

Adult Transition for Those with Autism

Kevin T. Blake, Ph.D., P.L.C.

Tucson, Arizona

PESI, Inc.

Eau Clair, Wisconsin

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Disclaimer

“Materials that are included in this course may include interventions and modalities that are beyond the authorized practice of mental health professionals. As a licensed professional, you are responsible for reviewing the scope of practice, including activities that are defined in law as beyond the boundaries of practice in accordance with and in compliance with your professions standards. “

Disclaimer

- None of the techniques described in this seminar will work for all adults with AD/HD. Every adult with AD/HD is different.
- There are no absolutes.
- All treatments have negative side effects. Some more than others. The presenter will do his best to cover the most common ones.
- The theories described in this seminar do not have the same amount of empirical evidence supporting each one of them. The presenter will do his best to describe the pros and cons of each.
- If you are concerned about a treatment technique described in this seminar ask the presenter about it.

Disclaimer

- **Speaker Disclosure:**
- **Financial:** Kevin Blake maintains a private practice. He is a stockholder in Johnson & Johnson, Inc. and Amgen, Inc. Dr. Blake receives a speaking honorarium from PESI, Inc.
- **Non-financial:** Kevin Blake is a member of the Children and Adults with Attention Deficit Disorders (CHADD), International Dyslexia Association, Learning Disabilities Association, and American Psychological Association.

Good Primers on ASD Transitioning

2018 07 14

Good Transitioning Primers for ASD Students

Baker, J. (2005). Preparing for Life: The Complete Guide for Transitioning to Adulthood for Those with Autism and Asperger's Syndrome. Arlington, TX: Future Horizons.

Autism Speaks

Family Services

Transitions Tool Kit

**Download free from
website:**

http://www.autismspeaks.org/docs/family_services_docs/transition.pdf

Autism Spectrum Disorder

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Autism Spectrum Disorder

People who were diagnosed with Asperger's disorder, autism, pervasive developmental disorder, and pervasive developmental disorder-not otherwise specified using DSM-IV®/DSM-IV, TR® criterion have autism spectrum disorder by DSM-5® criterion. Those with social communication problems only have social (pragmatic) communication disorder.

Author (May 18, 2013). Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). Washington, DC: American Psychiatric Association, 70.

Autism Spectrum Disorder is NOT New!

“People have probably lived with what we know today as autism spectrum disorders throughout history. Some of the earliest published descriptions of behavior that sounds like autism date back to the 18th century. But the disorder did not have a name until the middle of the 20th century.”

Centers for Disease Control and Prevention. Autism Information Center.

<http://www.cdc.gov/ncbddd/autism/overview.htm#is>

ASD's Central Difficulty

“Regardless of the diagnosed person’s global intelligence, savant-like talents, verbal ability, or mechanical giftedness, social difficulties are the primary source of impairment for most people with ASD and central to the diagnostic criteria of ASD” (p. 124).

White, S.W. et al. (2013). Multimodal Treatment for Anxiety and Social Skills Difficulties in Adolescents on the Autism Spectrum. . In A Scarpa, S.W. White, and T. Attwood (Eds.), CBT for Children and Adolescents with High-Functioning Autism Spectrum Disorders. New York, NY: Guilford.

What does **NEUROBIOLOGICAL** mean?

- “The latest thinking in this area is that ASD is a developmental neurobiological disorder, meaning that a variety of developmental changes occur in the brains of people with this disorder” (p. 5).
- At present few workers in the field of ASD believe that psychological or social influences play a major role in the development of this disorder” (p. 40).

Durand, M.V. (2014). Autism Spectrum Disorder: A Clinical Guide for General Practitioners. Washington, DC: American Psychological Press.

- “The field has come a long way since parents were considered to be the cause of autism spectrum disorders.” (p. 64)*

*Ozonoff, et al. (2002). A Parent’s Guide to Asperger Syndrome & High Functioning Autism. New York, NY, Guilford.

Kaiser, M.D., et al. (November 15, 2010). Neural Signatures of Autism. Proceedings of the National Academy of Sciences of the United States of America (PNAS). 7(107), 21,223-21228.

Autism and Genetics

“Autism (Spectrum Disorder, sic) is known to be a genetic disorder, at least in part.” (p. 2 of 3)

Author (No Date). Fact Sheet: Study to Explore Early Development (SEED). Center for Disease Control and Prevention. From website:
<http://www.cdc.gov/ncbddd/autism/states/new/CA/DDRE%20Fact%20Sheet%20July%202007.pdf>.

“It is now abundantly clear that ASD has a genetic component, with the best evidence suggesting moderate genetic heritability” (p. 41).

Durand, M.V. (2014). Autism Spectrum Disorder: A Clinical Guide for General Practitioners. Washington, DC: American Psychological Press.

There are 239 likely candidate genes for autism.

Issifove, I. et al. (October 13, 2015). Low load for disruptive mutations in autism genes and their biased transmission. Proceedings of the National Academy of Sciences of the United States of America (PNAS). DOI: [10.1073/pnas.1516376112](https://doi.org/10.1073/pnas.1516376112).

Autism & Genetics

- Of the 200 + genes related to autism about 70 are directly related to brain development
- The remainder are related to,"...psychiatric disorders and peripheral comorbidities that include cancer, cardiovascular disease, renal disorders, respiratory disorders and metabolic disorders, demonstrating a broader impact of brain-associated genes in other developing organ systems..."

- Some of these may be related to random errors of metabolism and/or mutations in mitochondrial DNA as well as unusual gut microbiomes that can negatively effect the brain.

--Stevenson, J.A. et al. (October 20, 2015).

- 40% to 70% of ASD population has significant GI problems

--Buie, T., et al. (November 7, 2014).

- About 7% of those with ASD have mitochondrial disease

--Korson, M., et al. (November 7, 2014).

- Recently scientists have discovered through brain imagery that brain has a lymphatic system. This caused the scientists postulated may indicate disorders like autism may have some link to inflammation.

--Louveau, A., eta al. (June 1, 2015).

References

Stevenson, J.A. et al. (October 20, 2015). The genetic intersection of Neurodevelopmental disorders and shared medical comorbidities-relationships that translate from bench to bedside. Paper presented at The Society for Neuroscience Annual Meeting, October 12-17, 2015, Chicago, IL, Program number: 490.11/E12.

Buie, T., et al. (November 7, 2014). Gastrointestinal Comorbidities of Autism Spectrum Disorders. Webcast; Cleveland Clinic Center for Continuing Education. From website: <http://www.clevelandclinicmeded.com/online/autism-spectrum-disorders/>.

Louveau, A., et al. (June 1, 2015). Structural and functional features of central Nervous system lymphatic vessels. Nature. DOI: 10.1038/nature14432.

Neuroanatomy of ASD

- Increased grey matter anterior temporal & dorsolateral prefrontal lobe
- Decreased grey matter occipital and medial parietal areas
- Significant reduction in size of cerebellum (fewer Purkinje cells)

Ecker, C., (February 8, 2012). Brain Anatomy and Its Relationship to Behavior in Adults With Autism Spectrum Disorder: A Multicenter Magnetic Resonance Imaging Study. Archives of General Psychiatry, 69(2), 195-209.

Durand, M.V. (2014). Autism Spectrum Disorder: A Clinical Guide for General Practitioners. Washington, DC: American Psychological Press.

- Large grey matter differences in the following:
 - cingulate, motor area, basal ganglia, amygdala, inferior parietal lobe, prefrontal lobe
- Reductions in white matter volume
- These differences are linked to autistic symptoms and persist throughout life.
- Estimates are 38% of those with ASD have intellectual disabilities

Durand, M.V. (2014). Autism Spectrum Disorder: A Clinical Guide for General Practitioners. Washington, DC: American Psychological Press.

Compassion



Compassion

- **Three things make humans behaviorally different from all other species:**
 - **Our capacity to delay our response to our environment (Bronowski, 1977).**
 - **Our capacity for compassion (Leakey, 1995).**
 - **Our capacity for long-term compassion (Grandin, 1995).**

Bronowski, J. (1977). Human and Animal Languages: In a Sense of Future. Cambridge, MA: MIT Press. pp. 104-131.

Leakey, R. (1995). Speech given to the National Press Club, Washington, DC, Played on National Public Radio.

Grandin, T. (1995). Thinking In Pictures: And Other Reports From My Life With Autism. New York, NY: Vintage.

Compassion

“In the summer of 1982 Kat was newly pregnant and Washoe doted over her belly, asking about her BABY. Unfortunately, Kat suffered a miscarriage. Knowing that Washoe had lost two of her own children, Kat decided to tell her the truth. MY BABY DIED, Kat signed to her. Washoe looked down to the ground. Then she looked into Kat’s eyes and signed CRY, touching her cheek just below the eye. When Kat had to leave that day, Washoe would not let her go. PLEASE, PERSON HUG, she signed.”

Fouts, R. (1997). Next of Kin: My Conversations with Chimpanzees. New York, NY: William Morrow.

Edwards, M. (Spring, 2000). Book Review. The Harvard Brain. From website: hcs.harvard.edu/~husn/BRAIN/vol7-spring2000/fouts.htm.

Compassion

Bonobo: Pan Paniscus Vs.

Chimpanzee: Pan Troglodytes

- Shares 98% of its genetic profile with humans.
- They have been compared to australopithecines
- “In physique, a bonobo is as different from a chimpanzee as a Concorde is from a Boeing 747.” (p. 3 of 14)

DeWaal, F.B.M. (March 1995). Bonobo Sex and Society. Scientific American. pp. 82-88. From Website: <http://primates.combonobos/bonobosexsoc.html>.

“Similar genetic variation in the human *AVPR1A* may contribute to variations in human social behavior including extremes outside the normal range of behavior and those found in autism spectrum disorders.” (p. 2187)

Hammock, E.A.D. and Young, L.J. (December, 2006). Oxytocin, Vasopressin and Pair Bonding: Implications for Autism. Philosophical Transactions of the Royal Society of Biological Sciences, 361 (1476), pp. 2187-2198. From Website: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1764849>.

Humans Vs. Chimpanzees Vs. Bonobos



Chimpanzee, Bonobos, Humans & Vasopressin

“Our two closest primate cousins – chimpanzees and bonobos –also have different lengths of this gene, which match their social behaviors. Chimpanzees, who have the shorter gene, live in territorially based societies controlled by males who make frequent, fatal war raids on neighboring troops. Bonobos are run by female hierarchies and seal every interaction with a bit of sexual rubbing they are exceptionally social and have a long version of the gene. The human version of the gene is more like the bonobo gene...”

“...It would seem that those with the longer version of the gene are more socially responsive. For example, this gene is shorter in humans with autism...” (p. 74)

Brizendine, L. (2006). The Female Brain. New York, NY: Morgan Road.

Interactive touch between humans can produce more oxytocin in the brain. It can even increase one’s level of trust.

Morhenn, V.B. et al. (November, 2008). Monetary sacrifice among strangers is mediated by endogenous oxytocin release after physical contact. Evolution and Human Behavior, 29(6), 375-383.

Teco, The Autistic Bonobo Toddler

- Bonobo social brain closer to humans than chimps.
- 18 month old bonobo, Teco, male is autistic.
- Has repetitive movements
- Strict adherence to routines, or gets agitated
- Repetitive behaviors
- Likes objects, not bonobos

- Likes parts of objects
- No joint attention
- Avoids eye contact
- At two months nursing difficulties

Deweert, S. (April 15, 2011). An Ape With Autism. New York, NY: Simons Foundation, Autism Research Initiative (SFARI). From website: <https://sfari.org/about-sfari/contact-us> .

Transgenic macaques show autistic symptoms.

Liu, Z. et al. (February 4, 2016). Autism-like behaviours and germline transmission in transgenic monkeys overexpressing MeCP2. Nature. DOI: 10.1038/nature16533.

What is Alexithymia?

1. **Tends not to have fantasies, no feelings and have sharply limited emotional vocabularies.**
2. **They have colorless dreams.**
3. **They cannot tell bodily sensations from emotions and are baffled by them.**
4. **They have great difficulty making decisions because they lack “gut feelings.”**

Goleman, D. (1995). Emotional Intelligence: Why It Can Matter More Than I.Q. New York, NY: Bantam.

Alexithymia



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Alexithymia

- Medial prefrontal areas explicit representations of the self
- Posterior superior sulcus detection of biological motion and representation of others
- Suggests the, "...ability to mentalize from a system for representing actions" (p. 1692).

Frith, C.D. and Frith, U. (1999). Intersecting Minds-A Biological Basis. Science, 286, 1692-1695.

- The medial prefrontal cortex allows for theory of mind
- *"...that successful social adaptation requires the 'dual task' ability to stay in touch with the needs of others while paying due attention to one's own needs." (p. 20)*

Lane, R. (2000). Neural Correlates of Conscious Emotional Experience. In L.R. Lane, et. al. (Eds.), Cognitive Neuroscience of Emotion. New York, NY: Oxford University Press, pp. 345-370.

Mirror Neurons

- Italian study of macaque monkeys in 1992
 - Known for years cells of premotor cortex fire just before movement.
 - Discovered that same cells fired in the same pattern when another primate was seen making the same movement!
 - Humans have these MIRROR NEURONS too.
 - They allow us to intuit others intentions and to feel their pain.

Rizzolatti, G., Fogassi, L. and Gallese, V. (November, 2006). Mirrors in The Mind.

Scientific American, 296 (5), pp. 54-61.

Lametti, D. (June 9, 2009). Mirroring Behavior. Scientific American, from website:

www.scientificamerican.com/article.cfm?id=mirroring-behavior.

Mirror Neurons

- **Mirror Neuron System:**
 - **Superior Temporal Sulcus**
 - **Inferior Frontal Cortex**
 - **Rostral Inferior Frontal Lobe**

--Goldstein, Naglieri, & Ozonoff, (2009).

- **Mirror Neurons:**
 - **Help us begin to generate appropriate social responses.**

Caggiano, V., Fogassi, L., Rizzolatti, G., Their, P., Casile, A. (April 2009). Mirror Neurons Differently Encode the Peripersonal and Extrapersonal Space of Monkeys. Science. 324 (5925), pp. 403-406; From website: www.sciencemag.org/cgi/content/abstract/324/5925/403.

“Studies show that the capacity to imitate the actions of others is now virtually an instinct at the level of neuronal functioning...The mirror-neuronal system has been linked to theory of mind and to empathy, among other human attributes related to EF (Executive Functions, sic.)” (p. 117).

Barkley, R.A. (2012). Executive Functions: What They Are, How they Work, and Why They Evolved. New York, NY: Guilford.

Mirror Neurons & Autism Spectrum Disorder

- “Broken mirror neurons” MAY explain isolation and lack of empathy.
- Those with autism spectrum disorder lack activity in many areas associated with mirror neurons.

Ramachandran, V.S. and Oberman, L.M. (November, 2006). Broken Mirrors. Scientific American, 296(5), pp. 62-69.

Uta Frith: Question Can you combine emotional working memory finding with mirror neuron research to explain ASD?

Answer: How do you explain a sociopath?

Frith, U. (November 1, 2007). Personal Communication. International Dyslexia Association 58th Annual Conference, Dallas, TX.

The Three Types of Empathy

- **Motor Empathy**
- **Cognitive Empathy**
- **Emotional Empathy**

Blair, R.J.R. (December, 2005). Responding to the Emotions of Others: Dissociating Forms of Empathy Through the Study of Typical and Psychiatric Populations. Consciousness and Cognition, 14 (4), pp. 698-718. From Website: www.sciencedirect.com/science?_ob=ArticleURL&_B6WD0-4H39727-2&_user.

- **Sociopaths:**
 - Excellent motor empathy
 - Excellent Cognitive Empathy
 - Poor Emotional Empathy
- **ASD**
 - Poor Motor and Cognitive Empathy
 - Better Emotional Empathy

Baron-Cohen, S. (2011). The Science of Evil: On Empathy and The Origin of Cruelty. New York, NY: Basic Books.

Mirror Neurons

“Our results show that this ‘mirror system’ integrates observed actions of others with an individual’s personal motor repertoire and suggests the human brain understands actions by motor stimulation” (p. 1243).

Calvi-Merino, B., Glaser, D.E., Greeze, J., Passingham, R.E., and Haggard, P. (2005). Action Observation and Acquired Motor Skills: An fMRI Study with Expert Dancers. Cerebral Cortex, 15 (8), p. 1243-1249.

Alexithymia and ASD

“...some individuals with ASD may experience characteristics of *alexithymia*, a diminished vocabulary to describe the different levels of emotional experience, especially the more subtle emotions” (p. 35).

Attwood, T, White, S.W., and Scarpa, A. (2013). CBT for Children and Adolescents with High-Functioning Autism Spectrum Disorders. New York, NY: Guilford.

Symptoms

- Difficulty identifying different types of feelings
- Difficulty distinguishing between emotional feelings and bodily feelings
- Limited understanding of what caused the feelings
- Difficulty verbalizing feelings
- Limited emotional content in the imagination
- Functional style of thinking
- Lack of enjoyment and pleasure-seeking
- Stiff, wooden posture

Author (January 23, 2003). The Alexithymia FAQ.
From web site:
www.anglefire.com/al4/alexithymia/

Emotional Salience Landscape Difficulties- Mirror Neurons

- **Problems in the amygdala and lack of emotional salience landscape may account for sensory sensitivity.**
- **These problems are found in those with Autism Spectrum Disorders.**
- **Insula/Amygdala : pain & disgust**

Ramachandran, V.S. and Oberman, L.M. (November, 2006). Broken Mirrors. Scientific American, 296(5), pp. 62-69.

When the child with Autism Spectrum Disorder looks into another's eyes:

- 1. The "...altered connection between the cortex and amygdala distorts (the) child's response.**
- 2. (The) Amygdala triggers the autonomous nervous system, raising heart rate.**
- 3. (As a result the) Child looks away to reduce stress." (p. 68)**

Treatment for Emotional Working Memory Difficulties

Frontal Lobe Difficulties

- **Stimulant Medication?**
 - Lessens Hyperactivity and Impulsivity in AD/HD, Combined Type Individuals
 - Hundreds of Double Blind Studies to Support

Barkley, R.A. (2006). Attention Deficit Hyperactivity Disorder, 3rd Edition. New York, NY: Guilford.

Hormone Difficulties

“Oxytocin and vasopressin contribute to a wide variety of social behaviors, including social recognition, communication, parental care, territorial aggression and social bonding.” (p. 2187)

Hammock, E.A.D. and Young, L.J. (December, 2006). Oxytocin, Vasopressin and Pair Bonding: Implications for Autism. Philosophical Transactions of the Royal Society of Biological Sciences, 361 (1476), pp. 2187-2198. From Website: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1764849>

Some Treatments For Mirror Neuron Difficulties

- Risperidone and MDMA (ecstasy):

To raise oxytocin levels

- Biofeedback:

To help control anxiety

- Oxytocin Nasal Spray

THE ABOVE ARE EXPERIMENTAL TREATMENTS!!!!

