

Navigating the pitfalls of ASD diagnosis and support: Guidelines from an autistic professional by Ava-Ruth Baker

(= updated version of 'Pitfalls in ASD diagnosis and support' presented at Autescape 2011 "Ownership of Autism", Wakefield, UK, August 22nd - 25th 2011)

Abstract: Attempts to provide ASD diagnosis and support vary widely in approach and quality, mostly 'outsider'-driven, the majority of ASD researchers, trainers and service providers being themselves non-autistic. The presenter, who trained under autism experts on both sides of the world, will share some of her own observations, experience and ideas from two decades working in this field, both before and after her own place on the autism spectrum was formally confirmed. This presentation attempts to shift diagnosis (albeit via some oversimplification and generalization) from a mystery belonging to professionals, into a process those seeking diagnosis can more easily understand and take ownership of. Shortcomings of current approaches to ASD diagnosis, counseling and support will be discussed, as well as the personal challenges of working as an 'insider' (autistic) in a field dominated by 'outsider' (non-autistic) personnel and biases.

Note about terminology: Terms to describe individuals on the autism spectrum and their 'condition' are used in differing ways by different speakers and writers. In this paper, I have used the terms 'autism', 'autistic', 'ASD' (autism spectrum disorder or preferably autism spectrum difference) and 'AS' (autism spectrum) to encompass all within the autism spectrum (except that when quoting others, the terminology used by the person quoted has been retained).

Current state of the art: interplay with mental health

Clear links exist between how autism diagnosis and support are provided, the misdiagnosis that's prevalent, and the mental health of autistics. The recently published book *Aspies on Mental health* (1) comprises personal accounts of this by eighteen aspies, mostly from the UK but strikingly similar to accounts prevalent here in New Zealand (NZ). As editor Dr. Luke Beardon writes (1, p14):

What is clear within the pages of this book is the power that the PNT [predominant neurotype] have, over many people with AS [Asperger syndrome], in particular the 'professionals' – and, even more in particular, mental health professionals. There are doubtless some good professionals out there in terms of understanding AS, though I would suggest they are very much in the minority ... Until there is a far greater understanding of AS and how the environment (especially the people within it) can and does influence people with AS, and until there are changes made in light of this, people with AS will continue to be vulnerable to mental ill health."

The difference between mental illness and mental ill health being, as he explains, that mental illness comprises primary psychiatric conditions (which most autistic people don't have but are often misdiagnosed with) like schizophrenia etc., whereas mental ill health comprises secondary conditions that many autistics do suffer, resulting from environmental factors like poor quality diagnosis, counseling and support; or being misunderstood by the PNT world etc. In relation to diagnosis he writes (1, p 10)

“Many of the diagnostic processes are potentially going to have a negative effect on an individual’s mental health. The very medically based deficit model of AS that is used ... tends to present AS in a very negative light ... [whereas] a dramatic change in how people are diagnosed could potentially reduce negative feelings about having AS which can lead to mental ill health”

and to misdiagnosis (1, p 100)

“It is essential that clinicians are provided with the appropriate training and support to differentiate better between the nature of AS and mental illness – otherwise it is highly likely that misdiagnoses will continue to blight the lives of individuals with AS who may require support – but are not mentally ill.”

Being a professional on the spectrum

My own work in this field developed from decades working as a GP with special interest in mental health, increasingly specializing in autism issues over the past two decades. I offer autistics and their families diagnosis, counseling, and other forms of support, entailing much ‘translating’ between ‘autistic’ and ‘neurotypical (NT)’ worlds. My training for this work included a post-graduate diploma in mental health, autism training under Dr. Tony Attwood, and training in DISCO diagnosis (the Diagnostic Interview for Social and COmmunication Disorders) under Drs. Lorna Wing & Judith Gould (choosing DISCO as I consider it the gold standard among today’s approaches to diagnosis). Together with extensive reading and personal development training in listening skills, conflict resolution etc.

