

# INVISIBLE AT THE END OF THE SPECTRUM: SHADOWS, RESIDUES, 'BAP', AND THE FEMALE ASPERGERS EXPERIENCE

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The original oral presentation with similar title was given to Inaugural World Autism Congress, Melbourne 2002.

The revised version below is referenced as:

Baker, A. Ruth (2004). *Invisible at the End of the Spectrum: Shadows, Residues, 'Bap', and the Female Asperger's Experience*. In March 2004 *Proceedings of Autism: Unlocking the Potential within* Autism NZ Conference, Christchurch, New Zealand. Or see [www.avaruthbaker.com](http://www.avaruthbaker.com)

## Keywords

Sub-clinical autism, broader autistic phenotype, autism in adult / female / gifted, diagnosis / misdiagnosis, counselling, disclosure, gender

## Abstract

What could or should be done for those individuals whose autistic traits seem insufficient for an autism spectrum diagnosis? Professionals may assign them to a sub-clinical category such as broader autistic phenotype (BAP), shadow syndrome or residual Asperger's Syndrome, or may discount or completely overlook their autism. For the individual concerned, however, knowing about autism may be the key to understanding their outwardly subtle yet inwardly agonizing difficulties, and thereby to finding autism-appropriate ways to realizing their potential. At particular risk of misdiagnosis or missed diagnosis are adults, females and gifted individuals. This paper, presented from the author's dual perspective of both personal experience and professional work in the area, draws on accounts from the autism community and the professional literature to explore some of the dilemmas around diagnosis, disclosure, counselling, and other issues of importance to those whose autism seems "mild" or "invisible."

## Terms and models at the end of the spectrum

As with the light spectrum, one can envisage two invisible ends to the autism spectrum. This paper concerns the so-called "higher-functioning" end of the spectrum, which one could loosely call "Asperger's and Beyond":

Beginning from the *biomedical model*: At this end of the autism spectrum, besides the familiar terms for those with formal clinical diagnoses, are an assortment of other terms coined by professionals for sub-clinical conditions. These latter terms include *residual Asperger's Syndrome in an adult* (1 p26); *autism shadow syndrome* (2); *loners* (3);

*autistic tendencies* or *ghost-ing* (terms used by clinicians); and *broader autistic phenotype (BAP)* (a term used by researchers, e.g. as reviewed in [4]), and refer to individuals who at their current level of functioning do not “seem to” meet full criteria for a formal autism spectrum diagnosis, even though they may have done during their childhood (as in residual Asperger’s Syndrome), or may currently meet one or two of the components of the triad of impairments but not all three (as in some definitions [5] of BAP). Some of these individuals may turn out to fully meet the criteria for a clinical autism spectrum diagnosis when assessed in more detail, or may do in the future as definitions and diagnostic boundaries change in this evolving field.

Within the autism community (6,7), the sociological term *AC* embraces both *autistic* individuals (those with a formal diagnosis anywhere along the spectrum) and *cousins* (those with autistic features but no formal diagnosis) as distinct from *NT (neurotypical)* which refers to non-autistic people. Those without a formal professional diagnosis may also be termed *self-diagnosed peer-confirmed* (if their self-diagnosis has been validated by other adults on the spectrum). This approach acknowledges the *ethnicity model*, as used by indigenous people and by the Deaf movement, whereby anyone belongs who identifies with and is accepted by that community as belonging. This is important for people at this little-acknowledged far end of the spectrum, as many of them identify more closely with autistic than with neurotypical people, and while they may be excluded by current professional diagnostic systems, they are included as cousins within the autism community. For those without a formal diagnosis, having even one or two autistic traits may still make life more challenging, and knowledge of autism may provide the best understanding and strategies for living with those traits, as will be outlined in this paper.

[Note that at the so-called:” lower-functioning” end of the spectrum, autism diagnosis and needs may also be overlooked (8,9). For example, though some dispute the value of adding an autism label to those already diagnosed with intellectual disability, others counter that recognizing the autism is vital because of their very different environmental and interpersonal needs compared to their *non*-autistic intellectually disabled peers, and their inability to voice those needs.]

