

Aspergers Syndrome (AS)

Information and Resource Package

Prepared for World Autism Awareness Day
Thursday, April 2nd, 2009

This handout is aimed at increasing the awareness of Asperger Syndrome in adults. Some of the material in it may apply to other disorders on the Autism Spectrum.

Basic Facts about Aspergers Syndrome (AS)

Fact: Asperger's Syndrome is an Autism Spectrum Disorder.

Fact: Autism Spectrum Disorders are neurological conditions characterized by widespread differences and difficulties with social interactions and communication. They are usually accompanied by severely restricted interests, often held to an extreme degree, and by highly repetitive behaviour.

Fact: The reason the word Spectrum is used is that these disorders cover a wide spectrum of signs, symptoms and ability to function. People with classic or Kanner's Autism display severely restricted abilities to function and communicate. People with AS or High Functioning Autism have a much greater ability to function and communicate. There are a number of disorders on the spectrum.

Fact: AS is different than introversion, social anxiety, ADHD, ADD or OCD, although all these conditions may be present in someone who has AS. Introversion and social anxiety are psychological conditions. AS is a neurological condition. The primary symptom of AS is a difficulty with social relationships. While ADHD, ADD or OCD may impact social relationships their primary symptoms do not involve difficulties with social relationships.

Myths and Facts about Asperger's Syndrome (AS)

Myth: People with AS cannot communicate or form relationships.

Fact: As mentioned, autism is a spectrum disorder. People on the spectrum, and people with AS, can display a wide range of abilities in many different areas. People with AS, and people on the spectrum can and do form lasting relationships.

Myth: Adults cannot have AS. Only children have AS.

Fact: AS is a neurological disorder. There is no cure for it. There are effective coping strategies that can help overcome the challenges that AS presents. AS does not disappear when someone becomes an adult. People with AS who are high functioning can feel pressured to hide and mask their differences by the time they become adults, so they can go largely unnoticed.

Myth: People with AS do not marry or have children.

Fact: A great many people with AS do in fact marry and have children, however the divorce rate is estimated to be very high, at 80%, when someone with AS marries someone without AS. In a marriage the AS partner cannot maintain a mask of normalcy forever. Their partner usually comes to suspect something is "wrong" in the relationship but often cannot figure out what this is.

Myth: AS is a psychological disorder.

Fact: AS is a neurological disorder, meaning the brains of people with AS function in different ways (or are "wired differently") than the brains of people without AS. People without AS are sometimes referred to as NeuroTypicals, or NTs, meaning their brains have typical wiring. There is some question as to whether AS gets better or worse over time. There is no question that a persons ability to cope with their AS can change tremendously over time, given hard work, help and support.

Myth: The reason people with AS can have difficulties in the areas of keeping commitments, organizing themselves, and giving emotional support is because they are just not trying hard enough, and/or they just don't care.

Fact: AS affects many areas of the brain, including those areas responsible for executive functioning and giving emotional support. Many strategies that can be used to overcome executive functioning deficits, including keeping simple lists. There are not many strategies that can compensate for an impaired ability to give emotional support. Partners of someone with AS need to develop support systems so they can get much of their emotional support from family and friends. They can also learn to recognize the physical efforts their AS partner makes to try and compensate for an impaired ability to give emotional support.

Myth: AS is rare. It is unlikely I know anyone with AS.

Fact: Surveys done by the Centers for Disease Control (CDC) in the US indicate around 1 in 150 children aged 4-17 have autism, a more restricted definition than being on the Autism Spectrum. Studies reported by the National Autistic Society (NAS) in the United Kingdom have found that between 1 in 110 and 1 in 86 children have a spectrum disorder. If a rate of 1 in 150 is assumed, and the latest estimates of the adult population of Victoria are used, there may be 1,500 adults with AS in Victoria.

Myth: It is easy to find counselling and other services for adults with AS and their families.

Fact: Despite a great need, at the present time it is almost impossible to find counselling or other services from any practitioner with experience with adults with AS.

Common Issues associated with Autistic Spectrum Disorders

Issue: Stress, depression and anxiety are common problems, both in people with AS, and in the people close to them. There is little understanding or support for adults with AS, or for their family and friends. This only makes things worse.

Issue: Diagnosing AS in an adult can be difficult. Because it is a spectrum disorder, people with AS can often display very different symptoms, and very different coping abilities. AS is often misdiagnosed as ADD, ADHD, OCD, Personality Disorders or Social Anxiety. It is true that many of these disorders are commonly co-morbid with AS. The nature of the social difficulties that people with AS have is unique.

Issue: Social isolation can be a huge problem for adults with AS. Adults with AS can have great difficulty finding and keeping friends. Due to difficulties with social relationships, they can also have difficulty finding and holding a job, even when they are otherwise qualified to perform the duties of a particular job. Jobs provide social contact and interaction. Without a job, social isolation increases. Financial hardship, due to difficulties with employment, can also be a major problem. These hardships do not just affect the adult with AS. These issues will also affect their partner, if they are married, and their family. Isolation is not just an issue for the adult with AS. Their NT partner may become increasingly withdrawn as social and other difficulties increase.

Issue: Difficulties in an NT/AS relationship can appear because each side has different capacities. Each side cannot always see the efforts their partner is making. Each side can come to believe that they are performing the bulk of the work in their relationship, while their partner is contributing little or nothing.

People with an ASD can believe that their financial and physical contributions are proof they care. When their NT partner requests needed emotional support, the ASD person can feel hopeless, and that nothing they do will ever be good enough for their partner.