- Temple Grandin's "squeeze machine"

- Hirstein's "squeeze vest"
Elmhurst College

- Risperidone or MDMA (ecstasy)

- Biofeedback

- Under Armor-- Compression underwear:

www.underarmour.com

Previous Slide References

- Author (1997). Use of “Atypical” Neuroleptics in the Treatment of PDDs. MedScape Psychiatry & Mental Health Journal, 2 (4): www.medscape.com/viewarticle/430897_5.
- Ramachandran, V.S. and Oberman, L.M. (November, 2006). Broken Mirrors. Scientific American, 296(5), pp. 62-69.
- Guastella, A.J., Einfeld, S.L., Gray, K.M., Rinehart, N.J., Tonge, B.J., Lambert, T.J., and Hickie, I.B. (April 1, 2010). Intranasal Oxytocin Improved Emotion Recognition for Youth with Autism Spectrum Disorders. Biological Psychology, 67 (7), 692-694; www.ncbi.nlm.nih.gov/pubmed/19897177.
- Grandin, T (1992). Calming Effects of Deep Touch Pressure in Patients with Autism, College Students, and Animals. Journal of Child and Adolescent Psychopharmacology, 1 (2). From website: www.grandin.com/inc/squeeze.html
- Ramachandran, V.S. and Oberman, L.M. (November, 2006). Broken Mirrors. Scientific American, 296(5), pp. 62-69.
- Author (1997). Use of “Atypical” Neuroleptics in the Treatment of PDDs. MedScape Psychiatry & Mental Health e Journal, 2 (4): www.medscape.com/viewarticle/430897_5.

Theory of Mind & Mirror Neuron “Software”

“Able individuals with autism spectrum disorders can with time and practice achieve awareness of mental states by compensatory learning.” (p. 977)

Frith, U. (2001). Mind Blindness and the Brain in Autism. Neuron, 32, 969-979.

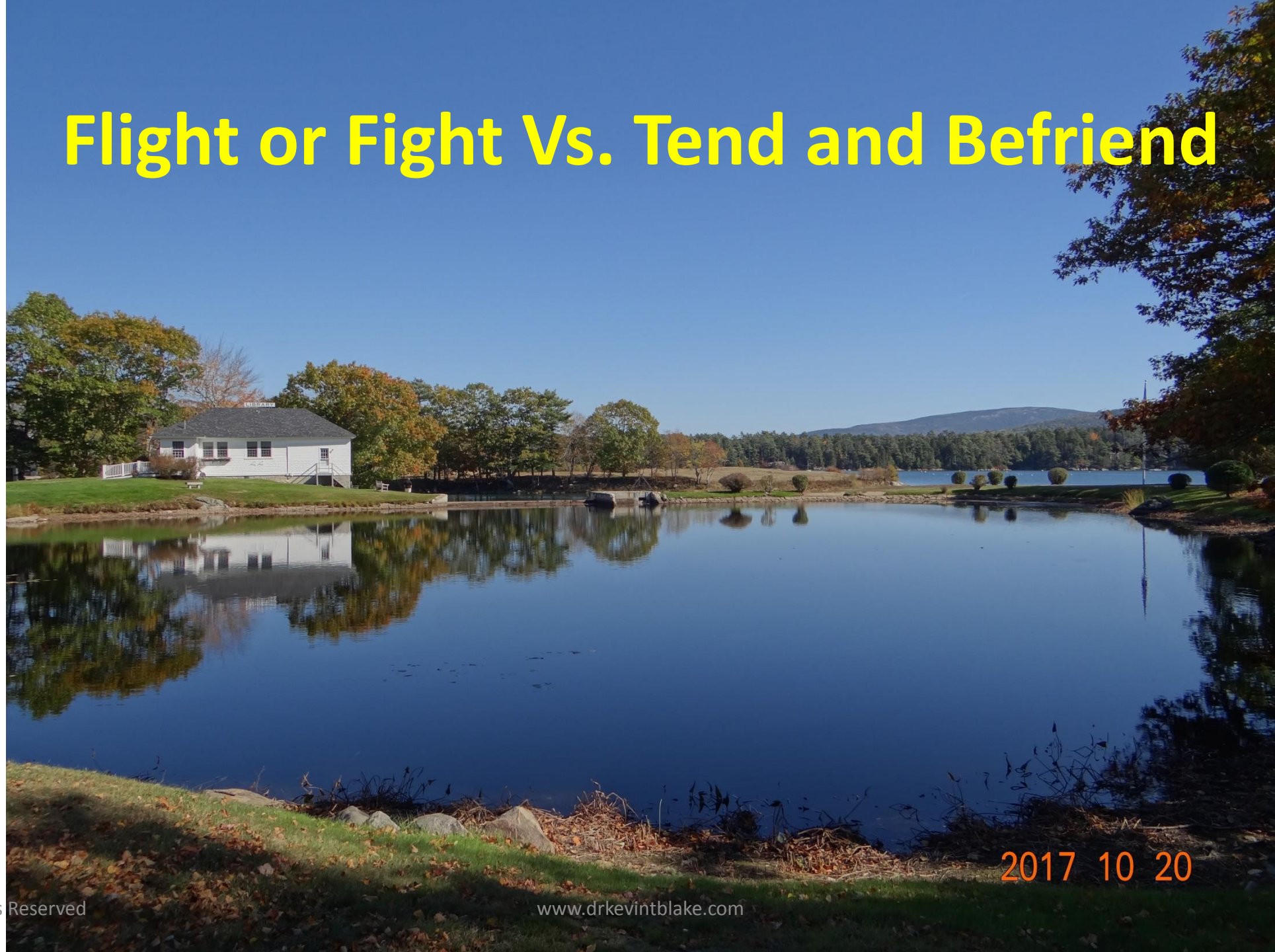
□ Possible Treatment Techniques

- **Carol Gray – Social Stories**
- **Laurel Falvo- Social Response Pyramid:**
- **www.thegraycenter.org**

Professionals Who Can Help With Alexithymia

- Psychologists-American Psychological Association: www.apa.org
- Psychiatrists-American Psychiatric Association: www.apa@psych.org
- Social Workers-National Association of Social Workers: www.naswdc.org
- American Association of Marriage and Family Therapists: www.aamft.org
- Counselors-National Board of Certified Counselors: www.nbcc@nbcc.org
- Behavioral Neurology/Neuropsychiatry-American Neuropsychiatric Association: www.anpaonline.org
- Speech Language Pathologist – American Speech-Language Hearing Association: www.professional.asha.org

Flight or Fight Vs. Tend and Befriend



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Flight or Flight Vs. Tend and Befriend

➤ **Fight or Flight Response:**
Herbert Benson, M.D.

Benson, H. (1983). The Relaxation Response. New York, NY: Outlet Books.

Benson, H. (1994). Beyond The Relaxation Response. New York, NY: Berkley Books.

➤ **Tend and Befriend:**
Shelly Taylor, Ph.D.

Taylor, S.E. (2002). The Tending Instinct: How Nurturing is Essential To Who We Are And How We Live . New York, NY: Holt.



“Savanna Anxiety”

“In general, when dominance hierarchies are unstable, glucocorticoid levels rise. This makes sense, because such instabilities make for stressful times. Looking at individual baboons, however, shows a more subtle pattern: given the same degree of instability, males whose ranks are dropping have elevated glucocorticoid levels, while male whose ranks are rising amid the tumult don’t show this endocrine trait.” (p. 263)



“Thus after factoring out rank, lower basal glucocorticoid levels are found in males who are best at telling the difference between threatening and natural interactions; who take the initiative if the situation is clearly threatening; who are best at telling who won or lost; and, in the latter case who are most likely to make someone pay for the defeat.” (p. 314)

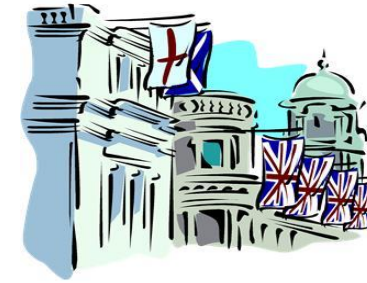
Saploski, R.M. (2004). Why Zebras Don’t Get Ulcers, Third Edition. New York, NY: Holt.

“Savanna Anxiety”

“Remarkably, this style is stable over the years of these individuals’ lives, and carries a big payoff – males with this cluster of low glucocorticoid traits remain high ranking significantly longer than average.” (p. 315)



Saploski, R.M. (2004). Why Zebras Don't Get Ulcers, Third Edition. New York, NY: Holt.



The “Whitehall” Study

“The Whitehall study of British civil servants begun in 1967, showed a steep inverse association between social class, as assigned by grade of employment, and mortality from a wide variety of diseases.” (p. 1387) A second “Whitehall Study” was conducted from 1985 to 1988. “...and found an inverse relationship between employment grade and prevalence of angina, electrocardiogram evidence of ischemia and symptoms of chronic bronchitis. Self-perceived health status and symptoms were worse in subjects with lower status jobs. There were clear employment grade differences in health risk behaviors including“...smoking, diet, and exercise, in economic circumstances, in possible effects of early-life environment as reflected by height, in social circumstances at work..., and social supports.” (p. 1387).

Marmot, M.G., Smith, G.D., Stanfeld, S., Patel, C., Head, J., White, I., Brunner, E., and Fenney, A. (1991). Health Inequalities Among British Civil Servants: Whitehall II Study. Lancet, 337 (8754), p. 1387-1393. From website: www.nicbi.nlm.gov/pubmed/1674771.

Social Anxiety



“Social anxiety can prevent you from accessing the social information you know to be true and the social skills you have intact...Unfortunately, social anxiety appears to be strongly correlated with having weaker social thinking and related social skills.” (p. 206)

Garcia Winner, M., and Crooke, P. (2011). Social Thinking At Work: Why Should I Care. San Jose, CA: Social Thinking.



Attwood (2002) gave an example of an Australian soldier who fought behind enemy lines as a lone sniper in Vietnam who said his social anxiety is much more pronounced than his PTSD from the war ever was.

Atwood, T. (July, 2002). Social Skills for Children with Asperger's and High Functioning Autism. Workshop presented on July 19, 2002 in Scottsdale, AZ: Future Horizons, Inc. 721 West Abram Street, Arlington, TX 76013.

Melting Down

“New research demonstrates that acute, uncontrollable stress sets off a series of chemical events that weaken the influence of the prefrontal cortex while strengthening the dominance of older parts of the brain. In essence, it transfers high-level control over thought and emotion from the prefrontal cortex to the hypothalamus and earlier evolved structures...”

“...As the older parts take over, we find ourselves either consumed by paralyzing anxiety or else subject to impulses that we usually manage to keep in check: indulgence in excess food, drink, drugs or a spending spree at a local specialty store. Quite simply, we loose it.” (p. 50)

Arnsten, A., Mazure, C.M., Sinha, R. (April, 2012). This is Your Brain in Meltdown. Scientific American, 306 (4), 48-53.

Melting Down

- Some people are more at risk of melting down due to genetic factors or previous stress exposure.
- “Chronic stress appears to expand the intricate web of connections among neurons in our lower emotional centers, whereas the areas engaged during flexible, sustained reasoning... -- start to shrivel.” (p. 53)

- With stress there is a shrinkage of the prefrontal gray matter while the amygdala enlarges.

Arnsten, A. et al. (April, 2012). This is Your Brain in Meltdown. Scientific American, 306(4), 48-53.

- Temple Grandin, Ph.D.'s amygdala is larger than normal.
- Her colitis left after she took an antidepressant for anxiety.

Grandin, T. (May 4, 2012). Autism and My Sensory Based World. Paper presented at the Conference On Autism & Asperger's Syndrome, Grandin, T., Cutler, E. and Moyes, R. Presenters, Tucson, AZ. Future Horizons; Arlington, TX.

Generalized Anxiety Disorder and ASD

“We know that young children with Asperger’s syndrome are prone to develop mood disorders...and some children seem to be almost always anxious which might indicate Generalized Anxiety Disorder (GAD)...they may be in a constant state of alertness, leading to a risk of mental and physical exhaustion.” (p. 17)

- **People with ASD are at great risk of having Social Anxiety Disorder (SAD).**
- **Those with SAD and ASD need cognitive behavioral therapy (CBT) and often medication. They will also need social skills training and self-esteem restructuring.**

Attwood, T. (2007). The Complete Guide to Asperger’s Syndrome. Philadelphia, PA: Jessica Kingsley.

Social Anxiety Disorder (SAD) & Unemployment

- **Patients with Major Depressive Disorder, or Anxiety Disorders have higher unemployment and work impairment than the norm.**
- **Patients with SAD are 2 ½ times more likely than those with Major Depressive Disorder, or other forms of Anxiety Disorders to be unemployed.**

Moitra, E., Beard, C., Weisberg, R.B., and Keller, M.B. (September, 2010). Occupational and Social Anxiety Disorder in a Sample of Primary Care Patients. Journal of Affective Disorders. doi: 10.1016/j.ad.2010.09.024.

“These findings highlight the particular need to assess the presence of under education and underperformance at work and/or unemployment in individuals with SAD, as they are at most risk for these impairments. Additionally, early detection and intervention with individuals with, or at risk for SAD may curb the impact of social anxiety or occupational attainment.”



The Genetically Shy

- **10 to 15% of newborns have an inherited enhanced startle response.**
- **A 20 year follow-up study of such children with fMRI imaging indicated they are still shy neurologically, especially to strangers.**

The amygdala is activated in the genetically shy when they are shown pictures of unfamiliar people. This would tend to indicate they feel fear and are overly vigilant when they see strangers. This does not occur in the non-shy.

Zimbardo, P.G. (2000). The Personal and Social Dynamics of Shyness: Adults and Children. Paper presented at the 50th Annual Arizona Psychological Association Conference, October 21, 2000, Tucson, AZ.

Schwartz, C.E. (June, 2003). Inhibited and Uninhibited Infants "Grown Up": Adult Amygdalar Response to Novelty. Science, 300(5627), pp. 1952-1953.

Social Phobia/Shyness



“Shyness may be defined experimentally as discomfort or inhibition in interpersonal situations that interferes with pursuing one’s interpersonal or professional goals.” (p. 497)

- Henderson, L. and Zimbardo, P. (1998). Shyness. Encyclopedia of Mental Health, 3, p. 497.
- Dittmann, M. (July/August, 2005). Stemming Social Phobia. Monitor On Psychology, 36 (7), pp. 92-94.
- Heimberg, R.G. et al. (1998). Cognitive Behavior Group vs Phenelzine Therapy for Social Phobia. Archives of General Psychiatry, 55, p. 1133-1141.

Two Subtypes:

1. **Specific Type- public speaking, eating in public, etc.**
2. **Generalized Type-very broad**
 - **These people shy away from treatment: 36% of those who meet DSM criteria actually get treatment**

Shyness in a Nutshell

- **“S”ELF-BLAME AND SHAME**
- **“A”VOIDANCE**
- **“D”ISTRESS**
- **“F”EAR OF NEGATIVE EVALUATION**
- **“I” MUST BUT I CAN’T**
- **“X”-POSURE: FEAR OF BOTH FAILURE AND SUCCESS**
- **“S”ELF SABOTAGE**



Zimbardo, P.G. (2000). The Personal and Social Dynamics of Shyness: Adults and Children. Paper presented at the 50th Annual Arizona Psychological Association Conference, October 21, 2000, Tucson, AZ.

Treating Shyness



I asked Zimbardo what he thought those who had neurobiological disorders who were genetically shy needed most and he said, “Training in the skills to make legitimate excuses.”

Zimbardo, P.G. (2000). The Personal and Social Dynamics of Shyness: Adults and Children. Paper presented at the 50th Annual Arizona Psychological Association Conference, October 21, 2000, Tucson, AZ.

Cognitive Behavioral Therapy and Antidepressant Medication works 80% of the time with 5 year follow-up. Thought to be best method of treatment.

Heimberg, R.G. et al. (1998). Cognitive Behavior Group vs Phenelzine Therapy for Social Phobia. Archives of General Psychiatry, 55, p. 1133-1141.

Treating Shyness



Zimbardo (2000) described a 26 week treatment program at his shyness clinic that includes the following:
Cognitive Behavior Modification/Cognitive Restructuring, Self-Esteem Restructuring, Support Groups, Practice, Medications, Video Social Skills Training, Encouragement, etc.

- www.shyness.com and www.shynessinstitute.com

Zimbardo, P.G. (2000). The Personal and Social Dynamics of Shyness: Adults and Children. Paper presented at the 50th Annual Arizona Psychological Association Conference, October 21, 2000, Tucson, AZ.

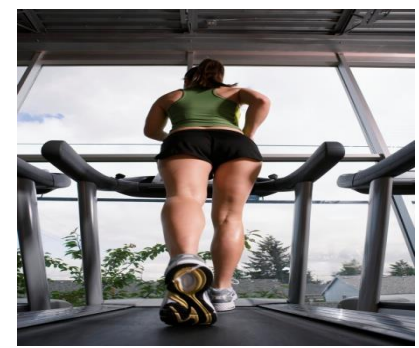
- Henderson, L. (2011). Improving Social Confidence and Reducing Shyness Using Compassion Focused Therapy. Oakland, CA: New Harbinger.
- Henderson, L. (2009). Social Fitness Training Manual: A Cognitive-Behavioral Approach to Treating Shyness and Social Anxiety Disorder. Berkley, CA: The Shyness Institute.

Treating Anxiety in Those With ASD

- **Cognitive behavioral therapy, social skills training, and antidepressant medication.**
- **Making sure therapies for autism continue (i.e., speech language therapy, occupational therapy, etc.)**

Durand, M.V. (2014). Autism Spectrum Disorder: A Clinical Guide for General Practitioners. Washington, DC: American Psychological Press.

Treating Shyness



Aerobic Exercise:

- “As for the trait, the majority of studies show that aerobic exercise significantly alleviates symptoms of any anxiety disorder.” (p. 92)

Ratey, J.J. (2008). Spark: The Revolutionary New Science of Exercise and The Brain. New York, NY: Little, Brown.

- Ratey, J.J. (2008). Spark: The Revolutionary New Science of Exercise and The Brain. New York, NY: Little, Brown.

Always consult a physician before starting an exercise program!

People and Organizations Who Can Help With Social Anxiety/Shyness

- American Psychiatric Association:
www.apa@psych.org
- American Psychological Association: www.apa.org
- American Association of Marriage and Family Therapists:
www.aamft.org
- National Board of Certified Counselors:
www.nbcc@nbcc.org
- National Association of Social Workers:
www.naswdc.org
- Anxiety Disorder Association of America:
www.adaa.org



Social Competence



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What is Social Competence?

“Social competence is an ability to take another’s perspective concerning a situation and to learn from past experience and apply that learning to the ever-changing social landscape. The ability to respond flexibly and appropriately defines a person’s ability to handle the social changes that are presented to us all.” (p. 1-2)

Semrud-Clikeman, M. (2007). Social Competence in Children. New York, NY: Springer, pp. 1-2.

Social Competence and Health

“There is sufficient empirical evidence that links social competence to mental and physical health...It has been linked to such varied disorders as anxiety, cardiovascular disease, juvenile delinquency, and substance abuse, to name a few.” (p. 1)

Semrud-Clikeman, M. (2007). Social Competence in Children. New York, NY: Springer, pp. 1-2.