### **Why “Invisible”?**

At this higher-functioning end of the spectrum, an individual’s autism may be considered invisible because an autism diagnosis is either overlooked altogether or is discounted as their condition appears so “mild”.

Referring to conditions at this end of the spectrum as mild or high-functioning can, however, be very misleading, as both autistic individuals (10, 11) and professionals (12, 13 p27) have pointed out. For instance, the apparent ability to sustain a job or marriage may mask considerable underlying struggle and confusion. Frith suggests (12 p21-23) that Asperger’s Syndrome might better be regarded, not as “a very mild form of deficit” but as “compensatory learning in the presence of a severe deficit”, a view with which many on the spectrum identify (though perhaps preferring the term difference to deficit). Frith continues:

Just how high is the cost, and how much effort is being spent in keeping up appearances? ... Presumed normality does not make allowance for sudden gaps in the carefully woven fabric of compensatory learning ... The uninformed employer might request something that for a normal person would be a trifling effort – unwittingly demanding a major effort from the Asperger individual. [resulting in] sudden panic [or] a catastrophic reaction like screaming [which] can cost a job.

However well those with so-called mild autistic conditions may seem to have mastered basic social skills, the more subtle social nuances remain an ongoing source of confusion and distress, as two adults from this end of the spectrum explain:

(14): Neurotypical social communication involves mind games that profess to show manners and caring, but can be traumatic for those of us who can't follow them: for instance often NTs *don't say what they mean, but still expect us to guess* what they really mean and to act accordingly. If we take their words literally, they get mad at us for being inconsiderate... For example, the hostess says, "please don't leave yet" and we are supposed to say, "yes, I must, I have to get up early tomorrow" and then leave. If we *do* stay instead, then the hostess will resent us for being inconsiderate by keeping them up late; but if we say "yes, I'll let you go to bed" then it would be an even worse breach of code, which might result in an argument "no I *really* want you to stay" etc. There are many other examples. Reflecting on my reaction to such experiences in my own life as an AC, it occurred to me that it's like what happens to a young child exposed to age-inappropriate stuff like sex. It's a feeling of something imposed on us, that on the one hand is incomprehensible with no context in our system, and on the other hand is so invasive that we can't just wave it off. I find the effect even worse than physical invasion. And it's what NTs call "basic manners" in simple cases and "caring" in more complicated cases!

(15): I used to say "Please tell me when you want me to go home, because I can't tell" and the hostess would say "No, I *wouldn't want to hurt your feelings* by doing that." So then I would try to gauge it right, but sooner or later the hostess would start being rude to me, and it turns out that was because I'd overstayed my welcome! Now wasn't her rudeness much more hurtful than simply telling me when it was time to go, like I'd suggested?

Thus, autistic traits may be seen but the diagnosis discounted because of apparent mildness or insufficient diagnostic criteria.

Another reason for discounting an autism diagnosis can be that the autistic traits are accompanied by other features mistakenly thought incompatible with autism, such as empathy, imagination, theory of mind or sense of humour. (For evidence that such features can indeed be compatible with autism, see for instance 11 p12; 13 pp 47 & 60-61; 16; 17; 18; 19; 20; 21.)

An autism connection may be overlooked altogether because of misdiagnosis. This can happen in various ways:

In some cases, as with obsessive-compulsive disorder and attention deficit disorders, *only one aspect* of the autistic individual's range of difficulties or differences has been recognised.

