

## **ABOUT ME**

I am a 54-year-old with Asperger's who is employed and reasonably integrated into society. I was diagnosed at 40.

I write about autism issues and speak internationally

I have a large online community that is actively discussing autism issues

My 21-year-old son also has Asperger's

I serve on various autism science and treatment review boards including Autism Speaks, INSAR, NIH, CDC and several universities

My books *Look Me in the Eye* and *Be Different* have been translated into over 20 languages and are sold in over 60 countries.

There is no such thing as a spokesman for the autism community.

The opinions expressed today are strictly my own.



# **ABOUT AUTISM**

- Autism is a spectrum disorder. People with autism can be broadly divided into three groups:
- 1 People with non-verbal communication impairment, but good ability to speak and understand language. I will call this the Asperger group.
- 2 People with more generalized communication impairment including significant language challenges. I will call this the autism group.
- 3 People with generalized communication challenges and significant comorbid conditions. I will call this the severe autism group.
- The degree to which a child is disabled by autism depends in large measure upon the severity of their autistic impairment.
- By the time autistic children become adults they will have developed coping skills which mask some of their autistic disability





## **COMMUNITY - SELF ADVOCATES**

- The degree to which an adult is disabled by autism is determined by many factors the most important of which is general IQ. People with higher IQ are better able to develop and implement coping strategies to mask disability.
- As adults, many of us "look and sound normal," yet we struggle disproportionally with relationships and jobs. Our opinions are often shaped by repeated social failure.
- In the autism world, we talk a lot about self-advocacy. However, the only autistic people able to self-advocate (in meaningful numbers) are those least impaired. There are some noteworthy exceptions online, where the typed mode of communication levels the playing field for those who do not speak.
- That tends to bias the self-advocate's discussion toward issues relevant to the Asperger population to the exclusion of more severely impacted individuals.

Self advocates tend to focus on work, relationships, and independent living.



## **COMMUNITY - PARENTS**

The most vocal parents tend to be those with severely impacted children, but there are active parents with children at all points on the spectrum.

Most active parents have children 5-15 years old.

- Parents tend to focus on basic social skills, and successful progress through school.
- Ideally, parents and children share a generalized goal of happy, healthy, productive and independent lives. Since parents and children are unique individuals, each affected differently by autism, they may have differing views of how the autistic person should conduct his life, even though the general goal is the same. That's especially true when the autistic person is older.



## **COMMUNITY - SCIENTISTS**

- Until quite recently the major emphasis in autism science was in genetics and other low-level work. Valuable as that work is, most of it has no quality of life impact for autistic individuals living today.
- Geneticists and biologists may tend to focus on severe autism because its effects can be modeled in animals. There are no animal models for Asperger's.
- We need to draw researchers from many other disciplines into autism research.
- Medical researchers must keep their ethical obligation to today's autistic population in mind.



#### HOW AUTISM AFFECTS US

Autism is at its heart a communication disorder. One practical manifestation of that is that autistic people have an inherent difficulty recognizing and accepting other points of view.

There is a tendency to feel "my way is the only way."

We may also believe "I have trouble with x, so x is the primary problem to be solved by autism scientists."

Organizing our thoughts and keeping ourselves focused and on track can be tremendously challenging. When we fail at that, our lives feel out of control. The result – fear and anxiety.



### HOW AUTISM AFFECTS US

Autistic people have difficulty interpreting signals from other people. We may not recognize sarcasm, or we may be easily misled. Our logical interpretation of a situation may be totally different from other people's emotional assessment, leaving us "in the wrong." The result – fear and anxiety.

The principal emotion felt by autistic people is fear. When you have difficulty understanding the world around you, it is natural to be fearful. Autism limits our ability to understand certain dynamics. We may withdraw, or defend ourselves by becoming angry and aggressive. That can shape our engagement with the world in counterproductive ways.



#### HOW AUTISM AFFECTS US

Many autistic people also suffer from organization and focus issues (ADHD), anxiety, and depression.

Our social challenges lead to frequent and sometimes continuous social failure. This translates into unwanted isolation, generalized loneliness, failure to form and sustain romantic relationships, and failure to get and keep a job. The result – depression, anger, withdrawal.



## **RESEARCHERS – KNOW YOUR CUSTOMER!**

Autism researchers must remember that their ultimate responsibility is to the autistic individuals, not their parents or guardians. In the end, everyone involved in autism research should be working toward the goal of improving quality of life and remediating disability for those on the spectrum.

The older a severely autistic person is, the more likely his own wants and needs are to be at odds with those of his guardians.

A less impaired autistic person may have no desire to change his behavior while those around him express strong desire for change.

This reality offers the potential for ethical conflict with autistic research subjects, when the research involves the possibility of cognitive changes.



## THE "OTHER PERSON" IN AUTISM

Substantially all current autism research is directed toward improving quality of life for the autistic individuals.

Should we be funding research into quality of life issues for families and caregivers?

There is a great deal of guilt, frustration, and anger among parents. Should we be looking at ways to moderate those destructive feelings?



# **ETHICS OF INFORMED CONSENT**

When experimental therapies or treatments change cognitive function there is the possibility that effects will go well beyond what researchers envision. For example, if a subject does better recognizing faces on a screen, his success interacting in the real world may be changed, with unforeseeable results.

How do we present this when obtaining consent? Is it risk or opportunity?





## **ETHICAL ISSUES – ADULT STUDIES**

It's common for studies to say, "Looking for research subjects with an autism or Asperger diagnosis . . ."

That's fine when working with school age children

What happens when we study middle aged adults, most of whom never got a formal diagnosis?





# **ETHICS OF DIAGNOSIS**

For children, diagnosis is usually necessary to gain access to critical services. For adults, an opposite situation may prevail. A diagnosis may subject adults to higher insurance rates, exclusion from employment, etc.

- An on the record diagnosis may be a godsend for parents of a child, but a curse for autistic adults who are trying to make their own way.
- If diagnosis is done as part of a study, should it become part of the medical record?
- Should adults be able to keep an autism diagnosis private? (not in record)
- Should adults be entitled to counseling; how to handle diagnosis?



## **EUGENICS – THE SELF ADVOCATE'S FEAR**

- The perceived threat genetic testing will lead to the deliberate elimination of autistic people.
- Scientists say prenatal testing will facilitate early intervention, with potentially dramatic results.
- Critics fear pregnant women will get a test and decide on an abortion instead of prolonged and possibly unsuccessful treatment of a "broken" baby.
- I believe the development of genetic autism tests is inevitable. What can we do to prepare for that day?
- We can develop statistics for the effectiveness of intervention. That will be a key decision making tool for parents.
- We can begin a campaign to educate the public; show that abortion is not the only reason for tests.





# THE FUTURE OF AUTISM

The real threat today – new studies show parents with one autistic child are far more likely to have additional children with autism. Parents with autism and one autistic child are at even greater risk. That news will have significant family planning impact.

As recently as five years ago autism was described as a rare, random event. Parents with one autistic child often went on to have more children.

Today, in light of current studies, many parents stop having children altogether.

With no genetic testing, just knowledge of family history, we can identify certain groups whose odds of having more autistic children are high

Genetic testing will allow us a higher degree of confidence in making predictions.

What can/should we do with this knowledge?





# THANKS FOR LISTENING

I invite you to continue this discussion in my online communities:

www.facebook.com/JohnElderRobison

Jerobison.blogspot.com

My speaking schedule is online at: Johnelderrobison.blogspot.com