Much though I love working in this field I’m passionate about and can make a difference in people’s lives through, and moved as I am by the courageous life-stories entrusted in me, I do struggle with the controversies arising from working as an ‘insider’ in such an ‘outsider’-dominated field. Feedback ranges from professional skepticism (that an autistic person could be capable of doing such work at all, let alone well) to client gratitude for my ‘insider’ understanding.

My conclusion from two decades of such work, is that we autistics working in fields like diagnosis, counseling, or other forms of support, have much to offer from our ‘insider’ perspective, but also need to meet the standards of quality, training and professionalism expected of anyone engaged in such work - perhaps even more rigorously than our neurotypical counterparts, to ensure we have sufficient insight, strategies and safety around our own autistic traits that we can draw on our autistic strengths without our autistic weaknesses tripping up either ourselves or our clients, or bringing the autistic community into disrepute.

Ensuring, for instance, that we learn to:

- be good listeners
- communicate with both clients and colleagues, whether NT or autistic, on their terms not only our own
- use our ability to focus on details to research things that our autistic clients seek answers to, but not to impose our own hobby-horses or biases on them
- train in inter-personal skills, professional ethics, autism knowledge in general, and actively engage in ongoing training both general, and in response to particular issues encountered in the course of our work

Are we ‘insiders’ the experts? This may depend how we apply our personal insights on autism. While our pooled lived experience gives the autistic

community expertise collectively, we're also individually unique. So in my opinion, being on the spectrum oneself doesn't mean any one or small group of us are experts on one another, or on autism as a whole, even though each of us may be the 'expert' on our personally unique functioning and needs. So for autistic as for NT professionals, important when giving information or advice, to clarify the basis of our advice. Simply saying 'I know because I'm autistic' may be just as misleading as 'I know because I'm a psychiatrist.'

Autism diagnosis

In essence, what current diagnosis typically involves, is gathering concerns, observations etc., then trying to fit the person and their issues into a diagnostic category or box (such as Asperger's Syndrome, diabetes, etc.) - each diagnostic box having its own set of 'criteria' that must be met to 'fit' that box.

Problems with concept of diagnosis

In my view, diagnosis of autism would be unnecessary in an ideal world, in accord with the *social model*, which considers autism a neurological 'difference' that only becomes 'disability' because of society's response to it. If society understood, accepted and accommodated our diversity as human beings, why would we need such labels or diagnoses as autism? But in the present social climate, they are needed to access funded supports etc – which means, for the time being at least, using what's known as the *medical deficit model*, which diagnosis belongs to.

Problems with diagnostic systems

Next, within this medical model (flawed though the whole concept of diagnosis may be) there are problems with the systems used to classify and diagnose autistic spectrum conditions.

The four most commonly used systems are

- **DSM** (2) and **ICD** (3) in their various revisions, each of which basically has a set of criteria for *each* condition they consider part of the autistic spectrum – for instance one set for autistic disorder, a different set for Asperger's etc
- **Gilberg et al 2001** (4) which relates only to Asperger's and uses a set of criteria completely different to DSM & ICD for that
- **And Wing & Gould's 1979** (5) which has a different set of criteria again: just one set that applies to all forms of ASD.

Who uses which of those and how, varies. Here in NZ, most professionals use DSM (with varying degrees of training in applying it to autistic conditions and in its shortcomings). I personally, like a number of professionals internationally, find Wing and Gould's and Gilberg's more useful. However one of the beauties of DISCO as an assessment tool, is that it can easily be applied to any of the above systems.

As for the problems with diagnostic systems:

Firstly, being all based on the medical deficit model, they focus on what's wrong with the autistic individual, what needs fixing in them, not in the environment or

society – and imply that autism is a matter for doctors, not society, to sort and solve. The emphasis on deficits also makes autistic features less likely to be valued, and more at risk of being eradicated by genetic modification, abortion or other types of eugenics or social / political / medical control.

Secondly, all except ASD are categorical, but autistic people don't usually fit neatly into categorical 'boxes' – as Lorna Wing and Judith Gould described in their presentation about the origin of the concept of the autistic spectrum (6)

“There were many more children who did not fit Kanner's or Asperger's criteria but who had all kinds of mixtures of features of these 'syndromes' ... The concept of a spectrum of autistic disorders fitted the findings better than the categorical approach. This does not imply a smooth continuum from the most to the least severe. All kinds of combinations of features are possible.”