In others, a behaviour is recognised but not the *underlying reason* for that behaviour, resulting in wrong or inadequate diagnoses: for instance, social phobia, if the distinction isn't sought between an irrational fear and a realistic appraisal of social performance [22], or anorexia nervosa if the real reason for unusual eating behaviour isn't recognised [23 p43]. The cycles reported by many on the spectrum (16) can be mistaken as a bipolar disorder. Seemingly bizarre descriptions of perceptions, fantasy life, novel use of language, or running thoughts or entire conversations out loud, can be mistaken for a psychotic disorder, if the individual's full developmental history and social developmental level is not taken into account (25, 26 pp 219-224; 27). In a child, oppositional and defiant behaviour may be the manifestation of an autistic child's cognitive (theory of mind) and modulating (emotions and behaviour) difficulties rather than a so-called "oppositional defiant disorder". Behaviours such as pathological demand avoidance, aggression, or attention seeking, may represent the autistic child's attempt to cope or socialize without adequate know-how (28, 29).

*Dual* diagnosis can also occur, but often only the more obvious diagnosis (e.g. depression) is recognised while the possibility of underlying autism is not even considered (24). This commonly happens when individuals at this end of the spectrum present, not seeking an autism diagnosis (being perhaps unaware of autism and / or of

their own early developmental history), but because of their *secondary or tertiary disabilities* (25) arising from their personal response, or the response of others, to their differences: For example, for the autistic adult anxiety or depression may be an understandable response to undiagnosed autism. Other psychiatric disorders may accompany autism, for instance even occasionally a brief psychotic episode (25) in an individual whose lifelong differences might still be better explained as autism rather than schizophrenia.

Thus, autistic individuals claim, and the research literature supports, that misdiagnosis and missed diagnosis are common (25, 26, 30, 31), that autism may mimic a range of psychiatric disorders (25, 31, 32), and that anxiety and depression frequently accompany autism, furthermore often presenting atypically (25, 32, 33, 34).

Populations at particularly high risk of missed or mis- diagnosis include adults, gifted individuals, and females:

The incidence of autism in adults (as in children) is probably close to 1% (8, 35, 36). So where are all these adults? Under-diagnosis among adults is probably common (37, 38 pp 29-30). A typical scenario is that their more florid signs in childhood were overlooked at a time when Asperger's was scarcely known, and are now "masked" by compensatory strategies (such as superficially normal conversation and eye contact) by the time they present to clinicians as adults. However they are still diagnosable providing the possibility is considered and properly assessed (1 p26, 25, 37).

Asperger's syndrome is also thought to be commonly missed among the gifted, though research on this is only preliminary (39). A common example is the low-achieving gifted child, whose poor performance is blamed on "attitude" or taken to be a simpler learning disability, while their other Asperger's signs are mistakenly attributed to their giftedness (13 p 364-5, 39). To distinguish whether such a child is gifted, has Asperger's, or both, requires some expertise in Asperger's, though some distinguishing clues have been outlined (39). It is vital that those who do have Asperger's are identified, as they may need a very different approach if they are to realise their potential.

As for the female expression of autism spectrum conditions, the scant literature about this suggests that they present differently and may be under-diagnosed (8, 13 pp12-16, 40, 41). Although girls have been said to have a better long-term prognosis than boys and be "more able to learn how to socialize and to camouflage their difficulties at an early age" (1 p 152), women on the spectrum point out that the challenge they face is compounded by society's higher expectations of intuitive social abilities in women than men, so that they still fall far short of the expected norms for their gender. The recent anthology "Women from another planet?" (42) explores and illustrates these and other issues faced by females on the spectrum. In females, the diagnosis of Asperger's may be overlooked because of low professional awareness, misinterpretation of behaviours, and their often-different presentation: For instance, their special interests may differ from those typical of Asperger's males, may be less obvious and less likely to be imposed on others. The full extent of their social difficulties may only show up when interacting with their female peers: For example, they may talk eloquently with the clinician, relate well with parents, tag along with the boys, yet be incapable of the typical chatter and other social bonding processes of their girl / woman peers (as recounted, for example, in 43 & 44). One autistic woman (45) reports that her behaviour as a child was interpreted as "unladylike rather than socially inept", and her perceptual problems as "hysteria". Certain developmental trajectories (common among but not confined to females on the spectrum) increase the likelihood of their autism being overlooked: For example, as awareness grows that they are somehow breaching the mysterious codes of social life, girls with Asperger's may stop being so obviously inappropriate but instead become

silent, anxiously careful, or adopt others' behaviours or personas (for instance 11 pp 2-3 & 261-3, 46 p22), so achieving a quasi-normality, though at the risk of remaining forever undiagnosed, marginalized, and still inwardly puzzled about the complexities of social life. The following are examples recalled by women on the spectrum from their own childhoods:

