Adult Files Upload
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Seeking an Adult Diagnosis
“I think my husband has Asperger’s, where can we get a diagnosis?”

Why seek a diagnosis as an adult?
There are many reasons to seek a diagnosis of ASD as an adult. Often those seeking a diagnosis have a child with ASD and have suspected for a long time that something is not quite right with their partner. A diagnosis can help put things in perspective and enable the adult with ASD to gain support to overcome difficulties, particularly when the person is having problems with issues such as unemployment, substance abuse or relationships. Adult females with ASD may be referred for or seek a diagnosis after experiencing mood disorders, anxiety, eating disorders and other mental health issues for many years.

Characteristics of Adults with ASD
• Above average intelligence
• Hardworking and focused in some areas
• Passionate
• Either very disorganised or completely neat
• Often wear similar clothing day after day regardless of fashion
• Have difficulty managing money or be very controlling of spending to the point of discomfort.
• Have problems with rage or may express no emotions at all/shut down
• Either have very little interest in sexual intimacy / their partner or have an overly high sex drive
• Poor eye contact
• May be physically clumsy, poorly coordinated or awkward
• Not understand the actions or emotions of their partner
• Can be often blunt or perceived as rude
• Very knowledgeable in fields related to their interest but have poor skills in other areas
• Display very rigid thinking
• Sensitive to noise/ light/touch/smell
• Forgetful or unaware of the significance of important dates or events – i.e. their spouses birthday, but have an infinite memory for numbers or facts- for example the model number of the DVD player.
• Poor planning and organising skills –i.e. day to day tasks, organising children, meals or shopping
• Unpredictable behaviour including intense mood swings or outbursts for no obvious or apparent reason.
• Problems with alcohol/substance abuse
• Problems retaining employment
• Poor personal hygiene
• Can be perceived as physically or emotionally cold towards their children
• Can be overbearing or obsessive towards their spouse/partner or children.
• Have obsessive interests or obsessions that take up a lot of the family’s financial resources, space or time.
• Prone to depression, anxiety, obsessive compulsive disorder, eating disorders, self-harm (particularly undiagnosed women with ASD)
Where to seek a diagnosis
Who assesses adults?
To seek an adult diagnosis you need a referral from a GP to a psychiatrist or psychologist. There are a number of Psychologists or psychiatrists in the Barwon area who are familiar with diagnosing adults with ASD. (For further information contact Gateways Support Services)
The federal government now has funding available through Medicare under the chronic condition and mental health care plan scheme. Appointments for assessment or counselling can be either bulk billed or reclaimed through Medicare.

Additional help
Counselling and support is available wither privately through a psychiatrist, psychologist or counsellor which can be funded as part of the mental health care plan scheme, or through public counselling services. It may be wise to see a counsellor once a diagnosis is given to help resolve feelings and define issues that may need to be worked out.

Other supports for adults with ASD are minimal but are available, there are many online support groups and message boards for people with ASD which can help make sense of what a newly diagnosed person may be experiencing.

After diagnosis
A diagnosis of ASD won’t solve any problems, but it may help make sense of what is going on. Problems with relationships, employment, substance abuse finance or family need to be dealt with as separate issues, with the diagnosis providing the context for how the problem is dealt with and which strategies used. Given the person has been diagnosed with ASD they may need to be specifically taught how to communicate with their partner in a respectful and meaningful way. A diagnosis will also give other family members something to take into consideration- not as an excuse for behaviour but a possible reason. Abusive or exploitative behaviour is never acceptable and should be treated as such. After diagnosis some people will be in denial and may not tell anyone. Others may want to share their news; this is a decision that is up to the individual. They are certainly under no obligation to disclose their diagnosis to anyone, including employers. Diagnosis and disclosure can have a big impact on a person’s self-esteem and self-image. It is important the person seeks some counselling or support to cope.