- **Social Support: Stress Buffering-**
Reduces the stressful event by promoting less threatening interpretation of the event.
- **Social Integration: Main Effect-**
Promotes positive psychological states, social motivation and pressure to care for oneself.
- **Negative Interactions:**
Relationships as a Source of Stress-
Elicits psychological stress and increases risk for disease.

Cohen, S. (November, 2004). Social Relationships and Health. American Psychologist, 59 (8), pp. 676-674.

Skills of Social Emotional Competence

- **Awareness of one's own emotional state**
- **Awareness of other's emotional state**
- **Emotional use of words**
- **Ability to cope with emotional distress**
- **Ability to attend to the reaction of others**

Semrud-Clikeman, M. (Spring, 2003). Executive Function and Social Communication Disorders. Perspectives, 29 (2), p. 20-22.

Semrud-Clikeman, M. (2007). Social Competence in Children. New York, NY: Springer.

Isolation and The Immune System

- ✓ From 1985 to 2005 the typical American said the average number of people they could rely upon to help them with a significant concern dropped from 3 to 2.
- ✓ In 2005 twenty-five percent reported they had no trusted friend they could rely upon which is double the rate of 1985.

McPherson, M., Smith-Lovin, L. and Brashears, M.E. (2006). Social Isolation in America: Changes in Core Discussion Networks Over Two Decades. American Sociological Review, 71 , 353-375.

- ✓ Lonely people have more active genes that promote inflammation and less active genes that inhibit inflammation.
 - ✓ This puts them at risk for some cancers, degenerative neurological disorders and cardiovascular problems.
- ✓ Lonely people's immune systems are geared toward fighting bacteria not viruses.
- ✓ Sociable people have immune systems geared toward viruses.
- ✓ 54% of 20,000 people from 18 to 80 said they feel lonely

Isolation and The Immune System

Azar, B. (May, 2011). The Psychology of Cells. Monitor On Psychology, 42 (5), 32-35.

Miller, G., Chen, E. and Cole, S. (January, 2009). Health Psychology: Developing Biologically Plausible Models Linking the Social World and Physical Health. Annual Review of Psychology, 60, 501-524.

Cole, S.W., Hawkley, L.C., Arevalo, J.M., Sung, C.Y., Rose, R.M. and Cacioppo, J.T. (2007). Social Regulation of Gene Expression in Human Leukocytes. Genome Biology, 8 (9), doi:10.1186/gb-2007-8-9-r189.

Cole, S.W., Hawkley, L.C., Arevalo, J.M.G. and Cacioppo, J.T. (February 15, 2011). Transcript Origin Analysis Identifies Antigen-Presenting Cells as Primary Targets of Socially Regulated Gene Expression In Leukocytes. Proceedings of the National Academy of Sciences of the United States of America (PNAS), 108 (7), 3080-3085.

Ostracism and the Brain

- All people when left out immediately experience social agony as physical pain.
- All animals use ostracism as a way to get rid of the burdensome. In non humans this is a death sentence.

Williams, K.D. (January/February, 2011). The Pain of Exclusion. Scientific American Mind, 21 (6), 30-37.

- The ostracized immediately feel experience significantly lower self-esteem, a lack of meaning in their life, a lack of control, sadness and anger.
- The can feel rejected by strangers and those they hate.
- This can cause physical and psychological illness.

Ostracism and the Brain

➤ In an fMRI study,...”As soon as students began to feel ostracized, the scanners registered a flurry of activity in the dorsal anterior cingulate cortex – a brain region associated with the emotional aspects of physical pain.” (p. 34)

➤ Also the insula activates and judges the severity of the pain.

Williams, K.D. (January/February, 2011). The Pain of Exclusion. Scientific American Mind, 21 (6), 30-37.

➤ “...social rejection and physical injury are not much different experiences and share underlying neural pathways.” (p. 35)

➤ fMRI studies have shown that painkillers can reduce the pain of social rejection.

➤ To reduce the pain of social rejection people will agree, mimic, obey, or cooperate with the rejecting group. Even if it goes against their beliefs and/or judgment.

Ostracism and the Brain

- **Depressed and/or socially anxious people take longer to recover from ostracism than others.**
- **“In extreme cases, ostracized humans may resort to aggressive or violent acts when they have lost hope of being included in any socially acceptable group.” (p. 36)**

- **What to do if you are ostracized:**
 - 1. Remove yourself from the situation and distract yourself.**
 - 2. Remind yourself of your strengths.**
 - 3. Exercise more control in your life; assert yourself.**
 - 4. Reconnect with family and friends.**

Williams, K.D. (January/February, 2011). The Pain of Exclusion. Scientific American Mind, 21 (6), 30-37.

Sensory Issues

Sensory Issues and Autism

- **Temple Grandin stated the #1 sensory problem for ASD is auditory. She divided this into two areas: 1. auditory processing; and, 2. over sensitive hearing.**
- **She indicated that many high functioning ASD adults complain of debilitating sensory issues; they exist, but research lags behind.**
- **She wrote, “ ‘There is no research to support sensory integration therapy with individuals with autism’ –tacitly suggesting the therapy is ineffective. The absence of clinical research does not mean sensory therapies are not viable for children and adults. It simply means research has not been done to date.”**

Grandin, T. (March 15, 2011). The Way I See It, Revised and Expanded 2nd Edition: A Personal Look at Autism and Asperger's. Arlington, TX: Future Horizons.

Sensory Issues and Autism

Researchers at the University of California Davis found that children with out a disability, those with developmental disorders and those with autism spectrum disorder all tend to have sensory issues, particularly in the smell, taste and auditory senses when they are very young, but they typically developing children grow out of them. Those with developmental disorders and ASD often do not.

McCormick, C., et al. (September 22, 2015). Sensory symptoms in children with autism spectrum disorder, other developmental disorders and typical development: A longitudinal study. Autism. DOI: [10.1177/1362361315599755](https://doi.org/10.1177/1362361315599755).

Multisensory Processing

Multisensory Processing in ASD

- Found that ASD children did not integrate multisensory (auditory-somatosensory) stimuli as well as non-disabled children.
- Will next investigate Sensory Integration Training for efficacy given these results.
- Molholm stated ASD children have difficulty simultaneously processing faces and voices.

Russo, N. et al. (October, 2010). Multisensory processing in children with autism: high-density electrical mapping of auditory-somatosensory integration. Autism Research. DOI: 10.1002/aur.152.

Rajarshi (Tito) Mukhopadhyay

- “I can do only one thing at a time. I can use my eyes or use my ears. Hearing my voice screaming would stop my eyes from looking...After hearing the words of her song (his mother’s, sic.), I would wonder why I could no longer hear my voice screaming. And, to my relief, I would realize that my voice had stopped screaming.”
- “I can do only one thing at a time. I can use my eyes or use my ears. Hearing my voice screaming would stop my eyes from looking...After hearing the words of her song (his mother’s, sic.), I would wonder why I could no longer hear my voice screaming. And, to my relief, I would realize that my voice had stopped screaming.”

Mukhopadhyay, T.R. (2011). How Can I Talk If My Lips Don’t Move? Inside My Autistic Mind. New York, NY: Arcade.

Prosopagnosia



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Prosopagnosia

Prosopagnosia

Rajarshi (Tito) Mukhopadhyay

“In order to get a permanent impression of someone’s face, I needed some time. How much time? It depends on how much interaction with the voice generating from the face has with me.” He identifies people by their voice.

Mukhopadhyay, T.R. (2011). How Can I Talk If My Lips Don’t Move? Inside My Autistic Mind. New York, NY: Arcade.

“A range of face-processing deficits can present in ASD. Sometimes, individuals have problems recognizing facial identity, gaze direction, gender, expression and lip reading...Most importantly, nearly all individuals with ASD have problems interpreting emotional expression. For some individuals with ASD, the impairment in recognizing emotional expressions seems only to affect certain expressions, most notably fear” (p. 144).

Bate, S. (2012). Face Recognition and its Disorders. Palgrave Macmillan.



Symptoms of Prosopagnosia

- **Extreme difficulty recognizing faces. Even with a person who is well known by the sufferer (i.e., a parent, spouse, best friend, etc.).**
- **Appears aloof/arrogant, does not respond to people they “know” when they see them.**
- **Often complain they cannot follow movies or TV shows because they cannot remember the identity of characters.**
- **They tend to recognize people by hair, gait, clothing, voice, context or other information.**

Author (August 14, 2007). www.faceblind.org/research, p. 1 of 3.

Prosopagnosia

Possible Associated Conditions:

- Problems with recognition of facial expression of emotion
- Problems with gender of face discrimination
- Problems with age of face discrimination
- Problems with **TOPOGRAPHAGNOSIA**: difficulty with personal navigation; getting lost easily
- ASD

Galaburda, A.M. and Duchaine, B.C. (2003). Developmental Disorders of Vision. Neurologic Clinics, 21 (3), 687-707.

➤ Remembering Faces:

- This is an important ability for survival.
- It lets you know “friends and foes.”
- It helps you maintain relationships.
- It helps you remember the social status of others.

Ratey, J.J. (2001). A User's Guide to the Brain: Perception, Attention and the Four Theaters of the Brain. New York, NY: Vintage.

Face Perception



- Adults and adolescents with Autism lack specialization for faces in the right fusiform gyrus, they use it for other things: toilet plungers, etc.
- Left fusiform gyrus (“Word Form Area”) responds somewhat to strings of letters of the same font and to real words not non-words.
- Letters are not processed like shapes or strings.

Gauthier, I. (November 3, 2004). Face Processing: Is It Hard-wired or Learned? Evidence from Brain Imaging Studies. Paper presented at the 55th Annual International Conference seminar, *The Neural Basis of Reading and Other Forms of Skill Acquisition*, Philadelphia, PA, Session: W-1.

Prosopagnosia

- Adults and adolescents with Autism lack specialization for faces in the right fusiform gyrus, they use it for other things: toilet plungers, etc.
- Left fusiform gyrus (“Word Form Area”) responds somewhat to strings of letters of the same font and to real words not non-words.
- Letters are not processed like shapes or strings.
- The Fusiform Face Area (FFA) responds much more to faces than to other objects.
- Nine different labs have found that those with Autism Spectrum Disorders have a hypoactivation of the FFA when viewing faces.
- Developmental Prosopagnosia and Developmental Agnosia are separate disorders.

Gauthier, I. (November 3, 2004). Face Processing: Is It Hard-wired or Learned? Evidence from Brain Imaging Studies. Paper presented at the 55th Annual International Conference seminar, *The Neural Basis of Reading and Other Forms of Skill Acquisition*, Philadelphia, PA, Session: W-1.

Gauthier, I., and Tarr, M.J. (1997). Becoming a “Greeble” Expert: Exploring Mechanisms for Face Recognition. Vision Research, 37 (120), 1673-1682.

Schultz, R.T. (2005). Developmental Deficits in Social Perception in Autism: The Role of the Amygdala and Fusiform Face Area. International Journal of Developmental Neuroscience, 23, 125-141.

Duchaine, B. and Nakayama, K. (2005). Dissociations of Face and Object Recognition in Developmental Prosopagnosia. Journal of Cognitive Neuroscience, 17, 249-261 (From Abstract).

Types of Prosopagnosia

“Face perception can be subdivided into two general types – recognition of person identity via the structures of the face and recognition of internal affective states based on the shape of individual features and changes in their relative distance from one another during the expression.” (p. 128)

Schultz, R.T. (2005). Developmental Deficits in Social Perception in Autism: The Role of the Amygdala and Fusiform Face Area. International Journal of Developmental Neuroscience, 23, 125-141.

Problems Making the Appropriate Facial Expression to Match How One Feels and What is Appropriate to The Situation:

Attwood's (2007) story of the boy with Asperger's Disorder who saw his mother crying and asked, **“What face do I make?”** (p. 134)

Attwood, T. (2007). The Complete Guide to Asperger's Syndrome. Philadelphia, PA: Jessica Kingsley, p. 130.

Recognizing Emotional Facial Expressions



- **Emotional Facial Expression Recognition:**
 - “Does this mean we come into the world expecting to see human faces and ready to respond with our own prewired facial expressions?” **Yes!”** (Ratey, 2001, p. 300)

Ratey, J.J. (2001). A User's Guide to the Brain: Perception, Attention and the Four Theaters of the Brain. New York, NY: Vintage.

ASD and Processing Facial Expressions

“Our findings suggest that an atypical implicit response to facial expression of emotion may form the basis of impaired emotional reactivity in autism and in the broader autism phenotype in relatives. These results demonstrate that the fMRI response to facial expression of emotion is a candidate neuroimaging endophenotype for autism and may offer far-reaching insights into the etiology of autism” (p. 1 of 7).

Spencer, M.D., et al. (2011). A novel functional brain imaging endophenotype of autism: the neural response to facial expression of emotion. Translational Psychiatry, 1, e19, doi: 10.1038/tp.2011.18.

Decoding Skill and Facial Expression

❖ Remembering Expressions:

- ❖ The non-disabled are “pre-wired” to find the human face and voice the most important stimuli in the world.
- ❖ Those with Asperger’s Disorder (AD) don’t look at the eyes they look at the mouth. Differentiated those with AD from non-disabled 100% of the time.

Klin, A. (October 11-12, 2001). Autism, Asperger’s and the PDD Spectrum. Seminar presented at the 33rd Annual Arizona Association of School Psychologists Conference, Mesa, AZ.

Volkmar, F. (April 23, 2003). Asperger Syndrome: Clinical Features, Assessment, and Intervention Guidelines. Seminar presented by New England Educational Institute, Phoenix, AZ.

- Positive emotions are the easiest to decode.
- Negative emotions are the most difficult.
- Poor interpreters of facial expression have less social acceptance and poorer adjustment.

Semrud-Clikeman, M. (Spring, 2003). Executive Function and Social Communication Disorders. Perspectives, 29 (2), p. 20-22.

Semrud-Clikeman, M. (2007). Social Competence in Children. New York, NY: Springer.

ASD & Face Processing

“A range of face-processing deficits can present in ASD. Sometimes, individuals have problems recognizing facial identity, gaze direction, gender, expression and lip reading...Most importantly, nearly all individuals with ASD have problems interpreting emotional expression. For some individuals with ASD, the impairment in recognizing emotional expressions seems only to affect certain expressions, most notably fear” (p. 144).

Bate, S. (2012). Face Recognition and its Disorders. Palgrave Macmillan.

Treatment of Prosopagnosia

“Prosopagnosics cannot be cured, but they can and do learn ways to recognize people.” (p. 70)

Grueter, T. (August/September, 2007). Forgetting Faces. Scientific American Mind, 18 (4), 68-73.

Facial expressions can be taught.

Volkmar, F.(April 23, 2003). Asperger Syndrome: Clinical Features, Assessment, and Intervention Guidelines. Seminar presented by New England Educational Institute, Phoenix, AZ

Gauthier, I. et al. (1997). Becoming a “Greeble” Expert: Exploring Mechanisms for Face Recognition. Vision Research, 37 (120), 1673-1682.



Computer Programs to Treat Prosopagnosia



- “Let’s Face It!” – Face Recognition Program and workbook for children and adolescents with Autism Spectrum Disorders (University of Victoria Brain and Cognition Lab & the Yale Child Study Center)
- Teaches facial recognition and emotion recognition in 20 hours!
- It is **FREE!**

From: <http://web.uvic.ca/~letsface/letsfaceit/?q=home>

Tanaka, J.W., Wolf, J. M., Klaiman, C., Koenig, K., Cockburn, J., Herlihy, L., Brown, C., Stahl, S., Kaiser, M.D., and Schultz, R.T. (2010). Using computerized games to teach face recognition skills to children with autism spectrum disorder: The Let's Face It! program, Journal of Child Psychology & Psychiatry, 51, 944-952.

Gordon, I., Pierce, M.D., Bartlett, M.S., & Tanaka, J.W. (2014). Training Facial Expression Production in Children on the Autism Spectrum. Journal of Autism and Developmental Disorders, 44, 2486-2498. DOI: 10.1007/s10803-014-2118-6.

Computer Programs to Treat Prosopagnosia



- Baron-Cohen, S. (2003). Mind Reading: An Interactive Guide To Emotions. Philadelphia, PA: Jessica Kingsley.

“Harry Potter” teaches facial expressions.

- Baron-Cohen, S., Drori, J., Harcup, C. (2009). The Transporters (USA Version). London, England: Changing Media Development:
www.thetransporter.com

“Thomas the Tank-Engine” teaches faces.



Computer Programs to Treat Prosopagnosia



- “Gaining Face”: www.StoneMountainSoftware.com
 - Cognitive Affective Training-Faces and Feeling Words: www.CAT-kit.com
 - Paul Ekman, Ph.D. (“Lie to Me”/SPOT – Surveying Passengers by Observational Techniques) CD ROMS:
 - Micro Expression Training Tool (METT)
 - Subtle Expression Training Tool (SETT)
 - Repeated presentations of METT & SETT to those with Autism Spectrum Disorders
- Available from: www.paulekman.com

Gaze Problems and Prosopagnosia

- People stare at you because they want to know if you are interested in them.
- Look toward peoples' eyes and cheekbones.
- Use media to disconnect sound from faces.
- If you don't use eye contact others will emotionally leave you.
- Watch TV with the sound turned off and look at the face.
- Watch children's shows like Barney and Sesame Street and observe the difference between the facial expression reactions of children and adults.
- You can see extreme emotions on soap operas, animated movies (i.e., Toy Story) claymation (Wallace and Grommit).

Garcia Winner, M., and Crooke, P. (2011). Social Thinking At Work: Why Should I Care. San Jose, CA: Social Thinking.

Auditory Processing Disorder



American Speech-Language-Hearing Association Definition of (C)APD

“Broadly stated, (Central) Auditory Processing [(C)AP] refers to the efficiency and effectiveness by which the central nervous system (CNS) utilizes auditory information. Narrowly defined, (C)AP refers to the perceptual processing of auditory information in the CNS and the neurobiologic activity that underlies that processing and gives rise to electrophysiologic auditory potentials. (C)AP includes the auditory mechanisms that underlie the following abilities or skills: sound localization and lateralization; auditory discrimination; auditory pattern recognition; temporal aspects of audition, including temporal integration, temporal discrimination (e.g., temporal gap detection), temporal ordering, and temporal masking; auditory performance in competing acoustic signals (including dichotic listening); and auditory performance with degraded acoustic signals”.

American Speech-Language-Hearing Association. (2005). *(central) auditory processing disorders* [Technical Report]. Available from www.asha.org/policy. DOI: 10.1044/policy.TR2005-00043.

Symptoms of (C)APD

- **Difficulty performing multi-step directions**
- **Poor listening skills**
- **Slow auditory processing speed**
- **Language problems –developing vocabulary and understanding the spoken word, etc.**
- **Problems with reading, verbal and reading comprehension, spelling and vocabulary**
- **Poor academic performance**

- **Behavior problems**
- **Problems remembering and recalling information presented orally**
- **Problems attending to auditory information**

NIDCD (no date). Auditory Processing Disorders in Children . From website:

www.nidcd.nih.gov/health/voice/auditory.html.