**Hiding (47):**

I had language skills, but it didn't do me much good. People didn't understand what I was trying to tell them. It didn't get me what I wanted, nor did it answer my questions. It was better to remain silent. As long as I was being 'good', people left me alone. I learned that life was easier for me that way.

**Mimicking play (47):**

Maybe 50% of the time, if invited, I would consent to play with them ... out of curiosity for what they were doing. Since I didn't understand ... I would simply wait until someone told me what to do. Later, I learned to ask for certain roles. I realized that if I asked to be the 'servant' or 'child' in pretend play that someone would always direct me. That way I didn't need to figure out what the game was all about. It was the first of many ways that I learned to hide my social confusion. I never did catch on, but I was learning to be like them.

**Mimicking behaviours such as eye contact (48):**

When other kids criticized me for not looking them in the eye, I was shocked! So even though it was unpleasant I started doing it, but then they accused me of staring. Eventually I found by trial and error that a rhythm of 3 seconds looking at them then 3 seconds looking away, stopped the comments (but still didn't gain me anything except less criticism).

**Or mimicking whole personalities (49):**

I did what others asked of me much as a robot would ... and I hid what remained of "me" deep inside a world of my own, where no one else was allowed ... As the demands on me grew, I developed different "characters" that had specialized knowledge and skills to "perform" as others expected me to perform.

### **To diagnose or not?**

Some professionals are reluctant to diagnose out of concern not to lumber those at this end of the spectrum with labels. Two adverse consequences of this for the individual are firstly, denial of access to the resources they need to make sense of their lives, and secondly, the burden of the even worse labels such individuals already carry. Most at this end of the spectrum have, throughout their lives, been assigned default explanations for their social inadequacies, in the form of *moral labels* such as "rude, ungrateful, obnoxious, weird, arrogant, selfish, over-anxious ('Just relax – be yourself') stupid, or lazy ('Just try harder')": labels either stated, or implied by the rejection, silences or laughter when they try to participate (13 p 403, 20, 25 p367, 42, 50, 51). An individual at this end of the spectrum, performing well in some aspects of life, is a prime target for such moral judgments, as others fail to understand how someone so capable in some areas could be so ignorant in basic social know-how, so assume they are either being deliberately difficult or just not caring or trying hard enough. Whereas often the contrary is true: one such teenager quotes from her (pre-diagnosis) diary (52), her repeated resolutions to try even harder to be more acceptable by being less selfish:

"It is so hard and painful to realize that a little thing like me cannot possibly mean anything to anyone else ... How I have wasted these 17 years in the attempt to impress others who couldn't care less. I somehow imagine myself in 60 years' time, an old lady surrounded by fragments of a wasted lifetime. ... The way to become unselfish is in the suffering of others. ... From now on I must live every second to the full in love of others and not myself."

Interestingly, research in the 1960s by the sociologist Garfinkel demonstrated (53, 54) the almost universal moral outrage expressed by ordinary people when the "assumption

of reciprocity of perspectives” (54 p82) was breached (by asking for clarification in the course of everyday conversation). In all but one case (taken as a joke), subjects seemed to interpret such breaches as deliberately uncooperative or hostile, responding for instance (53 p 43):

Surely I don't have to explain such a statement. What is wrong with you? Why should I have to stop to analyze such a statement? Everyone understands my statements and you should be no exception!

