

Autism and Autism Spectrum Disorders (ASD)

The Heartbreaks
and the
Victories

The origin of the word Autism

- "The word Autism is from the Greek word meaning self."

- Freedman, G. & Legnitto, Jan (Producers/Writers/Directors). (1996). Breaking the Silence Barrier [Videotape]. (Available from Films For The Humanities & Sciences, Box 2053, Princeton, NJ 08543-2053)

What is Autism and ASD?

- "Autism is a complex brain disorder that inhibits a person's ability to communicate and develop social relationships and is often accompanied by extreme behavioral challenges."
- Autism speaks. (2007). Home page. Retrieved February 17, 2007. from autism speaks Web site:
http://www.autismspeaks.org/press/pennsylvania_autism_bill.php

What is Autism and ASD? continued

- "The essential features of Autistic Disorder are the presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests. Manifestations of the disorder vary greatly depending on the developmental level and chronological age of the individual. Autistic Disorder is sometimes referred to as early infantile autism, childhood autism, or Kanner's autism."
- American Psychiatric Association. (2000). DSM-IV-TR Washington D.C. Author.

What is Autism and ASD? continued

- "One person with autism may have very different symptoms and behaviors than another. Because of these differences, doctors now think of autism as a 'spectrum' disorder, or a group of disorders with a range of similar features. A person with mild autistic symptoms is at one end of the spectrum. A person with severe symptoms is at the other end of the spectrum. Because of this, autism is now often called autism spectrum disorder (ASD)."
- Kyle's tree house. (2007). Home page. Retrieved February 17, 2007. from Kyle's tree house Web site:
<http://www.kylestreehouse.org/whatisautism.cfm>

The following diagnoses can fall into the category of ASD and yet, each diagnosis has specific diagnostic criteria in the current DSM.

- Autistic disorder
- Asperger's syndrome/disorder
- Childhood disintegrative disorder (CDD)
- Rett syndrome
- Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) or atypical autism

- Kyle's tree house. (2007). Home page. Retrieved February 17, 2007. from Kyle's tree house Web site:
<http://www.kylestreehouse.org/whatisautism.cfm>

What causes Autism and ASD?

- Autism used to be thought to be caused by cold or bad mothering.
 - Thankfully, that myth has been discarded.
 - What exactly causes Autism and ASD is still unknown however. Many researchers now think it may be genetic because it tends to run in families. Some parents still insist it is caused by mercury/vaccinations due to the onset often correlating with the timing of receiving the childhood series of vaccinations.
- Many theories are out there (e.g. environmental, prenatal or postnatal exposures, and etc.)
- Right now Autism is treated without the knowledge of what causes it.
 - Further research is needed.

Symptoms of Autism

- Exclusivity/lack of significant peer-to-peer relations such as:
- Repetitive and self-stimulating behaviors.
- Lack of consistent eye contact
- Low attention span for human interactions

Symptoms of Autism continued

- Developmental delays.
- Language challenges.
- A deficit in self-help skills.
- Academic disinterest or excellent academic achievement.
- Injurious behaviors (to self or others).

- Kyle's tree house. (2007). Home page. Retrieved February 17, 2007. from Kyle's tree house Web site:
<http://www.kylestreehouse.org/whatisautism.cfm>

Symptoms vary

- Not only does the degree of symptoms vary from person to person, so does the number of symptoms an individual has. Each case, or more importantly, each person is unique.

Treatments vary

- Treatments and interventions for autism vary greatly and those who serve the autistic and their families tend to favor one over all the others.
- For parents, this tends to equate to seeking different professionals and treatments at many different facilities.
- To complicate things further, one treatment or intervention may work for one child but not another (even within the same family).
- Often families have tried many different treatments and interventions before they find what works for their child or adult.

- “One of the biggest challenges facing parents with autistic children is finding good, reliable information about the many treatments out there.”
- Furthermore, for the parents to find the time to do the necessary research in order to find the right treatment while caring for the autistic child is extremely challenging in and of itself.
- Kyle’s tree house. (2007). Home page. Retrieved February 17, 2007. from Kyle’s tree house Web site:
<http://www.kylestreehouse.org/whatisautism.cfm>

A partial list of treatments and/or interventions

- Applied Behavioral Analysis (ABA)
- Training and Education of Autistic and Related Communication Handicapped Children (TEACCH)
- Floortime
- Occupational Therapy
- Relationship Development Intervention (RDI)
- Sensory Integration Therapy
- Speech Therapy
- Gentle Teaching