Further info
Web:
www.tonyattwood.com.au

Books
The complete guide to Aspergers syndrome- Tony Attwood
Aspergers from the Inside Out, Michael John Carley.
Aspergers in love- couple relationships and family affairs. Maxine Aston
Coming out Asperger, diagnosis, disclosure and self-confidence. Dinah Murray
Adult Relationships
Can people with ASD have normal relationships?
People with ASD can have “normal” loving relationships. Many people with ASD go on to have fulfilling relationships, marriages and have children. Couples in a relationship when one person has ASD may experience some issues related to difficulties with communication and social skills. Although couples in a relationship with ASD may have difficulties there are some strength’s to being in a relationship with someone with ASD such as; fierce loyalty, trust, intelligence, hard work ethic and intense focus.

Often the partner with ASD may not get a diagnosis until later in life, and usually once a child has had a diagnosis. The non ASD partner may have suspected for some time that something is ‘just not quite right” with their partner. A diagnosis can be helpful in explaining some of the behaviours of the person in the relationship with ASD and some of the issues that occur in the household. The individual and the couple should seek further counselling or assistance to work through issues together.

Difficulties experienced
• Many of the relationship difficulties experienced are related to the ASD partner not understanding the emotional needs of the other partner.
• The ASD partner may also be perceived to be controlling, insensitive or emotionally cold.
• They may have difficulties with domestic issues such as cleaning budgeting, shopping and other household basics.
• One partner usually takes responsibility for most of the burden of the household.
• The partner with ASD may not pay the other partner compliments, know instinctively when the partner needs a hug, or hold much sentimental value in gifts or other special occasions.
• Sexual relationships can vary, with sensory, intimacy and communication and sensory issues making sex and intimacy difficult, others report that their sex life is ‘normal’ and some report a high sexual activity.
• The family may become increasingly ‘closed’ or very private and not socialise with others or go on many outings.
• The partner with ASD will have difficulty with changing plans and being away from familiar environments.
• Men with as will often try and find a practical solution to an emotional problem – often not what women want.
• Women with ASD may be fiercely independent and controlling of their environment and situation which can impact on family members.

Points to note
• Verbal, physical or psychological abuse, threats or controlling obsessive behaviour is never ok regardless of an ASD diagnosis. The couple or the individual should seek help if these issues are arising.
• Unless a person with ASD is explicitly told, they will not automatically know how to meet their partner’s emotional needs. With time they can learn the right response to a situation.
• The non ASD partner may need to be very explicit about what they need from the
ASD partner – i.e. a hug, a cup of tea, or help with a specific task.
• The non ASD partner should develop an interest, hobby or other activity outside the
home and away from their partner, to enable them to have their own sense of identity
and keep up with social relationships.
• Support groups may have an important role in the life of the non ASD partner
• The couple should explore what having ASD means to them – how it affects the
individuals in the relationship and what to do about each aspect of it. Different or out
of the box solutions will be needed to solve some of the problems.
• Couple counselling in a traditional sense may not work unless the therapist involved
has an understanding and experience in working with couples with ASD
• People with ASD may not understand their non ASD partner and their emotions at
all, yet love them deeply and try to please them.
• Some people in an ASD relationship feel as though their partner is ‘deaf to their
feelings”
• As with young people with autism, visual supports, reminders and organisers can be
really helpful to assist in the organisation of household chores and tasks that need to
be completed

Resources
Article- Asperger marriage- viewing partnerships through a different lens
http://www.aspires-relationships.com
Books
An Asperger marriage, Chris Slater-waker
Asperger’s syndrome and long term relationships. Ashley Stanford
Asperger’s in love Maxine Aston

Work
Can a person with ASD work?

Work is an option for people with ASD depending on the skill set, interests, work
ethic and needs of the person.
There are 3 types of paid employment
Open employment-
• Employment in the mainstream market, earning a regular wage without assistance.
• This type of employment can be successful for people with ASD on the higher
functioning end of the spectrum who may be able to get along with others and can
hide their social and communication deficits.
• People in this type of employment tend to have specific skills and expertise and can
focus on one area of work, often without having to interact with others- i.e. computer
programming, research or other specific work.
• Women with high functioning autism may blend into mainstream work better than
men, often going into specific areas such as psychology, teaching or other
intellectually skilled professions after completing further study.
Supported wage mainstream-
• A person with ASD may find employment with a mainstream provider- such as a
supermarket -and be paid a supported wage
A supported wage is when the person is paid at level that is representative of the work they are completing.