Garfinkel reported similar outrage in response to other types of social breaches, for instance “standing very, very close to a person while otherwise maintaining an innocuous conversation ... [or] saying ‘hello’ at the termination of a conversation” (55 p198). These of course are the sorts of social codes that individuals on the autism spectrum typically though inadvertently breach so much of the time, and it is likely that the more their underlying cognitive struggle to make sense is rendered invisible by such things as their superficially excellent language, the more their breaches are interpreted and responded to as moral deviance rather than cognitive difficulty.

Another reason given by professionals for not diagnosing at this end of the spectrum, is the wish to be scientifically precise. But there are ways clinicians can honour both the diagnostic rules of medical science and the need of the individual client to have a meaningful explanation for their difficulties: For instance, in my practice, I give a brief explanation of the current state and limitations of diagnostic systems and boundaries, including terms like BAP, and the likelihood that definitions and boundaries will change over time, give them my honest opinion about where I think they fit, then suggest that acquaintance with the autistic community and its literature might help them dispel any remaining uncertainty and arrive at a cultural identity, through the degree to which they find themselves identifying with and accepted as belonging there. Thus, at this end of the spectrum, the ethnicity model may be more helpful than the biomedical model.

Within the autism community too, the value of seeking, obtaining and disclosing an official diagnosis based on the biomedical model, is debated. Seeking may result in being regarded as greedy (if pursued to obtain services) or self-indulgent (if not for services), causing the individual further embarrassment and guilt. Obtaining or disclosing a diagnosis without adequate follow-up support and constructive information may also be disastrous (as will be shown in the next section). Nevertheless, for those individuals seeking answers to their difficulties, identifying their condition by whichever model (biomedical or ethnicity) can be the key to self-understanding, self-esteem, and self-identity. As one young adult on the spectrum writes (56):

I think one reason why a diagnosis of ASD is helpful in high-functioning cases is that the symptoms can severely affect the quality of life without being obviously and dramatically a disorder. It is very easy for such a person to be categorized as shy, aloof and emotionally immature ... This inevitably implies that you must simply have a weak and inadequate personality, and should pull yourself together if you can. Anyone who is not obviously ‘pathological’ is either ‘normal’ or ‘inadequately normal’. People high in the ASD range are very vulnerable to falling into this no-man’s-land. ... But they should at least have the chance to find out about ASD and realize that they are not uniquely peculiar ... so that they have a context in which to gain insight into the nature of their difficulties ... I hate to think where I would be now if I hadn’t found out about it and got help ... I needed to find about ASD to be able to come to terms with myself. I spent years [until finding out about autism at the age of 20] trying desperately to conceal any sign of difficulty in public, and trying to pretend to myself that there was nothing wrong. ... I had never heard of autism. But knowledge of autism was precisely what was necessary to acknowledge my problems.

Having a label that cognitively explains rather than morally blames one’s shortcomings, opens the way to make sense of the many perplexing situations that have happened in one’s life, to make more realistic plans from knowing one’s strengths and weaknesses, which traits can be developed or changed, which can be compensated for and which

must be accepted and coped with. This is, as one autistic adult says, “working with autism, instead of against it” (57), or as another puts it (50) “Instead of failing to succeed at what you’re not, you can start learning how to succeed at what you are”.

Involvement in the autism community may provide, perhaps for the first time, an experience of meaningful and rewarding social life (50, 58), and the opportunity to learn from others on the spectrum. As another adult at this end of the spectrum writes (59):

Though therapy was helpful, I think I learnt a lot more from autobiographies by people with Asperger’s Syndrome, from other peoples’ experience with it, and being able to go ‘Oh, that happened to others’ and feeling a sense of relief that I wasn’t the only person. That has actually helped a lot with some of my self-judgements that were making me very depressed about myself.