A partial list of treatments and/or interventions continued

- Verbal Behavior Intervention
 - Facilitated Communication
 - Holding Therapy
 - Auditory Integration Therapy
 - Dolman/Delcato Method
 - And more...
-
- Autism speaks. (2007). Home page. Retrieved February 17, 2007. from autism speaks Web site: http://www.autismspeaks.org/press/pennsylvania_autism_bill.php
 - Kyle's tree house. (2007). Home page. Retrieved February 17, 2007. from Kyle's tree house Web site: <http://www.kylestreehouse.org/whatisautism.cfm>

That is not the end of the search for parents however

- Finding experienced professionals to diagnose autism can be challenging.
- Finding qualified staff to teach/apply a treatment or intervention in an area where a child lives can be challenging.
- Furthermore, finding qualified staff to teach/apply a treatment or intervention correctly can be challenging because many treatments have new or revised methods of treatment and training can be outdated.

Challenging is the key word

- As you will see in this clip, utilizing ABA challenges the autistic child to their limits, challenges the patience of the teacher, and even can generate controversy.
- Here is just an example the heartbreak and the victory in dealing with autism.
- The video I am showing you is an example of ABA.

For parents, this small progress is a huge victory

- (2001). Autism and Applied Behavioral Analysis. [Videotape]. (Available from Films For The Humanities & Sciences, Box 2053, Princeton, NJ 08543-2053)

Autism and ASD is increasing

- It is not yet known why the autism and ASD diagnoses have increased in recent years. Prevalent thinking is that the awareness and the understanding Autism and ASD of has increased so diagnosing has also increased
 - or
- because the cases of Autism and ASD have actually increased
 - or both of the above
- or
 - something yet unknown to us.

The latest statistics

- Autism Speaks reports that, "Autism Spectrum Disorders are diagnosed in one in 150 children in the United States [alone], affecting four times as many boys as girls. [that is 1 in every 94 boys affected]. The diagnosis of autism has increased tenfold in the last decade. The Centers for Disease Control and Prevention have called autism a national public health crisis...."
- The above statistics (if accurate) makes the commercial stating 1 in 166 children are diagnosed with Autism already obsolete information. That is how quickly things can change.
- Autism speaks. (2007). Home page. Retrieved February 17, 2007. from autism speaks Web site: http://www.autismspeaks.org/press/pennsylvania_autism_bill.php

Other Victories

- "Harrisburg PA (April 18, 2007) Autism Speaks Co-founders Bob and Suzanne Wright, along with Executive Committee Member and Cure Autism, now founder Jon Shestack and actor and advocate Joe Pantoliao, today joined with leaders of the Pennsylvania legislature as they announced the introduction of landmark autism legislation. The bill, introduced by House Speaker Dennis O'Brien and co-sponsored by Senator Jane Orie, would create a new 'Autism Spectrum' provision of the Pennsylvania insurance law. This provision would require private insurers to provide coverage of up to \$3,000 per month for essential early intervention services and therapies for individuals with autism, including, 'behavioral interventions' based on the principles of applied behavioral analysis and related structured behavioral programs for up to 40 hours a week."
- Autism speaks. (2007). Home page. Retrieved February 17, 2007. from autism speaks Web site: http://www.autismspeaks.org/press/pennsylvania_autism_bill.php

More needs to be done

- "Gary Goldstein, M.D. is a child neurologist and president of Baltimore's Kennedy Krieger Institute. Kennedy Krieger's Center for Autism and Related Disorders offers one of the nation's most comprehensive programs for the diagnosis, research, and treatment of autism spectrum disorders. Dr. Goldstein is the clinical scientific advisor to Autism Speaks."

Dr. Goldstein says:

- The current focus of research is threefold, “genetics, environmental triggers, and brain imaging technology.”
- A potential additional area of research is “prenatal and postnatal exposures like diet or chemicals.”
- “clinical trials are needed”

Dr. Goldstein says continued

- Millions of dollars have been raised and millions more are needed.
- "It's absolutely necessary to have more trained professionals who can work with autistic children."
- "We will most likely find subtypes of autism that will respond to treatment, and others that will take longer. The brain is so mysterious, and the disease is so baffling. It will be a slow process." But will we find a cure? Dr. Goldstein states, "ABSOLUTELY"
- Autism speaks. (2007). Home page. Retrieved February 17, 2007. from autism speaks Web site:
http://www.autismspeaks.org/press/pennsylvania_autism_bill.php

What is needed yet

- Much is needed (research and professionals who specialize in autism, respite for parents, and etc.) but right now one of the things that is needed most is public awareness to initiate public understanding of the disorder as well as the increasing prevalence of it.
- Awareness initiates public support (financially and emotionally).
- Public awareness pushes the government for funding and substantiates governmental funding.

- I hope I have done my small part to help increase public awareness.
Thank you for your time.
- Wendy Gochnauer