

ASD DIAGNOSIS AS AN ADULT

By SB & JG

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AS AN
ADULT

(available as a PDF by e-mail for free or as a handout [\$2] from asnzgroup@yahoo.com)

Note:

The authors chose to use the inclusive term Autism Spectrum Disorder (ASD) to encompass Aspergers syndrome (AS), Higher-functioning Autism (HFA), Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS), and related higher-functioning segments of the Autism Spectrum just for the purpose of this brochure.

Other types of Autism are logically excluded from consideration here because they have typically always been diagnosable during childhood because of their apparent and more severe symptomologies (e.g. Classic Autism, Rett Syndrome, and CDD).

The authors/compilers:

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Introduction

Gaining an ASD diagnosis as an adult has never been a simple matter for almost all who seek one. Aspergers syndrome, for instance, was until recently little heard of or understood by GP's, and even today few have more than a sketchy understanding.

Health Boards for years have made funding decisions that seek to specifically exclude adult assessment and diagnosis for this condition in almost every case – choosing to instead to invest health dollars in assessment and intervention services directed at children with Autism – rightly or wrongly gauging such services as being more effective.

What does not happen!

A typical route to diagnosis, if there was sufficient cause to believe you might have an ASD, would be to visit your GP. You would ask for a referral to a psychiatrist, a clinical psychologist, or a 'multi-disciplinary assessment team' located at a local Hospital. You would be seen by a specialist or a group of specialists who have plausible experience in diagnosing ASD in adults. However there is no funding specifically for that purpose that we are aware of.

Going private?

Very few adults caught by this anomalous decision-making are in a position to ‘go private’ and pay for an assessment and diagnosis themselves. More especially because it is how very common it is for their personal circumstances to contribute in the first place to their decision to seek a diagnosis... few having had access to a raft of accommodations, allowances, entitlements provided for by agencies, access to whom is driven by sighting an official diagnosis.

Still, for now, the only alternative is to go privately – with or without a referral - and to find another means to pay, a matter which we will canvass below.

Foot in the door already?

If you are already seeing a specialist for other or related reasons, for example, a psychologist because you suffer from depression or anxiety arising from little care being taken with you needs arising from ASD, then you might wish to raise the matter of referral with them instead. In certain circumstances, such a course of action may greatly improve the likelihood of Health authorities funding or providing you route to diagnosis.

The long Work & Income route

To attempt this increasingly well-trodden route there are some things you will need to prepare prior to making an appointment ‘for a Special Needs Grant for emergency medical treatment’ – no need to tell them more about the reason at this stage. But do explain to them that it is not an ‘emergency’ of the type that you need an appointment that day, etc.

If your cash assets are above \$900, you may need to check at www.workandincome.govt.nz for the exact amount they allow you to have and yet still get assistance.

Firstly, seek out a written quotation or estimate from a reliable Registered Clinical Psychologist who regularly provides assessment and Diagnosis, and perhaps post-diagnosis counselling. Your local Branch of Autism NZ Inc. may be able to assist you with this, or – alternatively – ask them for the name of your local Needs Assessment and Service Coordination agency (www.weka.net.nz has a searchable list of these too) and insist they notify you of a standard contact for such help.

Secondly, read the rest of this brochure – you are going to need specific examples of how you are disadvantaged in life by the condition you believe you may have, and enough knowledge to answer questions as wide-ranging as “Aspergers – how do you spell that?” to “Why should we provide assistance for such a mild/broad/unaccepted condition?”.

Thirdly, you will need to get a Medical Certificate from the front desk at any Work & Income Office for your GP to complete. Your GP will need to fill in all the mandatory fields, including:

- a diagnosis (or your GP must offer you a means to one!)
- the impact of the condition on your ability to work and
- the likely duration of that effect (it’s permanent, but the GP will enter 3 months)

Don’t be too worried if the GP chooses to be difficult about the “ability to work” part. If the form is incomplete, in Work and Income’s opinion, you can offer them consent to contact your GP to ask why and ask for any likelihood of you having an ASD (the W&I Form is

called UCVII, and get your case manager to note down the type of consent as ‘third party contact’).