Behavioral Symptoms of CAPD

- **“difficulty understanding speech in the presence of competing background noise or reverberant acoustic environments**
- **problems with the ability to recognize the source of a signal**
- **difficulty hearing on the phone**
- **difficulty following rapid speech**
- **difficulty or inability to detect the subtle changes in the prosody that underlie humor and sarcasm**
- **difficulty learning a foreign language or novel speech materials, especially technical language**
- **difficulty maintaining attention**
- **a tendency to be easily distracted**
- **poor singing, musical ability, and/or appreciation of music**
- **academic difficulties, including reading, spelling and/or learning problems.” (p. 5)**

Behavioral Symptoms of CAPD

- **difficulty learning a foreign language or novel speech materials, especially technical language**
- **difficulty maintaining attention**
- **a tendency to be easily distracted**
- **poor singing, musical ability, and/or appreciation of music**
- **academic difficulties, including reading, spelling and/or learning problems.” (p. 5)**

American Academy of Audiology (August 24, 2010). Diagnosis, Treatment, and Management of Children and Adults with Central Auditory Processing Disorder. From website:

www.audiology.org/resources/documentlibrary/documents/CAPD%20guidelines%208-2010.pdf.

What is Needed in a (C)APD Assessment

- **Occupational Therapist: Evaluates sensory systems**
- **Speech-Language Pathologist: Language assessment**
- **Psychologist: Neuropsychological and cognitive/emotional assessment**
- **Audiologist: Auditory evaluation**

Author (2016). Causes and Treatment. National Coalition of Auditory Processing Disorders. From website: http://www.ncapd.org/Causes_and_Treatment.html.

CAPD Diagnosis

“Administration of behavioral and/or electrophysiologic audiologic tests that have been shown to be sensitive and specific to dysfunction of the CANS is critical for a proper diagnosis of CAPD, in addition to assessments and collaboration with a multidisciplinary team.”

Bellis, T.J. et al (2015). Central auditory processing disorders in children and adults. Handbook of Clinical Neurology, Chapter 30, 129, 537-556. DOI: [10.1016/B978-0-444-62630-1.00030-5](https://doi.org/10.1016/B978-0-444-62630-1.00030-5).

(C)APD and Peripheral Hearing Loss

- (C)APD evaluations can be done on children, adolescents and adults.
- Such evaluations can even be done with those with peripheral hearing loss if special care and procedures are followed.

American Academy of Audiology (August 24, 2010). Diagnosis, Treatment, and Management of Children and Adults with Central Auditory Processing Disorder. From website:
www.audiology.org/resources/documentlibrary/documents/CAPD%20guidelines%208-2010.pdf.

Auditory Processing Disorder and Autism Spectrum Disorder

Japanese researchers found children with autism are significantly delayed in the development of their auditory processing system when compared to non-disabled children. This they believe causes the language difficulties typical in autistic children.

Yoshimura, Y., et al. (January 25, 2015). Atypical development of the central auditory system in young children with Autism spectrum disorder. Autism Research. DOI: 10.1002/aur.1604.

“...children with autism may have great difficulty with spoken language comprehension. However, it is the higher-order, global deficit known as autism that is the cause of their difficulties, not a specific auditory dysfunction”.

Bellis, T.J. et al (2015). Central auditory processing disorders in children and adults. Handbook of Clinical Neurology, Chapter 30, 129, 537-556. DOI: [10.1016/B978-0-444-62630-1.00030-5](https://doi.org/10.1016/B978-0-444-62630-1.00030-5).

Autism and Auditory Processing

British researchers reported results of a study that indicated that those children with ASD significantly different audiovisual, auditory, and visual processing of social facial, and speech stimuli than typically developing children. Those with ASD have significantly less activation in the brain areas that do the above processing and in the frontal lobe when exposed to social stimuli.

K.D. Tsatanis (2014) stated the problems with auditory processing often seen in those with ASD appear to be a part of their social world from infancy and can cause them difficulty in understanding social interactions as well as planning and coordination appropriate social responses.

Regener, P. et al. (May 13, 2016). An fMRI Investigation of Audiovisual, Auditory and Visual Processing in Autism Spectrum Disorder. Paper presented at the International Society for Autism Research, International Conference, Baltimore, MD.

Tsatanis, K.D. Neuropsychological Characteristics of Asperger Syndrome. From J.C. McPartland, A. Klin, and F.R. Volkmar (Ed.s), *Asperger Syndrome: Assessing and Treating High Functioning Autism Spectrum Disorders*. New York, NY: Guilford, 72-102.

Auditory Habituation in ASD Adults

Scientists found that adults with ASD are significantly slower than non-ASD adults at habituating to simple stimuli. They remained aroused longer after being exposed to sounds and they have a prolonged period of fear extinction of stimuli that is much longer. The researchers speculated this may explain why exposure therapy often takes longer in adults with ASD.

Top, N. et al. (May 13, 2016). Can't Tone It Down? Auditory Habituation in ASD. Paper presented at the International Society for Autism Research, International Conference, Baltimore, MD.

Treating (C)APD

“Intervention recommendations for CAPD diagnosis are based on the demonstrated auditory processing deficits and related listening and related complaints”.

Bellis, T.J. et al (2015). Central auditory processing disorders in children and adults. Handbook of Clinical Neurology, Chapter 30, 129, 537-556. DOI: [10.1016/B978-0-444-62630-1.00030-5](https://doi.org/10.1016/B978-0-444-62630-1.00030-5).

Recently top researchers in the field of CAPD stated that although the efficacy findings for auditory training for CAPD is somewhat limited current research support the use of auditory training.

Weihsing, J. et al. (2015). Auditory Processing Disorder for Central Auditory Processing Disorder. Seminars in Hearing, 36(4), 199-215. DOI: 10.1055/s-0035-1564458.

Dichotic Interaural Intensity Difference Training (DIID)

Children with CAPD have been found to have weaker auditory processing in their left ears (assuming their left brain hemisphere is their language dominate one) during dichotic listening that would be expected. When trained with dichotic listening with the intensity raised to the weak ear some children are able to raise the level of that ear to the level of their “strong ear”. This technique may also work with people with brain injuries that suffer similar weak ears as a result of this accident.

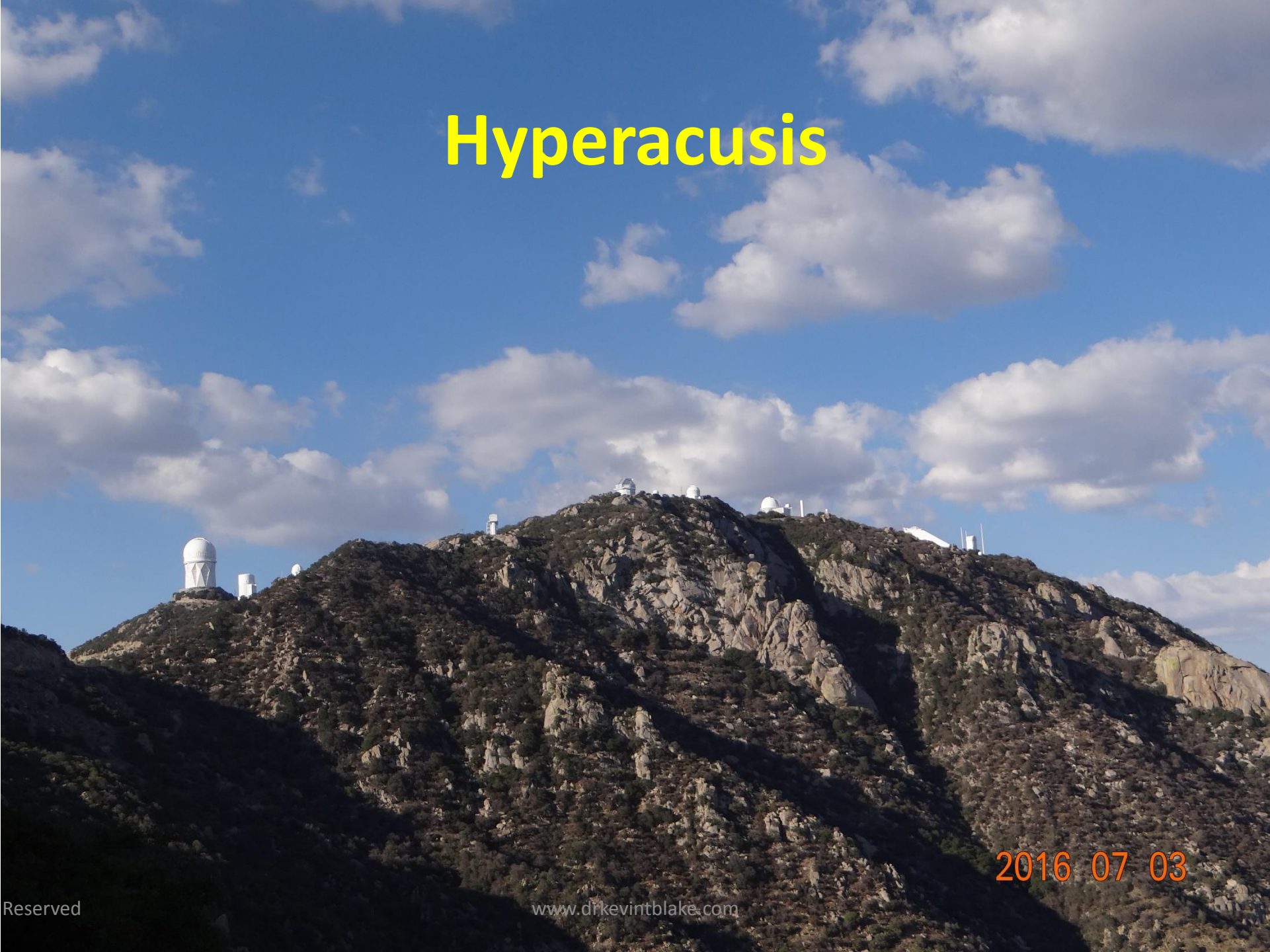
Musiek, F.E. (November 20, 2015). The Dichotic Interaural Intensity Difference (DIID) Auditory Training Procedure: A Commentary. Paper presented at the 2015 AuD Workshop – CAPD Diagnosis and Intervention: Practical Perspectives for Clinicians, University of Arizona, Speech, Language & Hearing Sciences, Tucson, AZ.

Other Possible Training Approaches

- Earobics (www.earobics.com)
- Fast ForWord (www.fastforword.com)
- Lindamood-Bell Programs (www.lindamoodbell.com)
- FM Loop system: www.harriscomm.com
- Sound suppression technology: www.bose.com

Discuss these with an audiologist from a university speech and hearing center.

Hyperacusis



Definition of Hyperacusis

The American Academy of Otolaryngology Head and Neck Surgery defines Hyperacusis as:

“Hyperacusis is a condition that arises from a problem in the way the brain's central auditory processing center perceives noise. It can often lead to pain and discomfort.”

Author (No Date). Hyperacusis: An Increased Sensitivity to Everyday Sounds. From website:
<http://www.entnet.org/content/hyperacusis-increased-sensitivity-everyday-sounds>.

The American Speech-Hearing Association Defines Hyperacusis as:

“Hyperacusis is a rare hearing disorder that causes sounds which would otherwise seem normal to most people to sound unbearably loud.”

Goodson, S. et al. (2015). Hyperacusis: Audiology Information Series . Rockville, MD: American Speech-Hearing Association. From website:
<http://www.asha.org/uploadedFiles/AIS-Hyperacusis.pdf#search=%22Hyperacusis%22>.

ASD and Hyperacusis

- **70 to 80% of those with Autism Spectrum Disorder have some form of Hyperacusis.**
- **The three types of sounds people with Autism Spectrum Disorder have difficulty with:**
 - **Sudden Unexpected Noises – dog bark, school fire alarm, etc.**
 - **High Pitched Continuous Noises - electric motors. toilets, etc.**
 - **Confusing Multiple Sounds – shopping mall, sporting event, etc.**

Attwood, T. (2007). The Complete Guide to Asperger's Syndrome. Philadelphia, PA: Jessica Kingsley, p. 135.

American scientists discovered through using evoked potential with adults with autism found they had more sensitivity to auditory stimuli than non-autistic adults.

Karhoshn, D.S., et al. (January 18, 2016). Atypical sensory reactivity influences auditory attentional control in adults with autism spectrum disorders. Autism Research. DOI: 10.1002/aur.1593.

Comorbidities to Hyperacusis

Hyperacusis has a high comorbidity with autism spectrum disorder (ASD). The CD 38 gene encodes partially with the oxytocin system and hormone which has been shown to be deficient in people with ASD, and has been shown to cause difficulties in auditory processing of social sounds, facial emotion recognition, and social behavior. Administering oxytocin has been found to help these and may help with hyperacusis.

Pereira, I. (July 9-10, 2015). Hyperacusis and autism: An entry point to learn about genomics and hearing disorders? Second Annual International Conference on Hyperacusis, Birkbeck College, University of London, London, England. From website: <http://hyperacusisresearch.org/hyperacusis-ich2-report/>.

Hyperacusis: Diagnosis

- Go to a “World Class” university medical center (i.e., Harvard Medical School, Vanderbilt Medical School, Mayo Clinic, UCLA Medical School, etc.) and have the following:
 - a thorough medical examination
 - a very detailed history taken (i.e., medical, family, educational, audiological, work, social, etc)
 - a thorough ear examination
 - a thorough hearing examination
 - a thorough hyperacusis examination that includes a loudness discomfort test.

The American Academy of Otolaryngology Head and Neck Surgery states the following is involved in an evaluation for hyperacusis”

- A full audiological evaluation
- An evaluation by an Otolaryngologist (Ear, Nose, & Throat Doctor)
- A medical physical

Baguley, D.M. (2007); Author (No Date). Hyperacusis: An Increased Sensitivity to Everyday Sounds. From website:

[http://www.entnet.org/content/hyperacusis-increased-sensitivity-everyday-sounds.](http://www.entnet.org/content/hyperacusis-increased-sensitivity-everyday-sounds)

Hyperacusis Treatments

- Ear plugs, sound suppression head phones/ear buds, ear muffs

BUT

- If someone does this it can cause them to be more sensitive to sounds after they remove the ear protection
- One option is 6 months to a year of sound desensitization therapy
 - Some believe that Auditory Integration Therapy (AIT) may be helpful, but the Association of Speech-Language Pathologists (ASHA) does not believe there is sufficient scientific research to indicate it works.
- What may work is biofeedback, relaxation training, and acupuncture

Goodson, S. et al. (2015). Hyperacusis: Audiology Information Series. Rockville, MD: American Speech-Hearing Association. From website:

<http://www.asha.org/uploadedFiles/AIS-Hyperacusis.pdf#search=%22Hyperacusis%22>.

Hyperacusis Treatments

- Some use exposure to “pink noise” with the hope that it will desensitize them to their hyperacusis.
- Pink Noise is similar to white noise.
- CDs with such sounds are available from the Hyperacusis Network, P.O. Box 8007, Green Bay, WI 54308; www.hyperacusis.net
- Relaxation training and hypnosis for anxiety control may be helpful, too.

Beth-Anne C. et al. (2015). Hyperacusis. Woodseats Close Sheffield, England: British Tinnitus Association. From Website: <http://www.tinnitus.org.uk/contact-us>.

The American Academy of Otolaryngology Head and Neck Surgery states on it’s website:

- There is no specific medical treatment
- Sound therapy using a white noise generation may be helpful

Author (No Date). Hyperacusis: An Increased Sensitivity to Everyday Sounds. From website: <http://www.entnet.org/content/hyperacusis-increased-sensitivity-everyday-sounds>.

Treatment of Hyperacusis

- **There are no cures**
- **Counseling and Sound Therapy with machines that expose the patient to low level background sounds help some.**
- **Neuropathic pain appears similar to auditory nociceptive pain and responds to medications that produce more of the neurotransmitter GABA.**
 - **The medications gabapentin (Neurontin®) and pregabalin (Lyrica®) have been found to help some with hyperacusis (first line treatment, works with 30% about 30% relief).**
 - **SSRI anti-depressants may also be helpful to some.**

Treating Hyperacusis in Those with Autism Spectrum Disorder

- Remove the sound from the environment
- Use sound suppression (i.e., silicone ear plugs, sound suppression – Bose Quiet Comfort headphones, a fan, etc.
- Explaining the cause and the duration of the painful sound may be helpful: Carol Gray’s “Social Stories” offer such information - <http://www.thegraycenter.org/social-stories>

Attwood, T. (2007). The Complete Guide to Asperger’s Syndrome. Philadelphia, PA: Jessica Kingsley, 221.

Auditory Integration Therapy

“There is no evidence that auditory integration therapy or other sound therapies are effective as treatments for autism spectrum disorders. As synthesis of existing data has been limited by the disparate outcome measures used between studies, there is not sufficient evidence to prove that this treatment is not effective...As such, there is no evidence to support the use of auditory integration therapy at this time.”

Sinha, Y., Silove, N., Hayen, A., Williams, K. (December 7, 2011). Auditory integration therapy for autism spectrum disorders. http://www.cochrane.org/CD003681/BEHAV_auditory-integration-therapy-for-autism-spectrum-disorders.

Touch



2018 05 17

Autism, GABA, and Touch

GABA and Tactile Defensiveness:

Researchers recently found that children with autism have reduced GABA which causes them difficulty in behavioral inhibition and tactile information processing (i.e., tactile defensiveness).

Puts, N. et al. (September 9, 2016). Reduced GABA and Altered Somatosensory Function in Children with Autism Spectrum Disorder. Autism Research. DOI: 10.1002/aur.1691.

Touch and ASD:

Children with autism have higher tactile thresholds than non-ASD children and the bigger the ratio the more autistic traits the ASD child has. The less inhibition to tactile stimuli the more ASD symptoms the autistic child has. This is connected to the GABA neurotransmitter system.

Tavassoli, T. et al. (June 2016). Altered tactile processing in children with autism spectrum disorder. Autism Research, 9(6), 616-620.

Sensory Issues and ASD

Sensory Processing in Those with ASD:

British researchers reported results of a study that indicated that those children with ASD significantly different audiovisual, auditory, and visual processing of social facial, and speech stimuli than typically developing children. Those with ASD have significantly less activation in the brain areas that do the above processing and in the frontal lobe when exposed to social stimuli.

Regener, P. et al. (May 13, 2016). An fMRI Investigation of Audiovisual, Auditory and Visual Processing in Autism Spectrum Disorder. Paper presented at the International Society for Autism Research, International Conference, Baltimore, MD.

Researchers at the University of California Davis found that children with out a disability, those with developmental disorders and those with autism spectrum disorder all tend to have sensory issues, particularly in the smell, taste and auditory senses when they are very young, but they typically developing children grow out of them. Those with developmental disorders and ASD often do not.

McCormick, C., et al. (September 22, 2015). Sensory symptoms in children with autism spectrum disorder, other developmental disorders and typical development: A longitudinal study. Autism. DOI: 10.1177/1362361315599755.