The person may also receive support through a job agency to help find them the job, prepare for work- i.e. training with conduct, grooming, and travel and help them to retain their job.

The employer may get a government payment as an incentive for employing the person with ASD.

**Disability Supported Employment**

- People with ASD who are able to work but require support can engage in what is known as Supported Employment if they are in receipt of a Disability Support Pension and a place at a business which provides supported employment is available.
- Supported Employment is provided by disability support agencies that run a business where employees have a disability and earn a small wage that is offset by the Disability Support Pension.
- Employees work under supervised conditions and training is provided.
- Supported employment is a fantastic opportunity for people with ASD or other disabilities to complete valued work and gain skills in a supervised environment.
- For more information about supported employment contact your local adult disability support service, disability employment agency, Centrelink or the Department of Human Services

**Voluntary Work**

- For people with ASD that may not yet be able to find paid work and want to contribute to the community, voluntary work is an option.
- Voluntary work helps the person with ASD build their independence, work and social skills and participate in the community.
- Voluntary work is available through many community organisations and a range of roles may be suitable for a person with ASD depending on their skills, abilities and interests.
- There are many volunteering organisations across Australia that can support people who wish to volunteer.
- For more information on volunteering in the Barwon region contact Volunteering Geelong 52 21 13 77 or visit http://www.volunteeringgeelong.org.au/home

**Ups and downs of work**

Often people with ASD are great employees – they are punctual, rarely take sick days, have a great eye for detail and can complete repetitive tasks very well. The other areas of work life are more difficult for a person with ASD –

- talking to or getting along with workmates, customers or clients,
- dressing appropriately
- knowing how to deal with unexpected situations
- avoiding work place bullies
- knowing how to talk to their boss
- Knowing how to ask for help, and who to ask or feeling too embarrassed to ask for help if trying to hide difficulties.
- Being organised, negotiating public transport and other day to day hassles of getting to and from work.
•Dealing with situations which may cause anger, aggression or give rise to meltdowns.

Do I disclose that I have ASD?

A person with ASD is under no obligation to disclose that they have ASD to their employer if in the mainstream work force and do not wish to. Disclosing ASD may bring more confusion than understanding as many people are not familiar with autism and how it affects people in the workplace. Sometimes it may be necessary to disclose to be able to get the supports needed to work effectively, or to negotiate any issues. Some statements to use which can help get needs met without disclosure include:

“I work best in a quiet space”
“I am best at task that involve”……
“I am more comfortable doing”……
“I find it difficult when…”

If company has an employee assistance program which provides counseling and or support it is useful to access it if needed to discuss any issues in the workplace. This is particularly important to help avoid meltdowns and diffuse stress.

Discrimination, bullying and harassment

If the person with ASD feels they are being bullied, discriminated against or harassed there are a number steps to take to redress it.
1. Deal directly with the person and tell them to stop
2. Report the issue to the line manager or Human Resources manager
3. If the matter has not been resolved report it to
   Bullying or harassment to Work safe Victoria
   Discrimination to the Victorian Equal Opportunity and human rights commission,
4. When making a complaint to anyone regarding bullying, harassment or discrimination it is good to document any issues such as
   • Name, dates, times
   • What happened?
   • Who it was reported it to?
   • What was the outcome?

It is important to use an advocate for support if needed when making a complaint regarding bullying, harassment or discrimination. For further information on advocacy see ADVOCACY.

Resources

Books
Coming out Asperger, Diagnosis, Disclosure and Self confidence. Dinah Murray
Asperger Syndrome Employment Workbook by Roger N. Meyer

Contact
Work Safe Victoria
1800 136 089 Or email info@worksafe.vic.gov.au
Tertiary education
People with autism have the right to a tertiary education, and often go on to be very successful students at TAFE and University. It is not always smooth sailing but with some minor adjustments and or supports people with autism can have very successful studies.