If Work and Income still baulk at the thought of assisting you, specifically ask the Case Manager to talk with the Regional Disability Advisor. Alternatively, the GP has the opportunity to mark your Medical Certificate that Work and Income are to ring for further information and discussion, and, again, Work and Income must seek your consent for this.

Ensure the GP has encoded “Aspergers Syndrome” and has rung Work and Income for the updated or correct code that Work and Income need to see on the form, that is - providing the GP does not already have it on a chart to look-up already.

A further list of typical things you must bring with you is located at:

<http://www.workandincome.govt.nz/get-assistance/main-benefit/sickness.html#legal-things>.

This naturally includes ID, Birth Certificates, Bank Statement, etc.

At the appointed Work & Income meeting, present the quotation to your case manager, and explain how you are severely disadvantaged or ‘stuck’ (for want of a better word) in life. Explain what normal things you cannot do without diagnosis, e.g. get supported living assistance, a benefit, vocational training, limited full-time access to a tertiary institution, special health care, suitable work and accommodation, find a community to be with, end harsh relationships or start harmonious ones, etc. Whatever.

Explain you are asking for them to consider all possible forms of assistance – either beneficiary or non-beneficiary (if you do not receive any benefit or do not want one).

Explain to your case manager that:

- you have a “serious hardship” to present to them
- your access to the “basic necessities of life would be at risk if a Special Needs Grant was not granted” for your diagnosis
- you have “special and unusual reasons for costs that has caused or contributed to” your income deficiency while you face the cost of diagnosis
- you have “special and unusual costs compared to others in a similar position to yourself (i.e. not necessarily people with an ASD, just people your age, etc.)

Ask for the repeated application of the legislation below to your case, i.e. repeated for each appointment it takes to get a diagnosis.

“13.3 Emergency Medical Treatment

13.3.1 The chief executive may make a Grant of not more than \$300 towards the costs of emergency medical treatment (including doctors' fees, prescription charges or hospital care).

13.3.2 The chief executive may make more than one Grant under clause 13.3.1 for a similar purpose in any 52 Week Period.

14 Other Emergency Grants

14.1 If the chief executive considers that special circumstances exist, the chief executive may make a recoverable or non-recoverable Grant of not more than \$200 towards the cost of any item or any service if the chief executive considers that without that item or service, the Applicant, or the Applicant's spouse or partner or a dependent child, would suffer serious hardship.”

Point out the likely and maximum number of appointments needed and the likely costs mentioned in the quotation they have before them.

Ask that they not pay the amount in a lump sum unless the payee requests specifically that of them (sometimes diagnosis takes more or less appointments than expected).

Ask that they not pay the first instalment until the payee requests that either (there is likely to be a waiting period with the Psychologist).

Ask that they contact the psychologist ('the payee') to request they become listed with Work and Income as an approved payee, or offer them assistance in achieving this if necessary. They will seek the banking details of the psychologist or the firm the psychologist works for in order to accomplish this.

If you are unsuccessful, note down in writing the reasons why and contact us for further advice. Also ask for their reasons in writing at the meeting with an eye to asking for a decision review after consulting with 'your advocates' further.

Trying the GP again?

If you choose to try the route through your GP again, all else having failed, you may be able to overcome your doctor's resistance by undoing a belief that you have a 'mild condition' ('less severe' is more accurate) and that a diagnosis would be either irrelevant or unnecessary. Some of the ways you could present your case that might alter your doctor's opinion appear below also.

Ways to raise the subject with your GP

Make sure the diagnosis is the only thing you are seeing your doctor about that day. If you try to drop it sideways into a consultation about another health issue the GP may not address it fully - or seriously.

Take a parent or support person who knows you well. Let them speak for you, but also say what you want them to say. That last point is an important one.

A good way to bring up the subject is to mention that you, or your support person, have been reading about ASD's and/or have also been in touch with Autism New Zealand Incorporated for further information.