Unfortunately the autistic spectrum is widely misunderstood by both professional and lay people, as a spectrum of severe to mild versions of the same thing. Not only when diagnosing but also when determining needs, whereas, as Wing and Gould continue (6)

“Individual needs are more accurately assessed from the profile of levels on different dimensions than from assigning a categorical diagnosis”

Using a dimensional model, would provide each autistic individual with a description of their own unique profile of autistic strengths and challenges, not just a 'Yes' or 'No' to fitting the autism diagnostic box.

Thirdly, but connected to that, the diagnostic criteria these systems use, focus on the triad and ignore other features like the sensory issues, executive function etc., that are often what autistics struggle most with.

Fourthly, a major problem from an autistic perspective, is that the criteria are based on 'outsider' observations of behaviors not on the meaning of the behavior for the person observed, or what might lie beneath it. For instance, is a repetitive behavior, a problem to get rid of or a brilliant coping mechanism? Are there autistic features hidden beneath the individual's efforts to pass as normal? Or beneath the anxiety or depression that may be all that's visible on the surface? Such questions are very obvious to me on the spectrum, but not necessarily to NT clinicians.

Problems with the process of autism assessment

Another big issue is, how these diagnostic systems are applied. For example how does a clinician determine whether or not someone fits any particular criterion? There's little formal guidance, as Tony Attwood writes (7, p40-41)

“The text in DSM-IV ...provides only cursory guidelines for the diagnostic process and a superficial description of the disorder ... Training, supervision and *extensive* clinical experience ... are essential before a clinician and client can be confident of the diagnosis.”

And Wing & Gould (6)

“The difficulty is how to define these [basic impairments] in operational terms and to specify the borderlines”

(in lay terms, difficulty detecting and measuring autistic features, and determining the cut-off point between autistic and not-autistic)

As a result, most diagnosing is much more subjective than people realize, much resting on the experience and attitudes of the particular professional seen. One of the reasons Wing & Gould developed **DISCO**, which at least has a systematic (so more objective) approach to this: DISCO defines what sorts of features are needed for each criterion, how severe or frequent, and the sorts of questions and details that need to be explored, including some that clinicians seldom think to ask. Altogether, there are over 400 questions to explore, with clear guidelines on how to ask them to get the most useful description (not just a Yes/No answer), and how to evaluate the responses.

Some of the other reasons I personally favour DISCO are that it can be used with all ages and abilities, whether autism is obvious or subtle etc. Also, that it can be coded for diagnoses in any of those commonly used systems, and considers all one's difficulties and needs, not just the label, not just the 'triad.'

But with any process of autism assessment, even DISCO, some of the qualitative nuances are still a matter of the clinician's judgment. For instance, how about the social criteria? Professionals often assume that all autistic people are either withdrawn, or wildly inappropriate – so if an adult seems to interact OK in the structured setting of an appointment; or if a child is seen by teachers out in the playground 'with' other children, they are often deemed not to meet the social criteria for autism - whereas the social difference can be more subtle than that, maybe only detected in unstructured situations with same-gender-peers. As Jane, for example, writes of the other girls at the 'sleep over' at the end of their time all together at a summer camp (8, p 41 & 158-9)

"Something had happened to them, individually and as a group, during the weeks of the camp, that had not happened to me ... The other girls had become friends with one another. Alone there, with no adult present to direct us, they chatted and whispered and laughed and interacted with seamless ease. How did they know what to say? They weren't talking about anything, and yet they talked constantly. My conversation was limited to specific subjects, not including anything as nebulous as girl talk or small talk. Moreover, they seemed to know each other in a way they didn't know me and I certainly didn't know them. I had been with them as much during the summer as they had been with each other; I had done everything they had done (as far as I could tell). And yet I was a stranger there. The only stranger in the tent. ... It was as if everyone else had studied a script and learned their parts beforehand. In fact, of course, they were improvising brilliantly, thanks to the social code capacity programmed into their brains."