Neurology, Autism and Touch

There are three types of nerve fibers related to touch:

- **A-beta = - they discriminate what is felt, are all over the body (especially the palm), are highly myelinated and send messages very fast.**
- **Two different types of C fibers that detect pain and itches –The information these transmit moves slower, but is richer.**

Denworth, L. (July/August, 2015). The Social Power of Touch. Scientific American, Mind, 26(4), 30-39.

Cascio, C. et al. (April 6, 2007). Tactile Perception in Adults with Autism: a Multidimensional Psychophysical Study. Journal of Autism and Developmental Disorders, 38(1), 127-137.

- **C - Tactile, or CT fibers - found on the hairy skin of the back and forearm, tuned to gentle touch, temperature, light touch, slow transmitting - unmyelinated CT fibers**
- **The CT Fibers appear to be geared more to feeling than sensing, and touch that is rewarding**
- **Touch is the first sense to develop in utero and is the most developed at birth**
- **People with autism appear to have difficulty with the CT- fiber system and forming social bonds; they often do not find gentle stroking as rewarding**

Tactile Defensiveness



“Asperger reported primarily on hypersensitive behaviors. Those who are hypersensitive feel actual physical discomfort when coming into contact with someone or something the rest of us are barely aware of” (p. 23).

Myles, B.M., Tapscott-Cook, K., Miller, N.E., Rinner, L., and Robbins, L. (2000). Asperger Syndrome and Sensory Issues: Practical Solutions for Making Sense of the World. Shawnee Mission, KS: Autism Asperger Publishing

Tactile Defensiveness



Roffman wrote, “ Individuals with problems in this area may use either too light or too tight a grip when they shake hands with others. They may also be hypersensitive to touch (p. 16). Roffman continued that such problems in a child can lead to problems in parental bonding, problems in getting a haircut and workplace problems in adulthood.

**Roffman, A.J. (2000). Meeting The Challenge of Learning Disabilities In Adulthood.
Baltimore, MD: Brookes.**

Tactile Defensiveness

“Particular parts of the body appear to be more sensitive, namely the scalp, upper arm and palms...The child may hate handling certain textures, such as finger paints or playdough. There can also be reluctance to wear a variety of clothing...” (p. 134).

Attwood, T. (1998). Asperger Syndrome: A Guide for Parents and Professionals. Philadelphia, P.A.: Jessica Kingsley.

Adults with ASD can experience light touch as exceptionally painful sensory experience. Light “affectionate” touch on one’s forearm can be particularly painful. Unanticipated touch can cause a startle response.

Scarpa, A., Williams-White, S., and Attwood, T. (2013). CBT for Children and adolescents with Autism Spectrum Disorders. New York, NY: Guilford.

Tactile Defensiveness

“Despite frequent anecdotal accounts from both professionals and parents that SI (sic. Sensory Integration Therapy) therapy can improve behavior and functioning, there is little scientific validation for this technique as yet. In fact, some studies have shown that SI interventions are no better than more traditional therapies...You may want to try them out, but as with all treatments...especially those for which there is little research support...be skeptical and carefully assess the benefits you see” (p. 102).

Ozonoff, S., Dawson, G., and McPartland, J. (2002). A Parent’s Guide to Asperger Syndrome & High Functioning Autism. New York, NY: Guilford.

Adult Tactile Defensiveness

Willey (1999) an adult with Asperger's Disorder made the following suggestions for what she called "Tactile Sensitivity":

- "If you dislike being touched, politely ask those around you to warn you before they touch you or ask them not to touch you at all. If you decide someone can touch you, let them know which you prefer, light or firm pressure.**

Willey Continued:

- If even the slightest sensation aggravates your nerves, try to move your work, study and other personal spaces as far away as you can from air vent currents, window treatments and other obstacles that might inadvertently brush against your body.**
- If you enjoy the sensation of deep pressure, you might put weights...in the pockets of jackets..." (p. 155-156).**

Willey, H.L. (1999). Pretending to be Normal: Living with Asperger Syndrome. Philadelphia, PA: Jessica Kingsley.

Adult Tactile Defensiveness



Willey Also Suggested:

- Get every garment made of materials that feel good.
- Cut hair short if you cannot stand to wash your hair.
- If you need to chew do so on paraffin wax, rubber tubing, gum or plastic straws.
- Use squeeze balls for motor restlessness.
- Bathing with brushes and scrubbing lightly or firmly

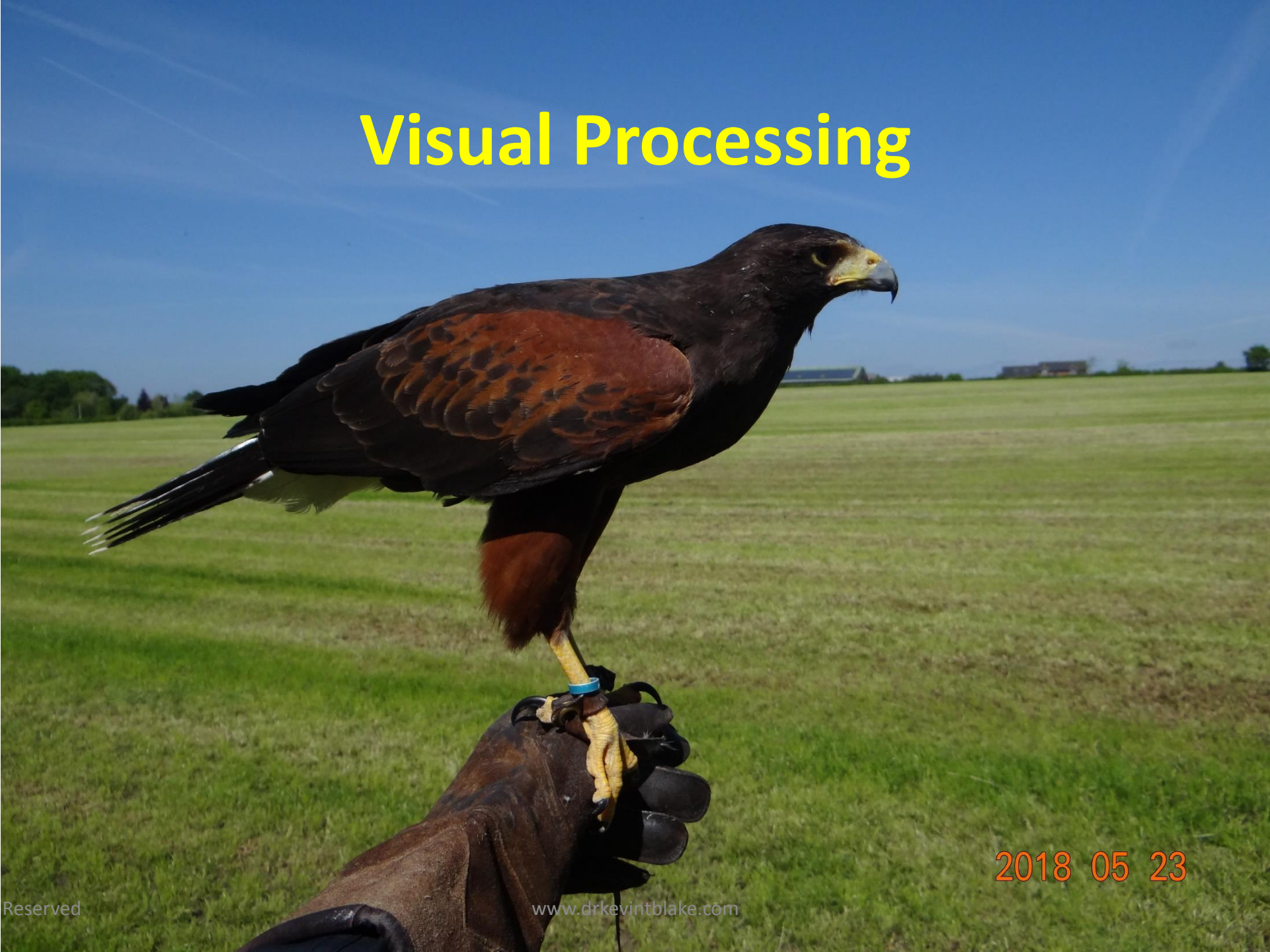
Willey, H.L. (1999). Pretending to be Normal: Living with Asperger Syndrome. Philadelphia, PA: Jessica Kingsley.

Tactile Defensiveness

- **Helpful Profession:**
 - **American Occupational Therapy Association:**
www.aota.org



Visual Processing



2018 05 23

ASD and Visual Processing Difficulties

- Temple Grandin reported that people with ASD often have visual processing difficulties.
- For this she suggested behavioral optometry and Irlen filters and colored overlays. She particularly likes the colored overlays and sunglasses because they are inexpensive and if they do not work the person is not out much.

Grandin, T. (March 15, 2011); (July 18, 2015)

- College of Optometrists in Vision Development (COVD): <https://www.covd.org/>
- Irlen International: <https://irlen.com/>
- North American Neuro-Ophthalmology Society: <https://www.nanosweb.org/home.cfm>
- Society for Behavioral and Cognitive Neurology: <http://the-sbcn.org/>
- American Neuropsychiatric Association: <https://www.anpaonline.org/>

Vision Therapy

“Vision problems can interfere with the process of reading, but children with dyslexia or related learning disabilities have the same visual function and ocular health as children without such conditions. Currently, there is inadequate scientific evidence to support the view that subtle eye or visual problems cause or increase the severity of learning disabilities. Because they are difficult for the public to understand and for educators to treat, learning disabilities have spawned a wide variety of scientifically unsupported vision-based diagnostic and treatment procedures...”

“...Scientific evidence does not support the claims that visual training, muscle exercises, ocular pursuit-and-tracking exercises, behavioral/perceptual vision therapy, “training” glasses, prisms, and colored lenses and filters are effective direct or indirect treatments for learning disabilities. There is no valid evidence that children who participate in vision therapy are more responsive to educational instruction than children who do not participate.

Handler, S.M. et al. (March 2011). Learning Disabilities, Dyslexia, and Vision. Pediatrics. From website:
<http://pediatrics.aappublications.org/content/127/3/e818.short>.

Vision Therapy

“Recent studies indicate that office-based therapy with home reinforcement is the most effective treatment for convergence insufficiency. Home-based treatment with pencil pushups or computer programs hasn't been shown to be as effective. But home treatment costs less and is more convenient and more readily available.”

Author (No Date). [Convergence insufficiency](https://www.mayoclinic.org/diseases-conditions/convergence-insufficiency/diagnosis-treatment/drc-20352739). From website: <https://www.mayoclinic.org/diseases-conditions/convergence-insufficiency/diagnosis-treatment/drc-20352739>.

ASD & Employment

National Accounting Office: 2009 ASD Report

❖ National Accounting Office of Great Britton reported in 2009:

- ½ of those with ASD in England met criteria for Intellectual Developmental Disorder
- Only 15 percent of those who have ASD were full-time employed

Burr, T. (May 28, 2009). Supporting People with Autism Through Adulthood. Comptroller and Auditor General (British) National Audit Office, Ordered by the House of Commons. London. Great Briton: The Stationary Office. www.nao.org.uk/autismdvd.

ASD After High School

“For youth with an ASD, 34.7% had attended college and 55.1% had held paid employment during the first 6 years after high school. More than 50% of youth who had left high school in the past 2 years had no participation in employment or education. Youth with an ASD had the lowest rates of participation in employment and the highest rates of no participation compared with youth in other disability categories. Higher income and higher functional ability were associated with higher adjusted odds of participation in postsecondary employment and education.” (p. 1042)

Shattuck, P.T., Carter Narendorf, S. Cooper, B., Sterzing, P.R., Warner, M., and Lounds Taylor, J. (May 14, 2012). Postsecondary Education and Employment Among Youth With an Autism Spectrum Disorder. *Pediatrics*, 129, 1042-1049. From website:
<http://www.clarionledger.com/assets/pdf/D0189267514.PDF>.

Charli Devenet: Adult on the Spectrum

“Although I have several advanced degrees, I have spent most of my life either unemployed or underemployed. By my mid-40s, I had learned to eke out a subsistence living by putting together a patchwork of part-time, low-paying jobs, all of which I was overqualified for. (p. 19)

- ❖ Charli has an Master of Arts Degree, Law degree and has passed the Bar**
- ❖ Charli works as a museum tour guide and legal researcher**

Grandin, T. (2012). Different...Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger's and ADHD. Arlington, TX: Future Horizons.

Social Motivation



2017 06 27

How to Motivate ASD Students to Learn Social Skills

- **After years of social rejection many ASD students want to be accepted for who they are and do not want to change to meet others expectations.**
- **One way of hooking them into learning social skills is to “invite” them to teach social skills to others.**
- **A good philosophy to adopt with ASD students about teaching them social skills is to say you are teaching them optional behaviors that may add to their ability to meet their goals. Acquiring these new skills will not threaten their uniqueness.**

Baker, J. (2005). Preparing for Life: The Complete Guide for Transitioning to Adulthood for Those with Autism and Asperger’s Syndrome. Arlington, TX: Future Horizons.

Denial: The Longest River in Egypt

Baker Recommends the following to get past “the Nile”:

- **Link needed training/service to their goals**
- **Make the process fun**
- **Use a reward system**
- **Work on strengths before weaknesses**
- **Get examples of successful ASD adults (Dr. Grandin)**
- **Encourage them to teach younger ASD students**

Baker, J. (2005). Preparing for Life: The Complete Guide for Transitioning to Adulthood for Those with Autism and Asperger’s Syndrome. Arlington, TX: Future Horizons.

Employment

2017 06 24

Barriers for Employment for those with ASD

Attwood, T. (2007). The Complete Guide to Asperger's Syndrome. Philadelphia, PA: Jessica Kingsley

- **Poor time keeping**
- **Poor organizational skills**
- **Lack of concentration**
- **Difficulty multitasking**
- **Poor social skills**
- **Difficulty coping with change**



State/Federal Work Transition

➤ **Pacer Center Project C3:**

- **Designed for those with disabilities to improve postsecondary and employment outcomes.**
- **Teaches parents and professionals about services available**
- **Helps children and adolescents with disabilities prepare for adulthood and self-advocacy**

➤ **www.pacer.org/c3**

College Internship Program

“CIP provides individualized social, academic, career and life skills instruction for students with Asperger's, Nonverbal, PDD-NOS, ADHD and other Learning Differences. Students obtain the skills necessary to inspire independence and expand the foundation on which they can build a happy and productive life.”

Website:

www.cipworldwide.org/about.html

Private Transition Programs

- **Options Program at Brehm (Carbondale, IL):**
 - Structured living environment and independent living skills training
 - Social skills training
 - Academic training:
 - College transition track
 - Certificate transition track
- **www.options.brehm.org**
- **“Chapel Haven West, Inc. in Tucson, AZ provides a residential transition program followed by lifelong supports for adults 18+ with mild developmental disabilities and those on the autism spectrum.”**
- **<https://www.chapelhaven.org/chapel-haven-west/>**

Other College Preparation Programs

- **Landmark College:**
 - Putney, VT
 - Website: www.landmark.edu/
- **Say YES (Your Education Solution) to College**
 - A College Transition Program for Students with Disabilities, Old Dominion University Campus
 - Phone: 757-683-3639
- **Wax, I.F., and Kravets, M. (2005). K & W Guide to Colleges for Students with Learning Disabilities or Attention Deficit Disorder, 8th Edition (College Admissions Guides). Princeton, NJ: Princeton Review.**



APSE: Association for Persons in Supportive Employment

- This is an association of on-site job coaches.
- Address: 416 Hungerford Dr., Suite 418, Rockville, MD 20850;
- Phone: 301-279-0060
- Fax: 301.279.0075
- Website: www.apse.org

Similar programs in Great Britton have had as much as a 70% employment rate for ASD adults over several years (Prospects Employment Service, National Autistic Society, Great Britton).

Attwood, T. (2007). The Complete Guide to Asperger's Syndrome. Philadelphia, PA: Jessica Kingsley, p. 299.

Workplace Accommodations

Job Accommodations Network
P. O. Box 6080
Morgantown, WV 26506-6080
Voice/TTY (in US): 1-800-526-7234
Voice/TTY (Worldwide): 1-304-293-7186
Fax: 1-304-293-5407
Web: www.askjan.org

- **The Job Accommodations Network has a link on its website called SOAR (Searchable Online Accommodation Resource):**
- **“A grocery stock person with Autism cannot remember to wear all parts of his uniform. JAN suggested taking a picture of the employee in full uniform. Give him the picture and allow him to use the picture as reference when preparing for work. Approximate accommodation cost is \$5”.**
- **<https://askjan.org/soar/MR/MRx.html>.**

Workplace Accommodations

- **Center for Assistive Technology and Environmental Access (CATEA):**
“...a multidisciplinary engineering and design research center dedicated to enhancing the health, activity and participation of people with functional limitations through the application of assistive and universally designed technologies in real world environments, products and devices”.
- **CATEA:** <http://www.catea.gatech.edu/>

AHEAD



- **Association on Higher Education and Disability (AHEAD):**
- **Comeau, L. & Cronin, M. (2011). The Essential Six, Volume One (A Parent's Guide: How to Pave the Road to Self-Advocacy for College Students with Learning Differences). Huntersville, NC: AHEAD.**
- **www.ahead.org**

Interest to Career Help

- **O-net Online: “O-NET Online has detailed descriptions of the world of work for use by job seekers, workforce development and HR professionals, students, researchers, and more!”**
- **www.onetcenter.org**



The Wall Street Journal

Temple Grandin says that articles about workplace behavior have been very helpful for her in learning about and understanding work environments. She recommends people on the spectrum subscribe to it to get helpful workplace hints.

Grandin, T. (2011). The Way I See It: A Personal Look at Autism & Asperger's Second Edition. Arlington, TX: Future Horizons.

American College Testing (ACT): Documentation Requirements

- **ACT Policy for Documentation to Support Requests for Test Accommodations on the ACT (No Writing) or ACT Plus Writing:**
<http://www.act.org/aap/disab/policy.html>
- **ACT Services for Students with Disabilities:**
www.act.org/aap/disab/



Self-Awareness & ASD



Self-Awareness

“Not only does accurate self-awareness help motivate the learning process, but it also leads to more efficient self-advocacy. With accurate knowledge one can plan better how to deal with otherwise frustrating situations.” (p. 11) “It takes a modicum of self-esteem to tolerate thinking about what difficulties you have. Many students who have had many academic and social difficulties are in no position to tolerate any critical feedback about their behavior. Without being able to tolerate such feedback their personal growth is stymied.” (p. 14)

Baker, J. (2005). Preparing for Life: The Complete Guide for Transitioning to Adulthood for those with Autism and Asperger’s Syndrome. Arlington, TX: Future Horizons.

Self-Awareness: Evaluation

The student needs a thorough evaluation which can be done by the public school's special education evaluation team, or the parent/guardian of the student can obtain this for the student privately. Such an evaluation should include, at the least, medical, neurological, developmental, psychological, speech and language, hearing and vision evaluations and can typically be obtained from the nearest university medical center.