Mention any pre-diagnostic tests you have completed, the scores, and the relevancy of the scoring. Give information on which tests they were (e.g. Attwood's Australasian Scale, Baron Cohen's Autism Quotient or Triple A) and make it clear these tests were intended to be completed by either the layperson who potentially has an ASD or their lay supporter - precisely to identify whether or not the matter of professional diagnosis should be pursued further.

A variety of pre-diagnostic tests are available free by e-mail from Asperger's Syndrome NZ Group at asnzgroup@yahoo.com. Please allow up to two weeks for a reply.

- Quick Test for You! (Pre-screening card with 17 short Yes/No questions – 5 minutes to complete)

- Take the AQ Test (Pre-diagnostic two page test with 50 shorter 5-scale questions – 30 minutes to complete)
- The Adult Australasian Scale (Pre-diagnostic 13 page test with 80 longer 7-scale questions – 2 hours to complete)

Describing the Triad of Impairments

You should then explain why ASD's are relevant to you. An ASD can either be characterised by something known as the triad of impairments - as defined in the manual used by psychiatrists internationally (the 'DSM IV') - or perhaps more practically as a profound disinclination to divide attention between two tasks along with all that might mean for a person's abilities and life. People with an ASD will be affected in some way by each of the three impairments in the triad. And perhaps almost always, a fourth - dyspraxia – either fine or gross motor dis-coordination ('clumsiness').

I have given some suggestions below for ways in which you could describe how this 'triad of impairments' relate to you. The autistic spectrum is very broad and two people with the condition may present very differently. Additionally, people with an ASD, naturally inclined to social non-conformity in many respects, are all decidedly individualistic. No one person will have all the traits mentioned, but in general most people with an ASD will have substantial challenges in the following three areas:

Social Communication

People with an ASD may be very good at basic communication and letting people know what they think and - even though less so - feel. Their difficulties lie in the social aspects of communication.

For example:

- they may have considerable or extreme difficulty understanding gestures, body language and facial expressions;
- they may not be aware of what is socially appropriate and have difficulty choosing topics to talk about or tend to talk about one topic only – their favourite;
- they may not be socially motivated because they find communication difficult, so they may not have many or any real friends and they may choose not to socialise very much, if at all.

Some of these problems can be seen in the way people with an ASD present themselves, for example - classic traits include:

- difficulty making eye contact or preference not to;
- repetitive or tortuous speech patterns;
- difficulties expressing themselves - especially when talking about emotions;
- anxiety in social situations and resultant nervous tics/routines.

You might want to highlight how such traits affect you with a specific high-impact example (e.g. I experience disabling anxiety at interviews or exams; prospective employers immediately presume I am unintelligent; I am never permitted sufficient time to complete asking a person out on a date).

Social Understanding

Typical examples of difficulties with social understanding include:

- difficulties in group situations, such as going to a pub or a party with a group of friends;
- finding small talk and chatting either very difficult or meaningless;
- problems understanding double meanings, e.g. not knowing when people are teasing;
- not choosing socially appropriate topics to talk about;
- taking what people say very literally, over literally.

You might want to also back this up with a specific examples of how disabling these challenges can be (e.g. I spend a lot of time trying to crowd-out feelings of loneliness; I get excluded whenever colleagues gather for social occasions; I experience disabling anxiety over thoughts I have been misunderstood or have done the same to others).

Imagination

This can be a slightly confusing term. People often assume it means that people with ASD's are not imaginative in the conventional use of the word, for example, they lack creative abilities. This is very much not the case and many people with ASD's are able or extremely able writers, artists, inventors and musicians. Instead, lack of imagination in Autism can include difficulty imagining alternative outcomes and finding it hard to predict what will happen next. It can also mean having difficulty with pretend play. This frequently leads to anxiety, often disabling anxiety. It can present as:

- an obsession with rigid routines and severe distress if routines are disrupted;
- problems with making plans for the future, and having difficulties organising your life;
- problems with sequencing tasks, so that preparing to go out can be difficult because you can't always remember what to take with you;
- unwillingness to join in games, even adult games, that involve pretending (in much the way a stick with a handle once became a 'gun' for a more typical child).
- finding that reading books of fiction quite distasteful, or certainly of less interest than 'real' books – non-fiction.