### **Important issues at this end of the spectrum**

The issues most pressing for adults at this end of the spectrum are rarely covered in books by professionals or parents, or at conferences (Autreat (60) being a notable exception), but are extensively discussed within the autism community. The range of topics, viewpoints, and strategies for coping and compensating, is wide. For instance:

#### **Diagnosis and disclosure**

Though for a person on the spectrum trying to make sense of their life, identifying their relationship to the autism spectrum is a key step, it is not one to be taken lightly. Adequate follow-up support through the next stages is essential, particularly considering their typical social isolation, and how many aspects of life autism impacts on. Stages may include (38) learning about the condition, shedding the old identity and mourning its loss, healing, and planning a new future. Depression is common during this process. Once individuals have come to terms with the diagnosis for themselves, they then face the question of disclosure to others, a complex challenge compounded by lack of professional knowledge of the issues involved, the individual’s own social difficulty anticipating the likely responses of others, etc. Aspects to consider include issues of confidentiality and trust, and decisions about whether, why, when, to whom, and how to disclose in each instance, balancing possible benefits against risks. Disclosing the diagnosis may result in better understanding and support, but alternatively those to whom it is disclosed may greet it with disbelief or other negative responses, such as “But you’ve managed OK in the past, so why do you need help now?”, “But you don’t seem any different to anyone else, we all have times like that”; or worse, as a teacher who disclosed her diagnosis recounts (56):

I did the wrong thing by telling a so-called trusted colleague I had autism. After being praised for years for how well I did my job by parents and colleagues, I wasn’t thought capable anymore so I was pushed out in a tactful way. Colleagues, family and friends didn’t want to visit or communicate any more. So please keep AS hidden if you want to have a professional and happy life!

Partial disclosure can be a good solution in some situations: disclosing only the issue most relevant to the particular situation, for instance *central auditory processing disorder* to explain why information need to be written, or *prosopagnosia* (*difficulty recognizing faces*) to explain that ignoring colleagues met away from the usual context (the workplace) is a neurological issue not snobbery.

#### **Career and work**

At this end of the spectrum, a different range of work difficulties present (16, 38). For instance, advisors with stereotyped ideas about suitable jobs may persuade against careers entailing empathy, unaware of the success stories of some autistic individuals

working in such 'unexpected' roles as teachers, therapists, pastors, salespersons, and caregivers (16, 21, 42).

For many here, the difficulty may be not so much one of obtaining a suitable job, but of repeatedly losing jobs for surprising reasons ("I burst my appendix!") or instances where even a high level of ability, ethics, care or resourcefulness can get autistic individuals into trouble if they fail to anticipate or heed the wider social implications of their good work ("I'm *too* good at quality control"; "My ethics were too high for the job;" "A co-worker laid a complaint about me comforting a client in pain"; "I was sacked for devising a better way of doing the job": all cases I've encountered where doing an excellent job for clients got the autistic individual into trouble with employers or co-workers).

### **Marriage and parenting**

As a growing literature is beginning to show (for example 22, 46, 61, 42: examples throughout the book), individuals on the spectrum *can* be good partners and parents, especially if allowed to devise their own unique solutions to challenges rather than expected to follow neurotypical models (which can prove extremely stressful for those on the spectrum).

### **Gender identity**

Discussed within the community, and referred to in some autobiographical writing (43, 62) is a not uncommon sense of being either "un-gendered", or confused about gender identity. Some have sought identity within the gay community, before recognizing that the crux of their identity issue lay in addressing autistic versus neurotypical identity rather than gender or sexual orientation.

### **Counselling**

Constant pressure to meet the demands of a society that fails to understand their needs and difficulties commonly results in stress, loss of self-esteem, identity issues, and failure (24, 25, 38, 63, 64, 65). They may thus present to counsellors with a wide range of issues.