“The Diagnosis”

I believe the student should be told their diagnosis as soon as they are cognitively and emotionally capable of hearing it. They will need to be able to speak knowledgeably about it as an adult to self-advocate and to receive mandated services. An effort should be made to emphasize their strengths and to inform them of their weaknesses. And let them know, everyone has both.

“The Diagnosis” & Life Planning Timeline

- **Jed Baker, Ph.D. recommends discussing two or three strengths per every one weakness the student has when they learn about their diagnosis.**
- **Jed Baker, Ph.D. has a nice life planning guideline in his book on transitioning:**

Baker, J. (2005). Preparing for Life: The Complete Guide for Transitioning to Adulthood for those with Autism and Asperger’s Syndrome. Arlington, TX: Future Horizons, 30-32.



Person-Centered Planning

**This, “...is an umbrella term used to describe several approaches to developing goals for the future and identifying the supports and resources a disabled person may need to achieve his/her goals.”
(p. 32)**

Baker, J. (2005). Preparing for Life: The Complete Guide for Transitioning to Adulthood for Those with Autism and Asperger’s Syndrome. Arlington, TX: Future Horizons.

➤ Such plans:

- Ensure the disabled individual is heard
- Begin with how they want to live today and build upon that to plan for tomorrow
- Take into account information from their family and friends about the person
- And, investigate government, private, church, family and friends that can provide support.

Person-Centered Planning

- **Places you can find person-centered planning programs:**
 - **Cornell University Person-Centered Planning Education Site:** www.ilr.cornell.edu/edi/pcp/courses.html.
 - **The Learning Community for Person Centered Practices:** www.elp.net
 - **Allen, Shea, & Associates:** www.allenshea.com
 - **Capacity Works:** www.capacityworks.com

Decision Making & Problem Solving

- Teaching children decision making skills should begin in preschool.
- **“Mary do you want milk, or orange juice?”**
- By adolescence they should be taught how to use a decision and problem solving process to help them become independent.

Walker, E. (2010). Decision Making/Problem Solving Solutions with Teens (Fact Sheet). Columbus, OH: Family and Consumer Sciences, Ohio State University
Extension: form: HYG-5301-98-R10.

1. Identify and define the problem
 - a. Consider goals and optimum outcome
2. Brainstorm all alternatives
 - a. Encourage serious ideas
 - b. Encourage silly ideas
 - c. Write them down and don't be judgmental

Teaching Decision Making & Problem Solving

3. Evaluate all options.

- a. Provide guidance and encouragement**
- b. Ask them permission to point out concepts they may not have thought of. This empowers them and fosters independence.**
- c. Help them determine if their decisions would infringe on the rights of others, is unkind, unfair, dishonest, etc. This is particularly important for ASD students with theory of mind issues.**

4. Choose an option that does not hurt others.

5. Commit to a plan to implement the option.

6. Evaluate the decision and its outcome

- a. Ask what was learned by this experience and how it can help in the future.**
- b. Discuss how the decision was made.**
- c. Have them take ownership of the decision.**
- d. Don't brow beat them.**

7. Give them a laminated page with the steps for decision making on it.

Walker, E. (2010). Decision Making/Problem Solving Solutions with Teens (Fact Sheet). Columbus, OH: Family and Consumer Sciences, Ohio State University Extension: form: HYG-5301-98-R10.

A Lifetime of Job Decisions

- **The average person in the U.S. has held 11 jobs in their lives between the ages of 18 and 44.**
- **It is important for the ASD student to learn career building skills and decision making because they will probably have many jobs in their lives. They will also probably need to be lifetime learners with regards to job skills.**

Bureau of Labor Statistics, U.S. Department of Labor (September 10, 2010). NUMBER OF JOBS HELD, LABOR MARKET ACTIVITY, AND EARNINGS GROWTH AMONG THE YOUNGEST BABY BOOMERS: RESULTS FROM A LONGITUDINAL SURVEY. Form: USDL-10-1243. From Website: <http://www.bls.gov/news.release/pdf/nlsoy.pdf>.

Motivation

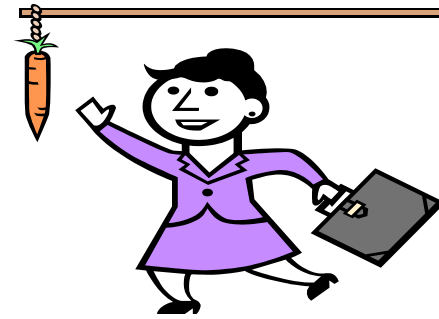
“After years of social rejection, they want to be accepted for who they are rather than be told they need to change. How then could I motivate them to want to learn new social behaviors without suggesting that there was something problematic about their social functioning?” (p. 1)

Baker, J. (2005). Preparing for Life: The Complete Guide for Transitioning to Adulthood for those with Autism and Asperger’s Syndrome. Arlington, TX: Future Horizons.

- **An individual can become so discouraged regarding their ability to get and keep a job they can begin to think a job is for other people not a loser like me.**
- **Parents of adult disabled children often become the “naggers” and the child becomes the “naggee” and this causes huge friction within a family.**

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

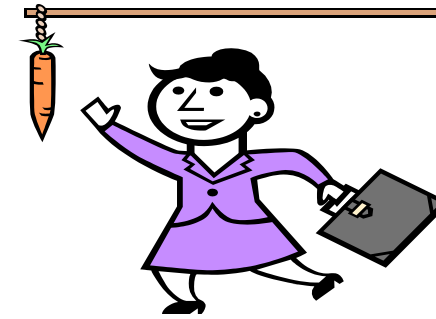
Motivation



- Hiring a “professional nag” may be the solution; the “Life Coach”:
 - The, “...partnership between a client and a coach that helps the client move toward goals and take actions that will enable them to become the person they want to be in a more focused and rapid way than they would be able to do on their own.” (p. 167)

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

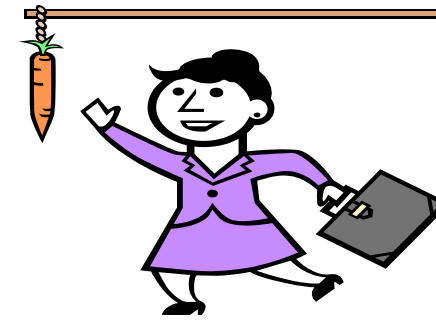
Motivation



One way to motivate ASD students to learn social skills is to encourage them to learn social skills so they can teach others, perhaps to younger ASD students. To be able to teach something you must learn a lot about it, hence they will have to learn the social skills.

Baker, J. (2005). Preparing for Life: The Complete Guide for Transitioning to Adulthood for those with Autism and Asperger's Syndrome. Arlington, TX: Future Horizons.

Motivation



- Life coaches change negative self-talk that gets in the way of success.
- The life coach enters into a relationship where client accountability is paramount. “When clients agree to take action and move forward with a coach, they are more likely to actually follow through because they have to report back to the coach in their next session.” (p.170)

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

How to Find a Life Coach

- **International Coach Federation:** www.coachfederation.org
 - **Suggestion:** try to get one with at least a Masters degree in a mental health field.
 - **DeAngelis, T. (2010). First-Class Coaching. Monitor On Psychology, 41 (10), 48:** <http://www.apa.org/monitor/2010/11/life-coaches.aspx>

One Stop Career Centers

Now Known as “CareerOneStop”, it is a partnership between the individual states and the U.S. Department of Labor that provides a whole menu of services, including career exploration and counseling, job training and listings, resume services, job interview training, and information on various careers Available at:
www.careeronestop.org/.

Vocational Rehabilitation

- **When you cannot do your job due to a disability you can receive services for free from your state's Vocational Rehabilitation Center.**
- **One works with a “VR Counselor” who helps you learn ways to work around your disability.**

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Vocational Rehabilitation

- One needs documentation of having a disability written by a physician and/or mental health professional.
- The VR Counselor will interview the client to determine how they are doing in one of seven areas:
 - Getting to work, etc.
 - Listening and talking to others
 - Self-care
 - Work skills

- Cooperating with others
- Making and carrying out plans
- Needed job accommodations

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.



Vocational Rehabilitation

- The VR counselor will help the client create an “employment plan” which meets their needs, will lead to a job, and is complete.
- The VR counselor will determine if the client needs additional training and will help them get it.
- The VR counselor will give them advice on what the right job for them is given their interests, abilities, skills and disability/needs.

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Volunteer Work



- **If all else fails consider volunteer work:**
 - **It gets the disabled adult child “off the couch”**
 - **May help them to develop some self-esteem**
 - **May help them develop some job skills**
 - **May help them get a job eventually through their volunteerism.**

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Career Counseling

- **Most community colleges offer extensive career counseling for young people, even those with disabilities:**
- **This would include:**
 - **An interview, an interest inventory, a career search, job shadowing and possible internships, volunteering, college majors and votech/trade schools training**
 - **What the person is not interested in is just as important as what they are interested in.**
 - **Also check out the National Career Development Association:**
http://associationdatabase.com/aws/NCDA/pt/sp/Home_Page

Skilled Trade Schools



“Trade schools can prepare you for a satisfying career that lets you use your hands to make a noticeable impact in the world. In fact, the skilled trades represent some of the smartest and most fulfilling job choices available today. If you enjoy building stuff, fixing problems, and doing work that is truly useful, then selecting a good trade school is one of the best ways to get closer to a life you can really be proud of.”

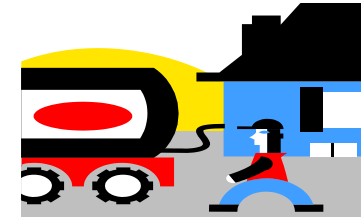
Author (No Date). Trade Schools, Colleges and Universities: Vocational and Skilled Trades. From website:

<http://www.trade-schools.net/directory/trade-schools-directory.asp>.

➤ Where to find Skilled Trade Schools:

➤ <http://www.trade-schools.net/directory/trade-schools-directory.asp>

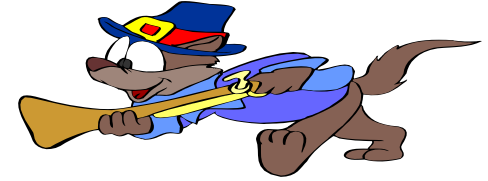
Types of Jobs



Often working a job at a large company doing a monotonous task works better. Adults with disabilities often thrive with repetition and are adverse to change. When you work for a small employer you often must do more things on the job.

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Career Counseling & Job Hunting



- **Resume and cover letter:** Use a resume/social media service
- **Interview:** be on time, dress appropriately, bring a pen and paper, no gum, soda, smoking, etc., be polite and smile. Practice, practice, practice for the job interview! A career counselor can help with all of the above, too.

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

- **Where to find a career counselor:**
 - **National Career Development Association:**
http://associationdatabase.com/aws/NCDA/pt/sp/Home_Page

Work Portfolio

- **One can use their special Interests in getting a job (i.e., interest in video games = job creating video games, etc.).**
- **One can create a professional portfolio of examples of their special interests as part of their resume.**

Attwood, T. (2007). The Complete Guide to Asperger's Syndrome. Philadelphia, PA: Jessica Kingsley, p. 195.

Disclosing of One's Disability

- **This is an important life skill for anyone with a disability.**
- **It is also fraught with “landmines”.**
- **A person with a disability needs to learn how the law applies to this, how to inform a teacher, professor, and/or employer about their disability confidently and knowledgeably as well as when it is safe and not safe to disclose.**
- **National Disability Rights Network (How to find Disability Law Centers in Your State): www.ndrn.org**

Work Support for ASD

“Findings suggested that support throughout the first few weeks is crucial. However, there remains a need for flexibility with support as several clients went through periods of change at work or had other problems which meant they had a temporary need for a boost in their support hours.” (p. 367)

Nesbitt, S. (2000). Why and Why Not? Factors Influencing Employment for Individuals with Asperger’s Syndrome. Autism, 4(4), 357-369.

Workplace Social Rules

“Where are the rules of the workplace written and how come it seems not everyone got the memo? The ‘memo’ it turns out, is something most people are born with – an intuitive sense that allows them to be naturally aware of social expectations and feeds them the information they need to follow the social code.” (p. vii)

“In most companies, each promotion requires not only advanced knowledge or abilities, but a higher level of social and organizational skills as well.” (p. 127)

Garcia Winner, M., and Crooke, P. (2011). Social Thinking At Work: Why Should I Care. San Jose, CA: Social Thinking.

Tony Attwood on Successful “Aspie” Employment Outcomes

“Where there is a successful outcome, common themes include the discovery of a mentor within the person’s family circle of friends and colleagues, who is able to provide guidance and encouragement, as well as the individual’s personal qualities of determination and perseverance...”

**“...Other keys to a successful outcome are employment during adolescence in the form of a part-time job and recognition that there is no career that should be avoided by someone with an autism spectrum disorder.”
(p. 3)**

Attwood, T. (2012). Forward; In Grandin, T. (2012). Different...Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger’s and ADHD. Arlington, TX: Future Horizons, p . 3-4.

Temple Grandin, Ph.D. Says:

“I am what I do.”(p. 5)

Grandin, T. (2012). Different...Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger's and ADHD. Arlington, TX: Future Horizons.

“I sold my work, not myself.” (p. 6)

Grandin, T. (2012). Different...Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger's and ADHD. Arlington, TX: Future Horizons

Temple Grandin On Her Employment History

“I always found opportunities for work by locating the ‘back door.’ I never landed a job by filling out a job application or doing a formal interview. I got my freelance business started by showing potential clients a portfolio of my work.” (p. 381)

Grandin, T. (2012). Different...Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger's and ADHD. Arlington, TX: Future Horizons

Temple Grandin's Employment Insights

- **Teens on the spectrum need a job.**
 - **Those on the spectrum need to learn how to do work that is assigned by others.**
 - **Those on the spectrum must learn to complete work in a timely fashion in a way the employer expects it.**
- Grandin, T. (2012). Different...Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger's and ADHD. Arlington, TX: Future Horizons.
- **Develop connections and a portfolio**
 - **Find mentors**
 - **Know what your potential employer wants**
 - **Do one project at a time**
 - **Find a career niche that fits abilities & skills**
 - **Don't fixate on being on the spectrum**
 - **Find a business manager**
 - **People on the spectrum continue to grow throughout life**

Work & ASD

- **“Many of us are workaholics. Many working AS adults report that we ‘have no life’ outside work. When we say this to others, our statements appear to be exaggerations...We know differently.” (p. 12)**
- **“As young persons, many of us didn’t learn that play has an intrinsic value in our lives” (p. 12).**

Myer, R.N. (2001). Asperger Syndrome Employment Handbook. Philadelphia, PA: Jessica Kingsley.

“You feel so exhausted daily just from ‘hanging on’ or controlling yourself that you feel drained, virtually unable to function. You need a full recharge of your batteries just to face the next day. *Result: You don’t have time for family, intimate relationships, friendship and otherwise diverse interests to balance your life outside of work. You realize you are working just to work.*” (p. 13)

Work & ASD

“Like other non-AS working adults, we accept the fact that work is often unpleasant. We bitch and moan about it just like NT (neurotypical) folks. There’s one important difference: Somehow, they manage to break free of their ruminations and get on with their lives.” (p. 12)

Beware of the “Cassandra Syndrome” ...Those at work not believing the professional documentation of your disability.

Myer, R.N. (2001). Asperger Syndrome Employment Handbook. Philadelphia, PA: Jessica Kingsley.

Work & ASD

“Many employment counselors are not comfortable with the idea that persons with disabilities are entitled to equal consideration for competitive employment (real, market-rate work). Some of us may not be ready for that kind of work either, but ultimately that is our decision to make, not theirs.” (p. 39)

- **“Buying Help”** regarding when and how to disclose and other work issues:
 - Professional Counselor, Employment Specialist, Job Coach, Job Developer, Vocational Rehabilitation Counselor
 - Voc Rehab has funds for training
 - Get training in how and when to disclose and other work related issues.

Myer, R.N. (2001). Asperger Syndrome Employment Handbook. Philadelphia, PA: Jessica Kingsley.



Work & ASD



- **“Buying Help”**: High school students over 16 can “buy help” through the federal school transition program due to the special education laws. Voc Rehab is mandated to be part of your transition team.
- **“A transition plan is geared towards assuring your success as an independent adult.”**(p. 50)
- **“Horse Trade”** skills and talents for accommodations not typically given to other employees.
- Go for the lowest tech accommodation
- Help employer lower their liability exposure and increase your productivity.

Myer, R.N. (2001). Asperger Syndrome Employment Handbook. Philadelphia, PA: Jessica Kingsley.

Dr. Temple Grandin



- **Six things needed for a successful career transition:**
 1. Gradual transition from school to work
 2. Work with supportive employers and teachers
 3. Mentors
 4. Educate employers and employees (your strengths and weaknesses)
 5. Freelance
 6. Make a skills portfolio
- Grandin, T. (1996). Making the Transition from the World of School into the World of Work. Bloomington, IN: University of Indiana Resource Center for Autism. From Website: <http://www.iidc.indiana.edu/index.php?pageId=599>**

Driving, Dogs, & ASD



2017 06 20

Driving, Dogs & ASD

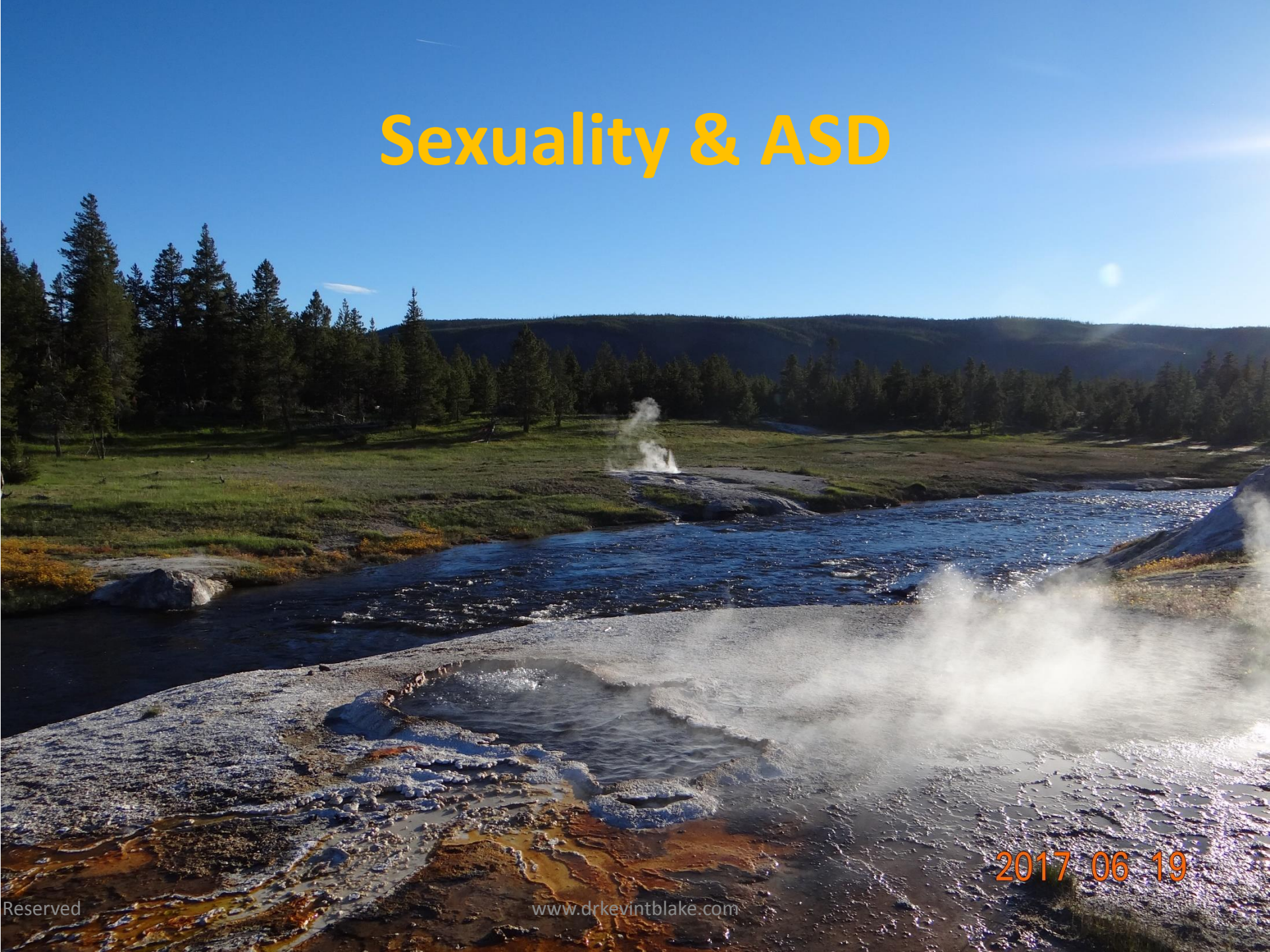
Only 1/3rd of those with ASD get their driver's licenses. They get them later than neurotypicals (9 months later). They also have trouble driving because they have trouble predicting the movement of objects.