But just as it's unlikely that camp staff would have perceived Jane's difficulty, so when my own parents' generation are asked for details of our social skills, they are often vague or unhelpful, as we children were typically just sent out to play, without our parents there to notice the finer nuances of how we got on, how well we picked up social cues etc.

Thus, measuring the social criteria by what parents or teachers noticed, can be very misleading at the 'subtle' end of the spectrum. And it can be really helpful, when you're being assessed yourself, to give a detailed description of what happens for you in social situations, so that your difficulties are not wrongly assumed to be shyness or social phobia.

Other common problems I've observed in current processes of assessment, include screening tools being used as though they are diagnostic, and

assessments that are much too brief or just 'token' (having decided in advance what the conclusion will be). Further common issues raised by those seeking an autism assessment include not having their concerns taken seriously, and difficulty accessing diagnostic diagnosis (lack of qualified clinicians, especially in adult diagnosis, in the public sector; lack of funding for assessment in the private sector).

Common fallout from such problems with diagnosis includes mis-interpretation of autistic issues (from an 'outsider' perspective or a 'know one autistic, know all' attitude), missed diagnosis (either failing to consider autism at all, or dismissing it as a possibility without properly looking at it), misdiagnosis, and un-diagnosing (taking away a previous diagnosis of autism) - amidst much disagreement among professionals and changing of labels, to the bewilderment of clients. Even a correct ASD diagnosis is typically delivered negatively ('This is what's wrong with you') and as the sole end-point of an assessment, without any help or suggestions for the future.

In contrast, features of a good diagnostic assessment, that are often lacking, include providing an autistic-friendly setting and communication style; assessing all areas of development not just the triad; a written report; and going beyond just the label by presenting autism in a positive way, together with supports and strategies (both general, and specific to the needs of the individual), facilitating access to insiders' views & autistic community, and preparation for the post-diagnosis journey ahead: outlining the likely stages in adjusting to the diagnosis, and where to get support for this. 'ASK', our support group for and by NZ adults, published a booklet in 2010 to welcome newly diagnosed adults to their place on the spectrum in a positive and helpful way. ASK's vision being that all professionals involved in diagnosis would offer the booklet to clients at the time of their diagnosis (the professionals hopefully reading it themselves too, and incorporating some of the ideas into their practice!)

Assessing and assisting those clients with some autistic features, but not quite enough to meet the current diagnostic criteria, poses a dilemma. Wishing to help them while still respecting today's official boundaries, my own approach is to tell them that diagnostic systems are still evolving, that though they don't quite meet today's criteria, they do fall within what's known as 'the broader autistic phenotype' (BAP), and that the autistic features they do have, may well be helped by learning about autism, contact with the autistic community, using the strategies autistic people find helpful, etc. The clients I've seen in this 'BAP' zone weren't seeking funded services, just understanding and strategies, so were happy with that approach. A novel solution some clinicians apparently use in this situation, is to assign a percentage to their 'degree of fit' -one woman for instance relating that she'd been diagnosed as 70% Asperger's, but still felt more at home in the company of autistics than of NTs. In the autistic community such people might identify as 'cousins' (though I suspect that many who identify as cousins, would meet today's criteria for an autism diagnosis if assessed properly).

So to summarize common problems with autism diagnosis today (some of which applies to support and counseling too) there are

- problems with diagnostic systems and the whole concept of diagnosis
- inadequate guidelines for the process of diagnosis
- inadequate training in autism, diagnosis and insider perspectives
- difficulties accessing a diagnostic assessment, especially for adults
- widely inconsistent quality of professionals and their approaches (whether public or private, autistic or non-autistic) resulting in arbitrary and controversial dismissing of the possibility of an autism diagnosis, un-diagnosing, misdiagnosing, misunderstanding autistic issues, negative portrayal of autism, and poor if any follow-on support. All of which can be dangerous, causing mental ill health, and occasionally suicide.

