

Biography: Dr. Ava Ruth Baker

Ava Ruth's experience in autism is both professional and personal (both she and her son being diagnosed as residual Asperger's Syndrome in 1997).

A gifted but odd child, she was obsessed with other cultures and languages, resolved to be an interpreter but trained in medicine and mental health, and after a circuitous life journey, finds her current niche interpreting between different autism perspectives (insider versus outsider), medical models (orthodox versus holistic) and research paradigms (biomedical / quantitative versus sociological / qualitative).

Her medical practice in Christchurch, New Zealand specialises in autism diagnosis and support for all ages. She was one of the contributing editors and writers of "Women from another planet?", an international anthology by women on the autism spectrum, published in 2003, and a co-founder of ASK, a charitable Trust offering support to and by New Zealand adults on the autism spectrum.

Abstract

Identifying autism spectrum conditions: What does it matter?

Some perspectives from an autistic doctor.

- Dr. Ava Ruth Baker

Does an autism label limit or liberate? This may depend on what model is used, what resources are accessed, and societal attitudes. This presentation considers a range of 'outsider' and 'insider' models, and outcomes that range from misunderstanding and misdiagnosis, to meaningful solutions and fulfilling life journeys.

Identifying autism spectrum conditions: What does it matter?

Some perspectives from an autistic doctor.

Paper presented to ACI Symposium, Israel July 2008

-Dr. Ava Ruth Baker

Terminology

In this paper, the terms AS (autism spectrum), & autism, refer to the whole autism spectrum (including Asperger's, PDD, etc.) while the terms NT (Neurotypical) and NS (non-spectrum) refer to person(s) not on the autism spectrum.

Labels and Models

Diagnoses are often thought of as labels, but they could also be considered as signposts. Signposts do something more than labels: they help people find their way on a journey.

There is often hesitation to seek, or make, a diagnosis of autism, due to concerns such as, the stigma of such a label. But the reality in the society we live in, is that autistic people usually end up labelled in some way or other: if not an official autism diagnosis, or unofficial identification within the autistic community, then misdiagnosis or moral labels. Each of these will set them off on a completely different type of journey.

Firstly moral labels: Especially at the so-called higher functioning end of the spectrum, most undiagnosed autistic people have been told, throughout their lives, that the cause of their problems is their many character defects (1,2): for example that they're rude, arrogant, selfish, obnoxious, weird-or-strange, stupid, lazy ("Just try harder" they say, even when the autistic person is trying their utmost!) or over-

anxious (“Just relax: be yourself” – but when autistic persons are ‘being themselves’, even more criticisms ensue). People witnessing their social blunders can’t believe that anyone could be so ignorant of basic social know-how, especially someone who seems so capable in other areas of their lives, so they assume they’re either being deliberately difficult, or just don’t care, or that they’re simply not trying hard enough. Often the undiagnosed autistic individual ends up believing them and putting immense effort into trying to change these alleged character defects – without success of course.

Professional labels:

When an undiagnosed autistic person undergoes a diagnostic assessment, they might end up with any of the following labels: a ‘clinical AS’ diagnosis; ‘sub-clinical AS’ (though most professionals discount this); a misdiagnosis (as there are many conditions that can and do get confused with autism) or no diagnosis at all (missed diagnosis) - which often comes with more moral judgments: For instance, an adult being assessed might be thought a malingerer or hypochondriac; or in the case of a child, the parent might be told their parenting is to blame – that’s very common too. So getting onto this professional pathway in the first place (by correct diagnosis) can be quite hazardous, with a real risk of ‘falling through the cracks’ (or ‘chasms’!). The professional pathway after diagnosis can be equally hazardous. To understand some of these ‘cracks’, or hazards, one needs to examine the foundations of this pathway, by looking at the current biomedical model, & what alternatives there may be:

Current biomedical ‘deficit’ model: The triad of impairments

As most of you will know, the key criteria used in all autism diagnostic systems can be grouped into three clusters often called the ‘Triad of Impairments’: impairment of social interaction, of reciprocity of communication, and of imagination (impairment of the last including seemingly inflexible or repetitive patterns of play, interests, activity or thought; difficulty seeing the other’s point of view; etc.). Most professionals ascribe these ‘impairments’ to underlying ‘deficits’ of theory of mind, and / or central coherence, and / or executive function.