People who are NT can believe, quite rightly, that they are responsible for providing all the emotional work required to keep the relationship going. They can wonder why they

are not receiving any emotional support in return. They can take this as evidence their partner does not really care about them.

People with an ASD often cannot see the emotional efforts their partners are making, so can feel their partners are bringing nothing to the relationship.

People who are NT can have a hard time recognizing that the physical efforts their partner makes are their form of caring, so may believe their partners are contributing nothing to the relationship.

Issue: The NT partner in an NT/AS relationship can start out being emotionally healthy but can end up very emotionally unhealthy, if AS is not identified and if steps are not taken to effectively address it. With time, the NT partner can become increasingly stressed as they take on more and more of the emotional support, and as they try to help with difficult AS behaviour and communication patterns. They can become over controlling or enabling or burn out.

Issue: The AS partner can realize that their AS is not curable, so can believe there is nothing that can be done for them. They can become a victim of learned helplessness. They can believe that because no action, behaviour or strategy can cure them, that no effort will be worthwhile. They can end up contributing less and less physical support to the relationship. It can be hard to help them see that although nothing can cure their AS, hard work can mitigate and overcome a lot of the challenges it presents.

Issue: The social isolation of the NT partner in any NT/AS relationship can increase over time as they see there is no understanding among family or friends for their situation. The AS partner may be contributing physically and financially to the relationship, so it may not be apparent to anyone that the NT partner is not receiving the emotional support they need. The AS partner may not feel comfortable having friends over, or having social gatherings at their house. This can increase the social isolation of the NT partner.

Issue!: Effective counselling services are needed to help adults with AS and their partners (if they are in long term relationships), work through and overcome many of these issues. Lack of counselling services only contributes to the difficulty adults with AS have forming and maintaining relationships, partnerships and marriages.

Local Resources – Assessment and Counselling

Dr. Kathleen Goodall

- performs assessments for AS using standardized tests

Ariadne Sawyer, MA CP, Peak Performance Plus Trainer

- superb life skills coach, training via phone & Internet, ariadnes@uniserve.com

More to come

- this list will be updated as I become aware of psychiatrists, psychologists, therapists and counselors with experience counseling adults with AS and their partners and families

Local Resources – Physicians who are “AS aware”

Dr. Kate Evans

- not taking new patients; available at the Bevan Avenue walk in clinic in Sidney

Local Resources – Speakers with Expert Knowledge of AS

Nathan Ory, M.A., Registered Psychologist (BC)

- speaker at conferences and seminars, author of “Working with People with Challenging Behaviours (2007)” for supporting lower functioning individuals with AS

Local Resources – AS Groups

Victoria Asperger’s Syndrome Meetup Group - <http://aspergers.meetup.com/209/>

- a social group for people with AS and their friends and family

Helpful Books on NT/AS Relationships by People In Them

Asperger Syndrome and Long-Term Relationships - Ashley Stanford

Alone Together: Making an Asperger Marriage Work – Katrin Bentley

An Asperger Marriage – Chris & Gisela Walker

Helpful Books on Aspergers By World Experts

Complete Guide to Asperger’s Syndrome - Tony Attwood

Life Stories written by People with AS

Look Me In The Eye: My Life with Aspergers – John Elder Robinson

The Way I See It – Temple Grandin

Pretending To Be Normal – Liane Holliday Willey

Autism: An Inside Out Approach – Donna Williams

Helpful Book on AS and Higher Education

Succeeding in College with Asperger Syndrome: A Student Guide – John Harpur, Maria Lawlor and Michael Fitzgerald

Links on the Internet for Adults in NT/AS Relationships

AS & Relationships that Work - <http://forums.delphiforums.com/asworks/start>

- A realistic and supportive forum for people that want their relationships to work

AS & Their Partners - <http://forums.delphiforums.com/asandpartners/start>

- A forum giving insights into accommodations that can help the AS partner
- Run by people with AS

AS Partners - <http://forums.delphiforums.com/ASPartners/start>

- A forum for NT partners that need to vent, and need understanding

OASIS - <http://forums.delphiforums.com/AspergerOasis/start>

- A superb forum for couples with AS children – must request access

Links on the Internet for information about AS

Tony Attwood's site - <http://www.tonyattwood.com.au/>

- The world's acknowledged expert – good audio clip bottom of page

The UK National Autistic Society - <http://www.nas.org.uk/>

- One of the better “official” sources of AS information and support

OASIS web site - <http://www.udel.edu/bkirby/asperger/>

- A good starting point for learning about AS

Future Horizons - <http://www.fhautism.com/Home/tabid/36/Default.aspx>

- Publisher of books and magazines, sponsor conferences

The All Wales Autism Resource - <http://www.awares.org/>

- Extensive information on AS; click on English to enter the web site
- See <http://www.awares.org/conferences/> for conference proceedings

Links on the Internet for adults with AS

The Autism Network International - <http://www.autreat.com/>

- Resources for AS people, run by people with AS

The Global and Regional Asperger Syndrome Partnership (GRASP)

- a wonderful organization for adults on the spectrum, run by and for them

Additional Local Resources

If **ANYONE** reading this handout is aware of any additional resources for adults with AS, especially psychiatrists, psychologists, therapists, or counselors with experience or interest in counseling adults with AS, please contact me so I can see if they are interested in being added to the list of local resources.

For More Information

Contact Chris McIntosh, cmasp@shaw.ca