Problems with Counselling, post-diagnosis support etc

Veronica, a psychologist on the spectrum, writes in '*Aspies on mental health*' (1, p49-50):

"I have experienced how the [mental health] system works from both sides of the desk. Mental health is defined by the person in any given room who has most of the power ... People with AS get labels of 'difficult', 'resistant to change', 'unable to form a relationship' 'unable to benefit from therapy' and so on" because the way they use language is different from the norm. When a typical mental health professional gets a whiff of abnormality, they are trained to dig for ... pathology ...when actually the behavior seen as abnormal by the [mental health] worker is perfectly functional and normal for the client"

The following account by Jo highlights some of the distressing but common mistakes in counseling (9):

Jo: And the counselor started saying things like "if the alleged abuse actually happened" and to me she was questioning my story, questioning whether it happened... I found that incredibly upsetting and destroyed my inclination to go to counseling.

And she reflects on the part her Asperger's may have played in not being believed:

Jo: I think that part of the problem was there's not always a congruence between my story and emotions. Often I can narrate what happened to me in an apparently emotionless tone and other times I can break down in tears at apparently much less significant things, or for no apparent reason I'll suddenly get very distraught because I'm overwhelmed by the whole experience of telling, but it isn't necessarily at the times you'd expect of a person ... That may have led to the assumption that this might be concocted. For instance the psychiatrist was surprised when I didn't seem distressed talking about being raped, I seemed like I could have been talking about somebody I didn't know particularly well rather than about myself.

Likewise, what autistics say in their typically honest upfront literal way, with no subconscious or hidden agenda, may be discounted, as Jo tells next:

My therapist ... often asked me questions to which I'd answer "I don't know", and at one point we had quite a breakthrough in the counseling when she turned around and said to me "You know when you say I don't know, it's not because you're denying me, it's not because of a transference relationship, it's not because of any of these things, I think you genuinely don't know", and at that point my mouth kind of dropped open and I thought, "What do you mean you think I genuinely don't know, of course I don't know, if I knew I would say wouldn't I?" ... I was totally astounded that all this time she'd been thinking that I knew but for various reasons I was covering up or something, not that I genuinely didn't know! After finding out more about

Asperger's Syndrome, she would, when I said I didn't know, actually look at what part of the question I didn't understand, or reframe it.

The effect of the uneven profile of ability and inability, common in autism, is also often overlooked, as Jo continued

A global thing that's clouded my relationships with people in the mental health profession, is that I have a high IQ, yet am quite unable to manage ordinary things that other people can, and this lack of social understanding sometimes caused intense frustration in the people I was working with. They'd listen to me talking academically and think they'd handed me a solution. But often I need VERY VERY explicit instructions on how to implement ideas and lots of repetition ... I get quite frustrated with a lack of directedness within therapy, it can be like slamming my head against a brick wall saying "I don't know how to resolve this issue, I'd like you know to hear your perspective, hear how you might deal with this sort of thing" – but instead the question's reflected back at me, "What do you think, how do you feel?" And I want to scream "If I could solve this by myself with what I have, I would!"

Thus, it's critical that therapy embraces the autistic individual's unique perspectives and style (of thinking, feeling, relating, learning, applying advice etc) and focuses on autistic-friendly strategies for the issues and dilemmas the individual is seeking help for, not on trying to challenge or change the autistic's innate way of being.

Ownership of autism diagnosis and support: collective and individual

Collectively, while waiting for society to change, and stuck with the medical model in the meantime, the autistic community could still lobby for changes in the afore-mentioned problem areas, and for standards of quality, training & professionalism for both NT & autistic providers of diagnosis and support. Maybe the autistic community could even provide training and leadership in this?

Then as an individual, how might you take more active ownership of your experience of diagnosis and counseling?

Firstly, the attached resource list has a list of books and website articles, all written by adults on the spectrum, with ideas and guidelines that could help you gain a greater sense of ownership of your process of diagnosis, post-diagnosis journey, counseling, and other supports.