Inappropriate psychotherapy is probably common, according to both professionals (24, 32, 37) and those on the spectrum (19, 56, 62 pp 121-3, 63, 66, 67). The latter tell of the disastrous consequences that may ensue, particularly for those whose autism has not been recognized. It is essential that therapy embrace the unique perspectives and style (cognitive, emotional and communication) of individuals on the spectrum (67), and focus on autism-friendly strategies for the issues and dilemmas they seek help for, not on trying to challenge or change their innate style. This is one of the prime reasons that identifying even sub-clinical autism is important (67). A few professionals do recognise the need, for instance (68) for "not just ... knowledge about Autism ... but also the willingness to listen to and learn from [these autistic clients] and to suspend one's judgment and natural desire to make sense in our terms rather than theirs, of what one finds".

The following account by a young woman on the spectrum (59), highlights some of the distressing but common mistakes:

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.

Such disbelief, an everyday experience for such individuals, but shocking in the context of counselling, may happen because of misunderstood autistic features such as atypical



responses to situations, lack of eye contact, or affective incongruence (16, 19, 50), as Jo describes:

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, the characteristic tendency of folk on the spectrum to speak in an honest upfront literal way, with little subconscious or hidden agenda (6, 50) may be discounted, as Jo recounts 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 Aspergers 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 characteristically uneven profile of ability and inability may result in advice beyond their capability, without sufficient detail or information, especially regarding social issues:

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!"

### **Help in everyday daily life**

The apparent cognitive and linguistic capability, and quasi-independence, of individuals at this end of the spectrum, tends to mask the severity of their social difficulty (24, 64). How to handle the social component of tasks that "appear" well within the capabilities of those at this end of the spectrum, such as shopping, phoning, or coping with a tradesperson or unexpected visitor, are thus frequent topics of discussion within the autism community. For those on the spectrum, social interaction is tiring work (51), so that, for example, the interaction expected by the "helper" may cause even more stress than the problem they are there to help with:

(59): The full effects Aspergers has on social relating is underestimated. It's assumed that the only social area it would impact on is making friends.

(22): I have GREAT difficulty with people in my house (or even yard), becoming physically uncomfortable with their presence in a very short time. Keeping focused enough to stay on task when anyone is around is near impossible.

(51): Talking to [my friend], or even keeping myself in the mode that allows me to respond adequately to her when she asks where the broom is, fatigues me as if I were a dyslexic and had to 'read' her throughout every minute of her presence."

This is one of the areas most misunderstood by neurotypicals, resulting in moral judgments as well as exclusion from the support of both formal services and the informal social networks that neurotypicals draw on in their daily lives.

(51): Someone who needs a lot of help but who can't afford to pay anyone for it and who can't get subsidized services for the disabled has no one to ask but friends and relatives ... such a relationship would demand things from me that would strain me to death ... [yet] (10) if only someone could help me ... I'd be able to remain in society and not only continue working, but be even more productive ... on the other hand, if I continue to be left to rot away, I'll have no choice but go to an institution and be an even bigger burden on society.

## Conclusion

**It is important to consider those who *may* be within, or just beyond, this invisible end of the spectrum:**

- those in whom autism may be overlooked completely: undiagnosed, misdiagnosed, or whose presenting problem is recognized but not their underlying autism spectrum condition
- those in whom autism is considered but discounted because they don't seem to fulfil enough criteria, are considered too mild, or show imagination, theory of mind, empathy or humour
- adults
- gifted individuals
- females

Such individuals need a full developmental assessment (with particular expertise if they are adult, gifted or female) as if they do indeed have autism or a related condition, whether or not fully meeting current diagnostic criteria, they need

- autism-based explanations and strategies for their differences and difficulties, to replace moral judgments
- follow-up support to accompany any diagnosis
- the opportunity to know about, and access, the autism community
- above all, understanding

As a woman in her 50s wrote after being diagnosed (56):

Stephen Covey wrote in his book "The Courage to Change", that the deepest hunger of the human heart is to *feel* understood, valued and respected. My recent Aspergers Syndrome diagnosis has helped me to feel these three things for myself, about myself, which I had never been able to before.

## Acknowledgements

The author wishes to acknowledge and thank friends in the autistic community for their input of ideas, lively discussion, and permission to quote.

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