Some people with ASD's over-compensate for this impairment by being extremely meticulous in their planning, and making extensive written or mental checklists. (Many females with Aspergers Syndrome however might have a great preference for works of fiction because of a need to make sense of such a 'foreign' world as that occupied by more typical folk.

You might want to convey the effect of this impairment with a specific examples also (e.g. I cope very poorly with change if it is not managed; My life is an aimless wandering one that occurs haphazardly from day-to-day, I cannot enjoy or join-in with the simple pleasures others take in TV soaps, story-telling without a point, and the less structured arts such as modern dance or painting).

Secondary traits of Autism

Besides the triad of impairments, as mentioned above, people with ASD's have a tendency to develop challenges that relate in some way to the triad, but are more a consequence of not having one's ASD-specific needs met. These are often called 'comorbids' and can include:

- obsessive compulsive behaviours - often severe enough to be diagnosed as obsessive compulsive disorders or OCD's;
- these can also be linked to obsessive interests in just one topic, for example - they might

have one subject about which they are extremely knowledgeable which they want to talk about with everyone they meet exhaustively;

- phobias - sometimes people with ASD's are described as having a social phobia but they may also be affected by other common fears such as claustrophobia and agoraphobia;
- acute anxiety - which can lead to panic attacks and a rigid desire to follow set routines that avoid triggers;
- depression and social isolation - especially common among adults who are alone, frustrated, or misunderstood;
- clumsiness - often linked to a condition known as dyspraxia. This includes difficulties with fine motor co-ordination such as difficulties writing neatly as well as – more commonly - problems with gross motor co-ordination such as ungainly movements, tripping and falling a lot, even on occasion appearing as though drunk.

Not having these associated problems does not mean you do not have an ASD, but if you have any of them, you might want to describe that in order to support the case you are making for yourself.

To conclude...

You do not need to go and describe every single one of these features. Your doctor may be more likely to respond if you give one good solid example from each area of the triad. Once you have explained why you think you have an ASD to the doctor, you could also show them a pamphlet or brochure from Autism New Zealand Incorporated, or share with them the 'GP's Guide to Adults with Higher-functioning Autism and Aspergers syndrome' that appears at the foot of this brochure.

You can order a brochure entitled 'Asperger Syndrome' by sending a stamped-addressed envelope to Autism NZ Inc, P O Box 42052, Christchurch 8149 or you can download information about Aspergers Syndrome at <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=212>.

What if the doctor disagrees?

If your doctor disagrees with your arguments in favour of continuing on to assessment and diagnosis, ask the reason why and make a record of it. If you do not feel comfortable discussing their decision immediately you can ask for a second appointment to talk matters through, or seek a second opinion from another GP – you have a right to this.

Reasons why you might (or might not) need a diagnosis

Diagnosis in adulthood can be viewed as a 'mixed blessing' by many. A significant number of people decide that they are happy with self-diagnosis and decide not to ask for a formal diagnosis.

Now, or in the future - whether justified in any way or not - having a formal diagnosis might lead to experiencing higher insurance premiums for one's life or vehicle, restrictions on driving non-automatic cars, being entered on a database somewhere for some purpose, being treated differently by the courts and corrections system, or being subjected to other proposed (negative) restrictions. There is no guarantee such information will always be of positive

benefit at every level of social organisation. But there are ways to avoid any negative effects.

That being said, there are a variety of important benefits currently for those that continue on...

Understanding yourself

Many of the people ASD organisations speak to have suffered from mental health problems and/or have been misdiagnosed as having mental health problems such as ‘atypical schizophrenia’ or a ‘learning disability’. They may even have been written-off as plain ‘bad’. They have known that they have specific difficulties for a long time without being able to explain them. A firm diagnosis can be a relief because it allows them to learn about their condition and understand where and why they have difficulties for the first time and do something about them or seek assistance. It can lead to them giving-up on unreasonable expectations they or others place on themselves, and give impetus to developing any special talents they have or strategies they desire.