As for recognising a good professional: there are some excellent written guidelines by Roger Meyer (see resource list) for evaluating a professional you're either already seeing, or contemplating seeing, for diagnosis or counseling. One good starting-point for finding one, might be to ask other autistic adults who they've found helpful, and then check out the following about whoever you're considering seeing:

- What training & experience do they have in autism diagnosis and issues for adults?
- What is their attitude and knowledge of 'insider' perspectives, post-diagnosis issues etc?
- With regards to communication, can they accommodate your style and needs? Are they a good listener?
- For diagnosis, which processes or tools or approach do they use? In my view, DISCO is ideal; ADOS is unsuitable for most adults; screening tools are for

screening, not diagnosis. Accounts by parents, teachers etc can be useful but also misleading or limited, for instance if parents are now old, or if they didn't observe in detail how you related to peers. Such accounts may be coloured by the parent's own attitude to autism and to reviewing their child's development (e.g. raising uncomfortable questions about their parenting, the possible need to consider a different explanation for their child's idiosyncrasies, than the one held for so many decades, etc).

- What sort of environment, timing and structure do their appointments involve?
- In counseling and support: who defines the agenda, priorities, needs? Do they respect your innate style or try to change it?

That a professional is themselves on the spectrum, is not in itself a guarantee of good quality – those of us on the spectrum still need to meet all the other criteria of good practice, and have sufficient self-awareness and strategies around our own autistic issues that these enhance rather than impair the therapeutic process.

As for how to get the most out of an appointment: what I find invaluable, whether I'm in the role of provider or client, is preparing for an appointment beforehand. For instance, alerting the professional beforehand, to any particular appointment needs you have (sensory, communication etc). And for a diagnostic assessment, preparing a written account of your 'differences' or 'issues', giving examples: This I find extremely helpful, giving a much fuller picture than trying to get it all out during an appointment (after all, a diagnostic assessment involves reviewing your entire life!).' It's also helpful to write down your own questions, and prioritize your issues and needs beforehand

Bringing a support person (partner, family member, friend, someone from work etc) can be helpful in many ways – for instance in a diagnostic assessment, to help corroborate and give examples of your differences and issues. This support person could also take notes, as such appointments can be intense, even overwhelming. And if that support person is NT, the appointment may also become a natural opportunity to practise translating between autistic and NT perspectives.

Finally, in spite of the many potential pitfalls, it can work out really well. As

Cornish writes about finding the right counselor (1, p84)

"What a godsend. Just not having to justify my way of being, my existence, was a unique experience in itself ... Just being accepted for who I am made all the difference ... [but] it took two years of intensive therapy ... to undo all the damage that had occurred at the hands of the NHS psychiatric staff, and how to forgive them too. It all went very well, and my life has never been better ... It is essential that you track down the right specialists, no matter how long it takes, how much it costs and how far you have to travel"

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8. Meyerding, Jane. Growing up genderless. In Jean Kearns Miller (Ed.) *Women from another planet?* **2003**
9. Grey, Jo. *Personal communication*, **2002**
10. Meyer, Roger. Articles at www.rogermeyer.com see Articles & writings: topic index: Counseling → the following articles
 - *Two Asperger adult shopping guides for finding a good diagnostician and a good personal counselor*
 - *Asperger Syndrome diagnosis and checklist for finding a good adult counselor*
 - *A new paradigm for more able late adult personal counseling*
11. Greally, John. *A brief guide for GPs to adults with higher-functioning Autism and Asperger's Syndrome*; www.asnz.exofire.net **2010**

Other resources for the diagnosis and post-diagnosis journey

1. *Asperger's from the Inside Out: A Supportive and Practical Guide for Anyone with Asperger's Syndrome*. Michael John Carley **2008**
2. *Beyond diagnosis: Welcome to the Autism spectrum!* by ASK Trust, PO Box 4206, Christchurch, New Zealand or 222.asknz.net. **2010**
3. *Ask and Tell: Self-advocacy and disclosure for people on the autism spectrum*, Ed. Stephen Shore **2004**
4. *Coming out Asperger: diagnosis, disclosure and self-confidence*. Ed. Dinah Murray **2006**
5. Two articles by Ava-Ruth Baker see www.avaruthbaker.com
 - *Invisible at the end of the spectrum* **2003**
 - *Autism and careers requiring empathy: Are they compatible?* **2006**