--Curry, A.E. et al. (April 4, 2017); Daily, B.P. et al. (June 13, 2014); Shepard, E. et al. (May 4, 2016)

➤ **Driver Rehabilitation Institute:**
<https://www.driverrehabinstitute.org/>

- International Association of Assistance Dog Partners': www.iaadp.org
- Autism Service Dogs of America:
www.autismservicedogsofamerica.com
- Wilderwood Service Dogs for Autism:
www.autism.wilderwood.org
- Assistance Dogs for Autism:
www.autismassistancedog.com
- Northstar Foundation/Service Dogs for Autism:
www.northstardogs.com/autism.shtml
- **4Paws For Ability:**
www.4pawsforability.org

Sexuality & ASD



2017 06 19

Henault & Attwood ASD Sexuality Study

- **Derogatis Sexual Function Inventory**
- **19 males, 9 females; Mean age 32, range 18 to 64; 21 Asperger's Disorder; 5 HFA; 2 PDD: Average IQ**
- **“Although all developed an interest in sexuality around age 14, 11 of the 28 participants were still virgins.”**
- **For those who had intercourse the mean age for their first experience was 22.**

Henault, I. (2005). Asperger's Syndrome and Sexuality: From Adolescence through Adulthood. Philadelphia, PA: Jessica Kingsley.

Sexuality & ASD

“By then he had learnt a way to escape his uneasiness of lack of communication. It was masturbating on the edge of the bed or sofa.”

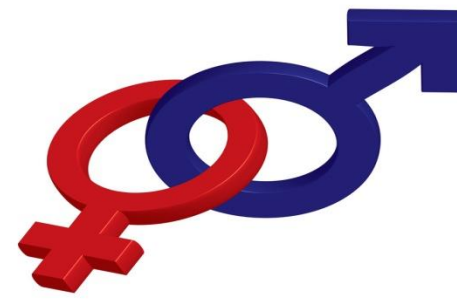
(Rajarshi (Tito) Mukhopadhyay)

“The desire for a girlfriend, which goes along with sex drive was so important to this young man that his failure made him consider whether life was worth living.” (p. 13)

Newport, J., and Newport, M. (2002). Autism-Asperger's & Sexuality: Puberty and Beyond. Arlington, TX: Future Horizons.

Mukhopadhyay , T. R. (2011). The Mind Tree: A Miraculous Child Breaks the Silence of Autism. New York, NY: Arcade.

“The Talk”



- Watch for signs of interest in sex: signs of masturbation (usually begins in middle school); “the hidden Playboy”; “forbidden” websites, etc.
- Most public schools begin introducing sex education late in fifth grade and it is mostly plumbing and how to not catch STDs.

Newport, J., and Newport, M. (2002). Autism-Asperger’s & Sexuality: Puberty and Beyond. Arlington, TX: Future Horizons.

“The Talk”



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- Most public schools begin introducing sex education late in fifth grade and it is mostly plumbing and how to not catch STDs.

- It is better to have the talk, “too early” than “too late.”
- Make sure you have it with you daughter prior to her first period.

Newport, J., and Newport, M. (2002). Autism-Asperger's & Sexuality: Puberty and Beyond. Arlington, TX: Future Horizons.

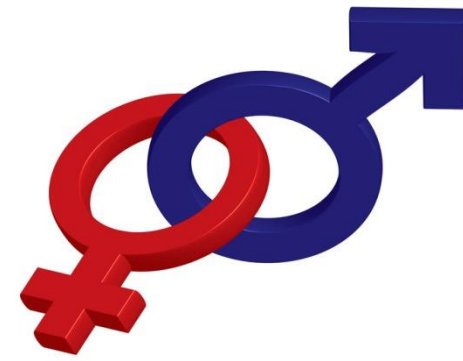
“The Talk”



- Use the signs of interests in sex as an entre to discussing sexuality.
- Find a good time and place for the discussion.
- Begin by asking them what they know.
- Tell them its OK to know these things, that sexuality is not “dirty” and correct their misinformation and/or interpretations in a kind way.
- Discuss you family’s values/ethics/morals related to sexuality.
- Go through age appropriate sex ed literature with your child.

Newport, J., and Newport, M. (2002). Autism-Asperger’s & Sexuality: Puberty and Beyond. Arlington, TX: Future Horizons.

“The Talk”



➤ What to discuss during the talk:

- Human anatomy with a diagram, discuss where it is appropriate to talk about sex, birth control, STDs and prevention, hygiene, responsibility, respecting wishes of partners, being left out, not using sex as a tool, “the talk” is not a one shot affair it is a process, warn them about “locker room bragging”, etc.

Newport, J., and Newport, M. (2002). Autism-Asperger’s & Sexuality: Puberty and Beyond. Arlington, TX: Future Horizons.

ASD & Masturbation

➤ **Henault (2014) stated:**

- **Masturbation must be addressed with those with ASD because it could lead to inappropriate materials (i.e., child pornography, etc.) and or inappropriate behavior (masturbating in public, etc.).**
- **She reported masturbation is the most common sexual behavior of teens with ASD.**

➤ **She continued those on the spectrum may masturbate compulsively, to distract themselves, or for stimming behavior.**

Henault, I (2014). Factors Influencing Sexual Development, In T. Attwood, I Henault, and N. Dubnin (2014). The Autism Spectrum, Sexuality and The Law: What Every Parent and Professional Needs to Know. Philadelphia, PA: Jessica Kingsley.

ASD & Masturbation

- **Public Masturbation**
- **Masturbation injury**
- **Believes masturbation is disgusting, etc.**
- **Fear of masturbation**
- **Cannot ejaculate or climax**
- **Masturbates constantly**

Hingburger, D. (1995) Hand Made Love: A Guide for Teaching About Male Masturbation Through Understanding and Video. Barrie, Ontario, Canada: Diverse City.

- **Teach:**
 - **Masturbation is healthy. Counter myths**
 - **Done in private**
 - **Appropriate sexual fantasy**
 - **Learn what is pleasurable**
 - **Us K-Y Jelly (water lubricant)**
 - **Masturbation DVDs:**
www.diversecity.com

--Henault, I (2005)

Medical Treatment for Compulsive Masturbation and ASD

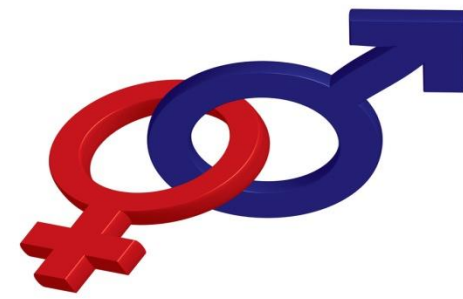
Doyle and McDougle (2012) wrote of using mirtazapine (Remeron), a tetracyclic antidepressant, in successfully managing compulsive masturbation and inappropriate sexual behavior.

Doyle, C.A., and McDougle, C.J. (September, 2012). Pharmacologic treatments for the behavioral symptoms associated with autism spectrum disorders across the lifespan. *Dialogues in Clinical Neuroscience*. 14(3), 263-279.

Scientist from Switzerland reviewed the case studies where medication was used to control masturbation in those with ASD. They concluded that mirtazapine and propranolol (Inderal) may be helpful, but there is very little research into this.

Chen, F. et al. (2016). Pharmacological management of inappropriate sexual behaviors in youth with autism spectrum disorder: A case study and review of the literature. Neuropsychiatrie de l'enfance et de l'Adolescence, 64, 163-167.

Dating & ASD



- **Parents must help their ASD children what most learn on their own.**
 - **Social gestures, Appropriate social risk taking, How to choose appropriate dates, What is an appropriate social activity, etc.**
- **If your ASD daughter has a boyfriend watch for exploitation.**

Newport, J., and Newport, M. (2002). Autism-Asperger's & Sexuality: Puberty and Beyond. Arlington, TX: Future Horizons.

ASD and Pornography

“The interest becomes unacceptable when the adolescent or adult with Asperger’s syndrome considers that (pornographic, sic.) photographs are a realistic representation of typical people and sexual activities on a first date. Fortunately we now have programs specifically to inform adolescents and adults with Asperger’s syndrome about appropriate levels of intimacy and sexuality.” (p. 193)

Attwood, T. (2007). The Complete Guide to Asperger’s Syndrome. Philadelphia, PA: Jessica Kingsley.

Excellent Materials On Sexuality and ASD

Henault, I. (2005). Asperger's Syndrome and Sexuality: From Adolescence through Adulthood. Philadelphia, PA: Jessica Kingsley.

Newport, J., and Newport, M. (2002). Autism-Asperger's & Sexuality: Puberty and Beyond. Arlington, TX: Future Horizons.

Attwood, T., Henault, I. and Dubnin, N. (2014). The Autism Spectrum, Sexuality and The Law: What Every Parent and Professional Needs to Know. Philadelphia, PA: Jessica Kingsley.

Author (2009). Sexuality and Disability: A Guide for Parents. Alberta, British Columbia, Canada: Alberta Health Services, Sexual and Reproductive Health Education and Health Promotion, p. 1-21.

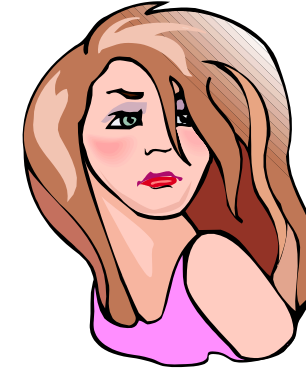
www.teachingsexualhealth.ca/media/pdf/Sexuality_Developmental_Disability.pdf

Henault's Programme for the Development of Sociosexual Skills

1. Assessment & Introduction
2. Intro to Sexuality & Communication
3. Sexual Relations & Behaviors
4. Physiology of Sex
5. Sexual Relations & Behaviors
6. Emotions
7. Birth Control & STDs
8. Sexual Orientation
9. Drugs
10. Abuse & Inappropriate Sexual Behavior
11. Sexism & Violence
12. Theory of Mind, Emotions & Intimacy

Henault, I. (2005). Asperger's Syndrome and Sexuality: From Adolescence through Adulthood. Philadelphia, PA: Jessica Kingsley.

Flirting and Social Abilities



"...a flirting plan is wired into us, and that it has been embedded in our genes and in our brain's operating system the same way and for the same reasons that every other sexual trait has been - by trial and error, with conservation of what works best." (Rodgers, 1999, p. 38)

"Enter creativity, humor and intelligence. Deployed in flirting they disclose more about an individual person than all the antlers do about leaching animals...They act as an honest signal that we've got a reasonably well put together nervous system." (p. 70)

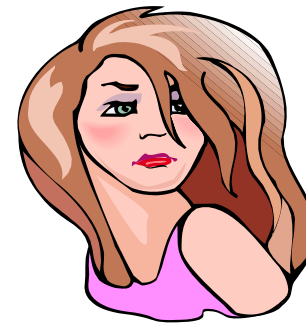
Rodgers, J.E. (February, 1999). Fascinating Flirting. Psychology Today, 32 (1), 36-41, 64-65, 67, 69-70

Flirting and Social Abilities

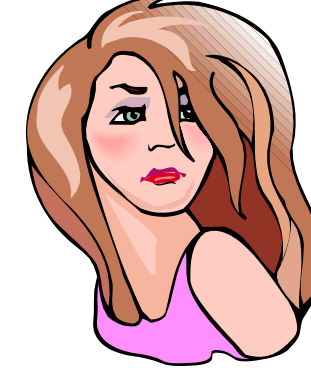


“The moment of attraction, in fact, mimics a kind of brain damage...In attraction, we don’t stop and think, we react, operating on a ‘gut’ feeling, with butterflies, giddiness, sweaty palms and flushed faces brought on by the reactivity of the emotional brain. We suspend intellect at least long enough to propel us to the next step in the mating game-flirtation.” (p.5)

Ellison-Rogers, J. (January/February, 1999). Flirtation Fascination. Psychology Today, (Document ID: 575), From website: www.psychologytoday.com/articles/index.php?term+pto19990101-000033&print=1 .



Flirting and Social Abilities



- It takes about seven seconds to form a first opinion about another person. Most of this is done non-verbally.

Nowicki, S. and Duke, M. (2002). Will I Ever Fit In? New York, NY: Free Press.

- Mating and relationships would be almost impossible without facial expressions.

Gladwell, M. (August 5, 2002). The Naked Face (Interview of Paul Ekman). The New Yorker, pp. 36-49.

- Attwood's (1998) story of the man with Asperger's Disorder in a singles bar.

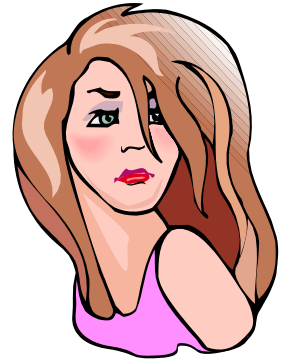
- Cordoni stated you need the same behaviors to get a job as you need to get a date.

Attwood, T. (1998). Asperger's Syndrome: A Guide for Parents and Professionals. Philadelphia, PA: Jessica Kingsley.

Cordoni, B. (1987). Living With A Learning Disability. Carbondale, IL: Southern Illinois University Press.

How to Treat Flirting Difficulties

- Social Skills training by Mental Health Professionals and Speech-Language Pathologists
- Treat Neurosocial Comorbidities & lack of muscle tone
- Try an “Emotional Seeing Eye Dog” (Grandin, 1995)
- Address age appropriate dress and grooming.
- Take care of complexion, etc.
- SIRC Guide to Flirting



Grandin, T. (1995). Thinking in Pictures: And Other Reports From My Life with Autism. New York, NY: Vintage.

Grandin, T. (2006). Animals in Translation. New York, NY: Simon and Schuster.

Newport, J., and Newport, M. (2002). Autism-Asperger's & Sexuality: Puberty and Beyond. Arlington, TX: Future Horizons.

Social Issues Research Centre (No date). SIRC Guide to Flirting, pages 1 to 16. www.sirc.org/publik/flirt.html.

Social Issues Research Centre (SIRC) Guide to Flirting

“Flirting is a basic instinct, part of human nature. This is not surprising: if we did not initiate contact and express interest in members of the opposite sex, we would not progress to reproduction and the human species would become extinct. According to some evolutionary psychologists, flirting may even be the foundation of civilization as we know it. They argue that the large human brain – our superior intelligence, complex language, everything that distinguishes us from animals – is the equivalent to a peacock’s tail: a courtship device evolved to attract and retain sexual partners. Our achievements in everything from art to rocket science may be merely a side-effect of the essential ability to charm.”
(Page 1 of 16)

Human Flirting Behavior



- **55% of first impressions come through appearance and body language.**
- **38% comes from your style of speaking, not the content of what you say.**
- **7% comes from the words you say**
- **Social Issues Research Centre (No date). SIRC Guide to Flirting, <http://www.sirc.org/publik/flirt.html>, pages 1 to 16.**



ASD and Appearance



- **Work on appearance and body language first**
 - **Age appropriate and stylish clothing and hair**
 - **Good hygiene and grooming**
 - **Cleaning up complexion (dermatologist, etc.)**
 - **Work on muscle tone (OT/PT/Personal Trainer, etc.)**
 - **Work on Body Language (Mental Health Professional and Speech-Language Pathologist)**

Those with Asperger's Disorder and High Functioning Autism have problems with Theory of Mind which can cause problems with receptive interpretation of non-verbal cues from others. It can also cause them problems in putting importance on their own non-verbal cues.

Klin, A., Volkmar, F.R. and Sparrow, S.S. (2000). Asperger Syndrome. New York, NY: Guilford.

WHAT DOES THIS MEAN? (CONT.)

Work on speech second (Speech-Language Pathologist):

“Aim for moderation in volume and tone, with enough variation in pitch and pace to hold your companion's interest. Also remember that a rising or falling intonation, especially when accompanied by a drop in volume, is a 'turn-yielding cue', whereby speakers signal that they have finished what they are saying and are ready to listen to the other person. When you hear these vocal signals, your companion is probably indicating that it is your turn to speak. When your companion hears these signals, he or she may well assume that you are 'yielding' the floor.”

**Social Issues Research Centre (No date). SIRC Guide to Flirting,
<http://www.sirc.org/publik/flirt.html>,
pages 1 to 16.**

WHAT DOES THIS MEAN? (CONT.)

Work on conversational content third (Speech-Language Pathologist and Parent) (**Practice, Practice, Practice!**):

“The 'art' of verbal flirting is really just a matter of knowing the rules of conversation, the unwritten laws of etiquette governing talking and listening. The best and most enjoyable conversations may seem entirely spontaneous, but the people involved are still obeying rules. The difference is that they are following the rules automatically, without consciously trying, just as skilled, experienced drivers do not have to think about changing gears. But understanding how the rules of conversation work – like learning how and when to change gears – will help you to converse more fluently, and flirt more successfully.”

Social Issues Research Centre (No date). SIRC Guide to Flirting,
<http://www.sirc.org/publik/flirt.html>,
pages 1 to 16.

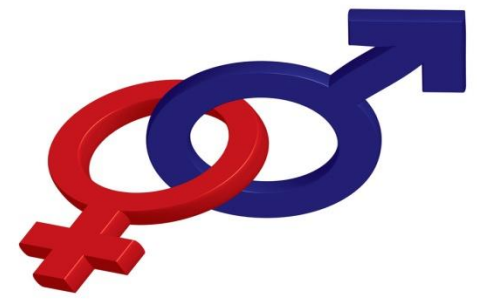
What is a Date?