Gaining the understanding of others

Many people suffer the consequences of being constantly misunderstood. Often the fact that someone has an ASD can lead to social isolation, teasing and bullying (not to mention the exquisite difficulty in detecting the difference between these). When the people close to you are able to understand that there is a reason for your particular challenges it is much easier for them to empathise with your situation and its absolute permanence. For people with an ASD... so much, so very much, is their challenge in life... but not their fault. An ASD means a profoundly different way of thinking... and being. To be atypical does not mean being abnormal. Acknowledgement of these truths and moderate allowances and accommodations being extended by friends and family mean the world to people with an ASD.

Receiving services appropriate to their needs

Some adults with an ASD may need support with day-to-day living, others may have little actual support needs – perhaps some assistance with relationships and a thing called ‘executive function’, which can affect their ability to make either big decisions or decisions that require a grasp of the ‘big picture’ – as opposed to detail.

If they are having their needs met it may be by people who do not understand Asperger’s syndrome and the specific difficulties associated with it – their help may even be inappropriate.

With a diagnosis, you can access autism specific services such as provided by Workbridge, Emerge, Supported Living Trusts, Tautoko Services, and other specialist agencies. You can know to use visual strategies when learning. You can look for comorbid conditions that sometimes accompany an ASD, even apparently unrelated matters such as susceptibility to fungal infections. You can read-up on strategies, seek specific advice for your type of ASD, and open many many more doors for the first time.

Joining the ASD community

It can be very helpful to meet up with other people who share your condition in order to learn

about their experiences and to impart some of your own. There are a variety of age/condition specific support groups available for ASD's and related conditions in New Zealand for some regions, as well as strongly supported web forums, chat sites and pen-friend groups. While you do not have to have a diagnosis of ASD in order to access such supports, it helps when seeking recognition and acceptance from one's peers.

There is a community for Aspies. There is a culture. It is important to find it. Just as we cannot be helped by round-the-clock social skill lessons, we can be helped by immersing ourselves in a people that accepts us just as we are, by having our talents engaged, by being recognised as gifted in some special way.

There is a need to be worked with and not on by agencies and professionals... and that goes for mum and dad too.

Further help

Gaining a diagnosis can be difficult and very few adults find it easy, so you are the only person who can decide if this is the best choice for you.

Please do not hesitate to contact us further at asnzgroup@yahoo.com or contact the Information Coordinator at your local branch of Autism New Zealand (the White Pages have their contact details or visit www.autismnz.org.nz) for further assistance.

We have Asperger's Syndrome. You are very much not alone – just yet to be connected.

Thank you for your interest - we personally wish you all the answers your heart seeks and needs, and the understanding for a bright future that you deserve.

GP's Guide to Adults with Higher-functioning Autism/Asperger's syndrome

Do you have any patients who don't have serious 'mental health' difficulties¹ and yet find it hard to fit in socially, have an unusual social style, may be unable to complete a tertiary course, have no friends, experience anxiety and stress, or cannot find stable employment? If so, they may have a higher-functioning type of Autism such as Asperger's syndrome (AS) or another ASD (Autism Spectrum Disorder). This is an intellectual difference of less severity than classic Autism, but nevertheless a profound and unapparent neurological and social condition that is permanent, often undiagnosed, and often attended by very troubling life circumstances.

What is Asperger syndrome?

AS is a developmental disorder on the autistic spectrum. If your patient list is 3,000, expect there to be between 40 male and 5 females with AS or a similar condition (Asperger's syndrome (Baird et al, 2000; Kadesjö et al, 1999; Ehlers and Gillberg, 1993)².

People with AS have at least average and more often higher intelligence (albeit often with lopsided IQ scoring patterns) and yet comparatively low social performance.