When seeking placement at a university or TAFE it is important to not only look for courses that interest you and match your skills and ambitions but also to look at the amount of support you can access.

All universities and TAFE institutions have a student support unit which provides free support for students with disabilities. This support can include:

• Orientation to the university/TAFE and introduction to key staff
• Support with note taking in class
• Support regarding physical access
• Adaptive equipment
• Specialist tutorial support
• Support with vocational education and counselling
• Other support which you may need relating to support needs due to disability.

It is important to register with student support and speak to them regarding your needs. They are required to keep your information in the strictest confidentiality.

Speak with your lecturer, tell them you have ASD and let them know of any particular things they can do to help you, such as using visuals or checking you have understood a particular point. You may need to seek special consideration for exams, or altered exam papers – i.e. presenting the same information, but written in a different way.

Tertiary providers are required to provide you with materials, assessments and exams in formats you can access. You may need to provide evidence of your need to have modified materials or apply for special consideration.

Things you can do
• Ensure you have the correct books and learning materials
• Ensure you have correct timetable information, a map and know where to go
• Be organised- easier said than done, seek help with organising your notes, reading materials and assignments.
• Get a tape or digital recorder, seek help with taking lecturer notes, or take a laptop as handwriting will be difficult –taking in and writing down the information at the same time is challenging if you are unable to write fluently.
• Pre read whenever you can so you will be familiar with what will be covered in class/what you may be expected to do.
• Get the correct semester dates.
Access learning materials on line - most universities now have study guides, lecture notes and learning materials posted on line for you to access.

Other things
Public transport
- If you will be using public transport to get to university/TAFE it is important to learn the route and the timetables in advance prior to going on your first day and to practice travelling the route.
- Know what to do if the train/bus/tram/ is cancelled or delayed
- Have appropriate money or travel card
- Know who and where to seek help from if needed
- Learn where the toilets, library, cafeteria, book shop, first aid and student facilities are located at the university.
- Learn when where and how to evacuate if needed and how to locate or call security if needed.
- Carry a map of the university or TAFE campus with you in case you get lost.
- Be very mindful of your own safety and security – always keep your bag and valuables with you.

Other ways to access tertiary education
Many students with autism access tertiary studies on line as most universities and TAFE’s offer off campus study. This can be a great way for people with autism to continue studies without having to deal with hassles such as using public transport and accessing large confusing, noisy buildings.

Rights
- You have the right to access tertiary education with the modifications you need to access the course, materials or classrooms.
- Be upfront with student support services and your lecturers about any modifications you will need.
- Get support from an advocate if you are having difficulties in accessing the modifications and services you need.
- If you have any issues with the university not making reasonable modifications so you can study ensure you contact student services or the Victorian Equal Opportunity and human Rights Commission.
  Victorian Equal Opportunity and Human Rights Commission
  Phone: 1300 891 848 or complaints@veohrc.vic.gov.au
What Is Advocacy?

• Advocacy is when a person or an agency supports a person with ASD (or other disability) to ensure their rights are upheld and to make decisions about their lives.
• Many families of individuals with ASD find themselves in the role of advocate from the time of diagnosis through the lifespan of the person with ASD.
• A self-advocate is a person who speaks up for themselves to ensure their rights and needs are met.
• Self-advocacy is not easy. There are agencies that can help you gain advocacy skills and negotiate the complex maze of services, supports and legalities that go with the life of a person with ASD.
• Advocacy is NOT taking over the life of the person with ASD, speaking for the person or making decisions for them without consulting them.
• Advocacy is about providing support and information to enable the person to make the best decisions and to communicate those decisions through the advocate if necessary.
• The motto for advocacy is “nothing about me without me”

Who Can Be An Advocate?