“Going out with someone in an identified setting such as a restaurant, cinema, or cultural event with the intent of getting to know them better to see if you would be interested in developing a romantic relationship.” (p. 253)

Baker, J. (2005). Preparing for Life: The Complete Guide for Transitioning to Adulthood for those with Autism and Asperger’s Syndrome. Arlington, TX: Future Horizons.

Immaturity

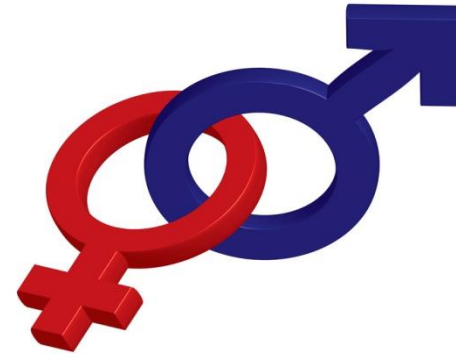


Anne Ford wrote, “The most successful dates or boyfriend-girlfriend relationships I have seen in the LD community are between two adults with similar levels of disability who act more like best friends than lovers...When you find someone like that, other quirks and oddities of behavior don’t matter that much.” (p. 64-65)

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Where to Find a Date

- School & school social clubs
- Youth groups
- Places of worship and specialized clubs/groups sponsored by them
- Job training center
- Friends and family
- Internet
- Singles events
- Gym, library, dance clubs, parties, etc.



Baker, J. (2005). Preparing for Life: The Complete Guide for Transitioning to Adulthood for those with Autism and Asperger's Syndrome. Arlington, TX: Future Horizons.

Rules for Internet Dating



- Do not give out your home address or phone number.
- Always meet for the first time in a public place far from home (i.e., restaurant, coffee shop, etc.).
- Realize everything said on the internet is not true.
- Use a reputable internet dating service for added security.

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

ASD and Sexual Harassment

“We do recognize that problems with sexual expression and experiences can lead to a person with Asperger’s syndrome being charged with a sexual offence. The charge tends to be for sexually inappropriate behaviour rather than sexually abusive or sexually violent behaviour...The person may have difficulty distinguishing between kindness and attraction, and assume a friendly act was an indication of romantic or sexual attraction.” (p. 339)

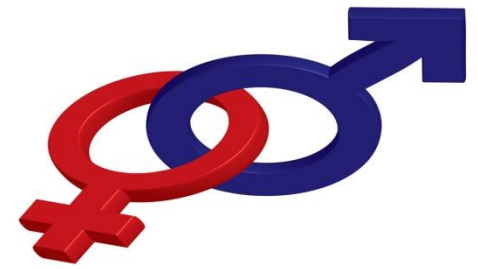
Attwood, T. (2007). The Complete Guide to Asperger’s Syndrome. Philadelphia, PA: Jessica Kingsley, p. 130.

Charli: An Adult on the Spectrum

“...I often engaged in activity that today would be called ‘stalking.’ While I truly intended no harm, I experienced unbearable loneliness and if some handsome young man appeared on the periphery of my solitary life, my better judgment deserted me.” (p. 38)

Grandin, T. (2012). Different...Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger’s and ADHD. Arlington, TX: Future Horizons.

Sexuality and ASD



- Kids with an “invisible disability” and an aid in a mainstream class are often seen as weird and shunned.
- The more the child is seen around the school without the aid the better.
- More restrictive environment can be a dumping ground: Conduct Disorder & Victim
- Without intensive social skills training in childhood the child will not be prepared for puberty.

Newport, J., and Newport, M. (2002). Autism-Asperger's & Sexuality: Puberty and Beyond. Arlington, TX: Future Horizons.

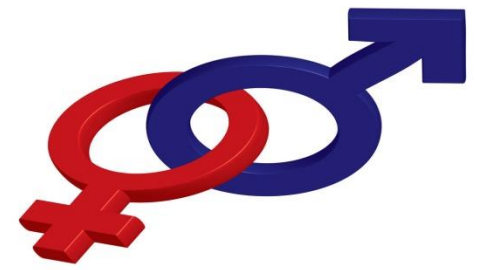
Sexuality and ASD



- Have your kid assigned a “**social helper student**”:
 - The child with excellent social skills in your class, who is a “good citizen” and good student.
 - Train the helper student in how to be a helper student.

Thompson, S. (1996). Neurobehavioral Characteristics Seen in the Classroom: Developing an Educational Plan for the Student with NLD. From NLD on the Web:
www.nldontheweb.org/thompson-5.htm .

Sexuality and ASD

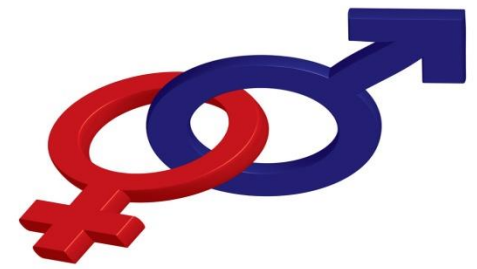


“An associate is someone who helps you perform an activity. This is someone you can trust long enough to complete that activity...Many autistic adults who find partners report those partners entered their life as trusted associates, people who could be relied on to share necessary or even enjoyable activities. “(p. 26-27)

- **The person with ASD should be taught that just because someone is a trusted associate does not make them a potential date!**

Newport, J., and Newport, M. (2002). Autism-Asperger's & Sexuality: Puberty and Beyond. Arlington, TX: Future Horizons.

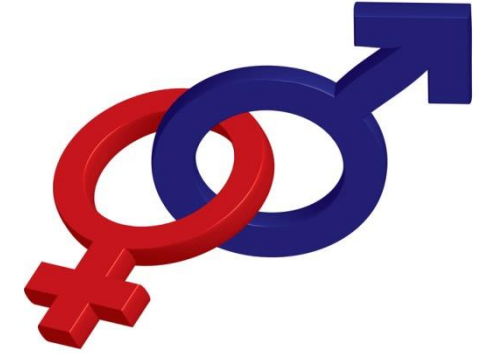
Sexuality and ASD



- Often the ASD child and adolescent does not have any friends, however, forcing them to interact socially may cause more harm than good.
- Get them involved in after school activities, clubs etc. they might be interested in and they will find others interested in the same things.
- Encouraging them when they start to show interest in someone.

Newport, J., and Newport, M. (2002). Autism-Asperger's & Sexuality: Puberty and Beyond.
Arlington, TX: Future Horizons.

ASD and Sexuality



Sports, PE (adaptive/or not), aerobic exercise, working with a fitness instructor etc. can help with appearance, confidence and fitness if done in a way that meets the child's/teen's needs.

Newport, J., and Newport, M. (2002). Autism-Asperger's & Sexuality: Puberty and Beyond. Arlington, TX: Future Horizons.

Examples of “The Rules”



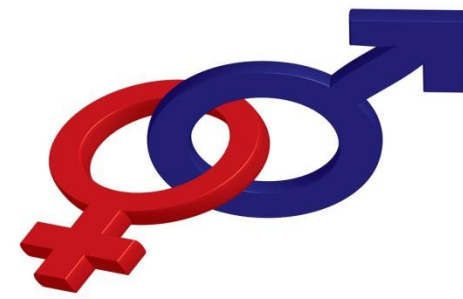
- If someone says “no” to going on a date with you three times (with more than one week between invitations) the person is ‘saying nicely’, “no I do not want to go out with you.” Don’t ask them again.
- Don’t expect physical contact on the first several dates. Maybe hold hands on second date, kiss at door good night.
- Don’t ask him in on the first several dates.

Ask Questions & Be Mannerly



- “Be friendly and engaging”- Ask open ended questions about them (teach this)
- Teach them how to respond to questions about themselves. Short, truthful, etc.
- Remember the best pick up line is, “Hi my name is...”
- Use proper table educate.
- Don’t eat too fast or too slow.
- Choose activities and food your date and you would probably like.
- Avoid your “special topic”. Try to show interest in their special topic.
- The pace for all this is **SLOW!!!**

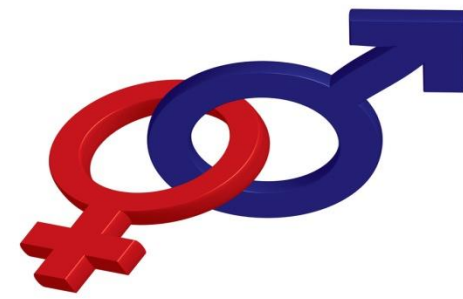
Touching



- The first touch should be on the forearm/back of shoulder (typically non-threatening).
- If not rejected later touch hand.
- Later hold hand...
- If they say, “NO” then NO means NO!

Social Issues Research Centre (No date). SIRC Guide to Flirting,
<http://www.sirc.org/publik/flirt.html>,
pages 1 to 16.

Celibacy



“I have remained celibate because doing so helps me to avoid the many complicated social situations that are too difficult to handle. For most people with autism, physical closeness is as much a problem as not understanding social behavior.” (Dr. Temple Grandin, p. 133)

Grandin, T. (1995). Thinking In Pictures: And Other Reports From My Life With Autism. New York, NY: Vintage.

Anita Lesko: Adult on the Spectrum

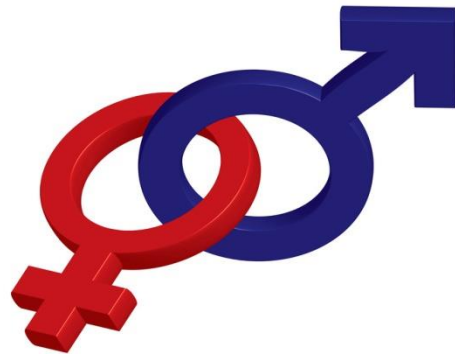
➤ Registered nurse anesthetist & aviation photojournalist

“I haven’t been on a date for 14 years. I realize this is shocking to most people, but it just happened this way because of all the things I’ve been doing with my time. I didn’t make a conscious decision not to date – it just happened.” (p. 201)

Grandin, T. (2012). Different...Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger’s and ADHD. Arlington, TX: Future Horizons.

Sex Therapists and Educators

- **American Association of Sexuality Educators and Therapists:**
www.aasect.org
 - There are professionals in this organization that work with those with disabilities.



Estate Planning & ASD



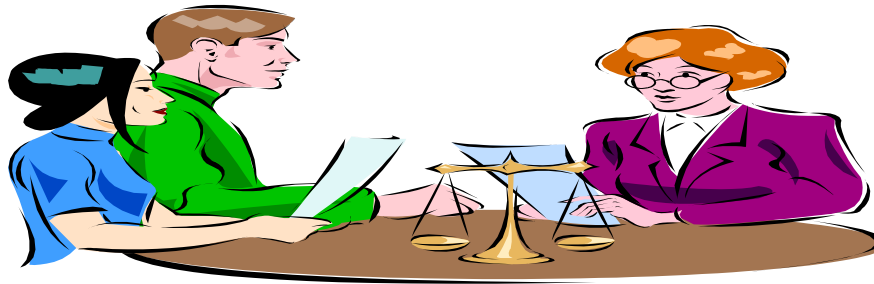
Guardianships, Powers of Attorney, Etc.

- **Guardianship:** Legal relationship created by court to take care of incompetent person.
- **Conservator/Guardian:** Name of person appointed by court.
- **Limited or Partial Guardianship/Temporary Guardianship.**
- **Durable Power of Attorney:** Can some make decisions for partially independent adult
- **Health Care Proxy:** Medical power of attorney
- **Joint Checking Account**

King-Nash, S. (April-May, 2010). Facing the Future: Guardianship, Conservatorship & More-Understanding the Options for your ASD Adult. Autism File, 43, 54-56.

Estate Planning

The expert who should help you with this is a ***Certified Elder Law Attorney (CELA)***. You can find one of these in your area by going to the National Elder Law Foundation website: www.nelf.org



Estate Planning

The simplest method of funding a trust for a child with a disability is typically with a term or whole life insurance policy.

Craig H. Wisnom, Esq. (February 20, 2012). Personal Communication. Tucson, AZ.



Estate Planning

“Those of us whose adult children have severe learning disabilities need to be able to answer the following questions:

- **Do you know the difference between a will and trust?**
- **Have you written a Letter of Intent?**
- **What is a Special Needs Trust?” (p. 214).**

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Estate Planning

“A will is a disbursement of your assets after you are gone...After you die, your estate is divided up according to your wishes, with your disabled son or daughter getting enough to live on (hopefully) for the remainder of their lives. Wills can be contested, which means another relative could block the disbursement of those assets until a court settles the matter.” (p. 215)

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Trusts



“The terminology can also be quite confusing. When most people are talking about a "Trust", they are talking about a "Revocable" "Living" Trust, a Trust you set up while you are alive, which you can change whenever you wish. There are other types of trusts, including trusts that can be set up under your Will after your death ("Testamentary Trusts") such as a trust for a child until a certain age. There are also "Irrevocable Trusts" which are set up for more specialized purposes such as estate tax planning or asset protection.”

Bogutz and Gordon (2008). Do I Need a Revocable Trust? Tucson, Arizona:
www.bogutzandgordon.com/estateplanningfaqs.html#q7.

Special Needs Trust

- **This is a type of trust that is set for your disabled relatives after you die.**
- **It is typically irrevocable. This means it cannot be changed and it cannot be contested in court.**
- **The assets in the trust belong to the trust not to your disabled child.**

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Special Needs Trust

Even though you may believe your child may not need an SNT because you have sufficient financial resources and /or you child may not be “that impaired” you may need to consider one. “In short there are certain government programs and services that cannot be purchased privately; these programs require qualification for Medicaid.” (p. 1)

Gallant, K.B., Iannantuoni, R.A., Pitney, D., Fetrow, K., and Gupta, S.S. (October, 2011). Understanding and Administering The Special Needs Trust. Heckscher, Teillon, Terrill & Sager, P.C.

Special Needs Trusts

“Such trusts are called many names, including spendthrift trusts, special needs trusts, discretionary trusts, special person trusts, etc. The key factor is not the actual name of the trust, but the specific terms of the trust.” (p. 1)

**Bogutz & Gordon (2003-2010). Third Party Special Needs Trusts (Supplemental Benefits Trusts). Tucson, AZ:
WWW.BOGURTZANDGORDON.COM.**

Third Party Special Needs Trust

“When a SBT (Special Benefits Trust/Special Needs Trust, sic.) is set up for a disabled, handicapped, or mentally ill person by someone else, it is called a Third Party Trust. Typically the trust is created and the money comes from parents or other family members. The SBT can be created in a Will, in the parents’ own Revocable Living Trust, or even as a stand-alone document. Money can be put into the SBT by any third party, but cannot be put into the trust by the disabled individual or his/her spouse.”
(p 1 of 5)

Bogutz & Gordon (2003-2010). Third Party Special Needs Trusts (Supplemental Benefits Trusts). Tucson, AZ:
WWW.BOGURTZANDGORDON.COM.

Special Needs Trusts

- **“...if the money already belongs to the disabled individual...that money would have to be put into a First Party Special Needs Trust that must have significantly different and less advantageous features than a Third Party Special Needs Trust.” (pp. 1-2).**

Bogutz & Gordon (2003-2010). Third Party Special Needs Trusts (Supplemental Benefits Trusts). Tucson, AZ: WWW.BOGURTZANDGORDON.COM.

First Party Special Needs Trust

- **“Once the money is placed in the trust, the beneficiary cannot withdraw it , or direct how the trustee will spend it. The trustee must have full legal control over the money, and although the trustee may consider requests made by or on behalf of the beneficiary, the trustee is free to say “no” to any request.” (p. 3)**

Bogutz and Gordon (2003-2010). First Party Special Needs Trusts: A primer for Injured Individuals or Disabled Persons and Their Families (SSI Recipients). Tucson, Arizona: WWW.BOGUTZANDGORDON.COM.

First Party Special Needs Trust

- **“When the disabled beneficiary dies, any money remaining in the trust must be paid back to the state Medicaid Agency for any services provided during the beneficiary’s lifetime. Only after the State has been paid back can the remaining funds (if any) can pass on to the disabled person’s family.” (p. 3)**

Bogutz and Gordon (2003-2010). First Party Special Needs Trusts: A primer for Injured Individuals or Disabled Persons and Their Families (SSI Recipients). Tucson, Arizona: WWW.BOGUTZANDGORDON.COM.

Estate Planning

To be able to receive Social Security Supplemental Income, Medicare and Medicaid the child (or, adult child) cannot have:

- **Countable (stocks, bonds, checking accounts, etc.) assets of no more than \$2000.00**
- **Income more than \$2022.00 per month (2010)**

Bogutz and Gordon (2003-2010). First Party Special Needs Trusts (ALTCS Recipients). Tucson, Arizona:

WWW.BOGUTZANDGORDON.COM.

Estate Planning

“Non-countable assets consists primarily of a home of unlimited value, one vehicle per household if used for transportation, household belongings and furniture, clothing, personal jewelry, and pre-paid burial accounts.” (p. 3)

Bogutz & Gordon (2003-2010). Third Party Special Needs Trusts (Supplemental Benefits Trusts). Tucson, AZ: WWW.BOGURTZANDGORDON.COM.

Special Needs Trust

- If your child needs funds they request them from the trustees of the trust for your child's benefit.
- The trustees will distribute funds to help your child maintain their standard of living, but will protect them from being taken advantage of, etc. per your instructions.

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Special Needs Trust

➤ How to set up a special needs trust:

- Most major brokerage firms have Special Needs financial advisors.
- Most major law firms have elder law attorneys who can help you create a special needs trust.
- Certified Elder Law Attorney (CELA): www.nelf.org

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Special Needs Trust

- **Some elder law attorneys recommend disowning your disabled child in your will in order to assure they will not inadvertently inherit more than \$2000.00 worth of assets upon your death.**
- **It is a good idea to review your Special Needs Trust, estate plans, etc. every 2 to 3 years as laws change.**

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Special Needs Trust

- It is best to have people/institutions that are not related to your family as the trustee(s) of the special needs trust.
- A bank trust department may be best.
- You should stipulate how successor trustees can be appointed in the document.

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Letter of Intent

This is a letter that describes your disabled child in intimate detail which you add to and revise from time to time. It put a human face on your child for the trustees, attorneys, banks, etc. You describes you child's interests, likes and dislikes, hobbies, medical issues, disabilities, etc.

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

In Conclusion

- You should let your child know they will not be abandoned when you die.
- There will be someone who will care for them after you are gone.
- You have taken great care creating the above documents because you love them.
- And you will always love them.

Ford, A. (2007). On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD. New York, NY: New Market.

Special Thanks!

- **Craig H. Wisnom, Esq., CELA**
Bogutz and Gordon, P.C.
Tucson, AZ



Thank You!



- **Kevin T. Blake, Ph.D., P.L.C.**
- **Office: 520-327-7002**
- **E-mail:**
kblake@drkevintblake.com
- **Fax: 520-795-3575**
- **Mail: 5210 East Pima, Suite 200,
Tucson, AZ 85712**