was a 'loner'.

After two years the Lord called me out of engineering into seminary, where I graduated with the top marks academically, although I took virtually no part in student affairs. I believe that the bishops thought that my B.Eng. from McGill meant 'Bachelor of English'! While at seminary I met my wonderful wife of fifty years! A doctor said this year that she must be a saint for having put up with me for that length of time. I agreed.

Apart from the Christian faith and aviation, subjects such as cosmology, space-time, quantum mechanics, black holes and string theory are *among* my interests. Others include matters of global warming and social justice.

After a few years in parish work, I needed a break from the stress, took a leave of absence, and became the head of mathematics and senior physics teacher at a small secondary school, while occasionally preaching for different denominations. Some students thought of me in terms of Mr. Spock, my favourite character in Star Trek. After nine years, I returned to full time ministry, and was forced to retire at sixty years of age on disability due to severe asthma and Malignant Hyperthermia.

Without the grace of God and the support of many people, and in particular that of my wife Doreen during our fifty years of marriage, I would never have reached this point and grown in cognitive empathy as well as having some affective empathy. My younger daughter, a psychiatrist, wrote one time, saying that she was proud to have a father who had done so many things and done them well. I give thanks for my loving family and the friendship of many people.

Don Wilson