People with AS have difficulties communicating effectively with others, often having problems making appropriate conversation, sometimes being pedantic/eccentric/verbose, with

poor understanding of others' non-verbal behaviour, and sometimes having difficulty with intonation of voice ('flat effect'), facial expression and – commonly – making and maintaining eye contact.

They have difficulties interacting with others, problems forming close relationships with peers and difficulties knowing how to 'read' others, act in groups, or understand the humour of others. Many people with AS strongly desire social contact but are less able to understand the reciprocal nature of normal social interaction. In consequence, their attempts at interaction can sometimes seem rather awkward or proceed unsuccessfully. This can leave the person prone to teasing, or to being isolated as an adult. It can also make the person appear socially 'inappropriate'.

People with AS have a need for routines, and may have very restricted interests. This may not be obvious, unless you ask. The person may depend on others for the routines of daily life, in a way not expected given their apparent intelligence.

Be aware that adults who have AS may have learnt to 'cover up' their problems or strategise around them - tryingly. Signs of the disorder will often be quite subtle, which is why they encounter great difficulty getting the support they vitally need.

For further advice, please contact Autism New Zealand Incorporated on 0800 AUTISM (Monday - Friday, 9am - 5pm), or telephone the Office of Disability Issues at the Ministry of Health on 04 496-2000.

Questions to consider when talking with adult patients who may have Asperger syndrome

Does he or she:

1. Find many social situations and interaction, especially groups, confusing (even though OK one to one with a doctor)?
2. Often find it hard to guess what other people are thinking and feeling, or why they are laughing at a joke?
3. Find it difficult to make and maintain close friendships?
4. Have a history of problems at school: difficulties getting on with teachers or students. Was he or she teased or bullied?
5. Find it difficult to find satisfactory employment or stay in work?
6. Have any hobbies or interests which take up a lot of their time, especially when younger?
7. Get worried or annoyed about changes, especially unexpected changes?
8. Display difficulties with communication, and appear to lack social intuition?
9. Experience difficulty dividing their attention satisfactorily between tasks or switching between tasks?
10. Have a problem with making or maintaining the normal rhythm of eye contact and listening cues in conversation?

If the answer to most of these questions is 'yes', and your patient wishes to proceed, it may be worthwhile discussing with the local Health Board responsibility for assessment and diagnosis, funding criteria, access and wait list issues. Or completing a Medical Certificate to justify Work and Income assisting with payment for the same process but privately.

Six reasons why opportunity for diagnosis is important

Asperger's syndrome, for instance, is not a mild condition – it is a 'less severe form of Autism'. AS is a fully recognised permanent intellectual disability described in both the ICD-101 and DSM-IV2 international classification systems. If someone meets the criteria, he or she should be accorded the human right of at least an opportunity to be diagnosed.

♣ Diagnosis enables individuals to make sense of their often-tragic past, and can assist them in avoiding continuance in terms of further experiences of considerable disadvantage, being targeted, and being misunderstood.

♣ Diagnosis enables individuals to make necessary adjustments for their future living in terms of care and compatibility.

♣ Diagnosis enables individuals to justify expenditure or to argue for funding to alter their environment (e.g. spectacles for light sensitivity, soundproofing, internet/email communication preferences, etc.)

♣ Diagnosis can help others - families, friends, partners, and carers to better understand and cope with the individual's needs, and challenges.

♣ Diagnosis can help the individual locate local support and social skills groups, and get more appropriate support from employers, social and housing services, benefit agencies, colleges, and other organisations.

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References

1. Those adults who have Asperger's syndrome and have developed serious mental health difficulties should have been referred on already.

2. Baird et al (2000) - A screening instrument for autism at 18 months of age: a 6-year follow-up study. *Journal of the American academy of child and adolescent psychiatry*, 39 (6) pp 694-702; Kadesjö et al (1999) - Brief report: autism and Asperger syndrome in seven-year-old children: a total population study. *Journal of autism and developmental disorders*, 29 (4), pp 327-331; Ehlers and Gillberg (1993) The epidemiology of Asperger syndrome. *Journal of child psychology and psychiatry*, 34 (8), pp 1327-1350.