• An advocate can be anyone you feel comfortable with supporting and representing you.
• They should be someone who can listen to both sides of a situation and support you to interpret the situation without bias.
• They should support you in your decision to make an informed choice.
• An advocate can be a friend or family member, sometimes a case manager or other service professional or a professionally trained advocate from an advocacy agency.
• When a person is deemed unable to make their own decisions they may be appointed an advocate by Victorian Civil Administrative Tribunal through the Office of the Public Advocate.

What Can An Advocate Do?

An advocate is a support person who can
• Attend meetings with you
• Take notes
• Help interpret the situation for you or remind you of what happened in the meeting
• Speak on your behalf in necessary and you would like them to.
• Support you to make a complaint if needed.
• Support you to read or understand material such as policy, legislation or service guidelines

Self-advocacy Support

Self-advocates are people who advocate and speak for themselves. Training is available people advocating for themselves who would like to develop their skills further. This includes families speaking for themselves to gain access to services or education.
Agency's that can help with advocacy

VALID
Valid supports people with a disability to self-advocate. They provide training and information and have produced a range of resources in easy read formats which are excellent.
Phone: 1800 655 570 (Rural Victoria only)
Website:  http://www.valid.org.au/
Address 235 Napier Street Fitzroy Vic 3065

The Association for Children with a Disability provides systemic advocacy for families of children with a disability particularly in the areas of service provision access and education.
Phone: 1800 654 013 (rural callers)
Website: www.ACD.org.au
Address: Suite 2, 98 Morang Road, Hawthorn Victoria 3122

AMAZE, previously known as Autism Victoria, provides systemic advocacy for people with autism in the community and represents the interests of people with autism to government, in healthcare and education. They do not provide individual advocacy, but may be able to provide you with further information and support on how to be a self-advocate or negotiate with services.
Phone: 03 9657 1600
Email: info@amaze.org.au
Address: 24 Drummond St Carlton Vic 3053

Advocacy Agencies in The Barwon Region-

ASSERT 4 ALL (formerly Barwon disAbility Resource Council (BDRC.)
Assert For All provides support with Individual Advocacy, Self Advocacy and training and support for families/ carers who are advocating for their family member with a disability.
They provide support to people in the Barwon region including Geelong, Bellarine Peninsula, Queenscliff, Lara, Torquay, Anglesea and Golden Plains.
Phone: (03) 52218011
Email: info@bdrc.org.au
Address: 48 Mckillop Street Geelong VIC 3220

Colac Otway Region Advocacy Service (CORAS)
Provides individual advocacy and support for people with disabilities in the Barwon South West Region
Phone: 03 5232 1009
Email: coras@bigpond.com
Address: 50A Rae Street Colac Vic 3250
Disability Rights and Advocacy Service Inc. (DRAS)
Provides individual and systemic advocacy support to people with disabilities living in the City of Greater Geelong and Borough of Queenscliff

Phone: (03) 5221 8033
Email: info@dras.org.au
Address: 38 Myers Street Geelong VIC 3220

Southwest Advocacy Association Inc (SWAA)
Provides individual and systemic advocacy for people with all types of disabilities throughout south west Victoria. (Warrnambool, Corangamite, Glenelg, Moyne, Southern Grampians)

Phone: (03) 5561 4584
Email: swadvocacy@bigpond.com
Address: 31 Princess Street, Warrnambool,

Villamanta Disability Rights Legal Service Inc.
Villamanta provides free state-wide disability related legal and justice issues. Villamanta has a free call telephone advice information and referral service. They also provide legal case work, community legal education and training, policy and law reform work and sell a number of publications.

Phone: 1800 014 111 for legal advice between 1pm - 3pm on weekdays. Or 52292925
Email: legal@villamanta.org.au
Address: 44 Bellarine St Geelong 3220

Office of the Public Advocate
The role of the office of the public advocate is to protect the rights of people with disabilities in Victoria. They also have many publications and resources available.

Phone: 1300 309 337
Web: www.publicadvocate.vic.gov.au
Address: 5th Floor 436 Lonsdale Street Melbourne Victoria 3000