This model may be considered controversial for a number of reasons:

Firstly it’s categorical.

Secondly, its emphasis on ‘deficits’, ‘the triad’ and ‘outsider’ observation of behaviours rather than ‘insider’ experience, implies that autistics ‘lack’ imagination, theory-of-mind, empathy, feelings, interest in socialising, humour etc. This is misleading, as there is increasing evidence that these aren’t necessarily *lacking* in autism, they may just develop or manifest *differently*. (1, 3, 4, 5, 6). It also overlooks AS strengths, & the strategies that AS people use, consciously or unconsciously, to cope, understand, learn or do things better (1, 2, 6). Some of these strategies may appear to an outsider weird or dysfunctional, like some repetitive behaviours, so may be mistaken for problems to get rid of, instead of strategies that are actually helping the person function better than they would without them. Other strategies may help an AS person ‘pass as normal’: Thus, others might not detect their autism, or the extent of their social confusion, or the amount of effort they’re expending to maintain that façade of normal.

Another problem with this model is that with so much emphasis on the ‘triad’, other issues that commonly come with autism are overlooked, even though they may be the very issues that the autistic individual or their family wants answers for. For instance:

- sensorimotor issues (sensitivities, clumsiness etc)
- sleep, feeding & toileting problems
- executive function problems; attention-shifting; inertia
- processing differences, overload, shutdown

- rage attacks / meltdowns / windups
- the waxing and waning of problems, sometimes due to identifiable stressors, but sometimes in regular cycles, perhaps due to unexplained biorhythms
- associated physical health problems, especially those involving gut, endocrine, nervous or immune system

These problems with the biomedical model can lead to (1) misdiagnosis, missed diagnosis, misunderstanding about the nature of autism, and inappropriate advice and treatment, like trying to eradicate an adaptive strategy, or autism itself, rather than seeking solutions for whatever specific issues are problematic for the autistic individual.

Some professionals are now starting to describe the 'triad' in terms of 'qualitative differences' rather than 'deficits'. There are also some improved assessment methods: One such is the DISCO developed by Lorna Wing in the UK (7), which among other advantages assesses functioning across a whole range of domains, not just the triad, and also guides clinicians in how to apply this to the various current diagnostic systems to minimize misdiagnosis and missed diagnosis. However the wording in the diagnostic manuals is unchanged, and that's what's generally used as the gold standard for diagnosis. So in the hands of clinicians with limited knowledge of autism in all its possible guises, missed diagnosis and misdiagnosis are likely to continue to be common. As Tony Attwood writes (8, p 40-1) "The text in DSM-IV, intended to supplement the criteria, 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." Although this was written in relation to Asperger's Syndrome and DSM-IV, the same cautions should apply to the diagnosis of all conditions on the autism spectrum, using any diagnostic system.

But there are alternatives to the standard biomedical model: I'll show just a few that I find useful.

Firstly, it can be helpful to think of how a person presents, as 'layers': with autism 'hidden' beneath layers of adaptive strategies or other conditions. This is not so much an alternative model as an 'expanded' biomedical model that shows that how other factors affect the way autism presents. So at the centre is the individual's 'core syndrome' (9), their difference, in this case autism that may be undiagnosed. Covering this are other layers: firstly the individual's own responses to their differences, like anxiety, or coping / compensatory strategies which may be either adaptive or maladaptive; then the fallout from how others respond to their differences, like poor self-esteem from stigma & victimization; then there may be other conditions, that may be due to the above or coincidental, like depression. Common end results may be feeling a misfit, a pervasive sense of underachievement despite all one's efforts, or feeling totally overwhelmed by life. Thus, by the time an undiagnosed autistic presents for help or diagnosis, maybe as a teenager or adult, this core condition may be so buried beneath layer upon layer of other problems or adaptive strategies, that only the top layer or two (for instance depression) is correctly diagnosed. The possibility of underlying autism isn't even considered, and if it's not considered, it won't be seen beneath all those layers.

This 'layers' model illuminates one of a number of ways misdiagnosis and missed diagnosis commonly occur. Another is that autistic traits may be seen but discounted because of flawed assumptions such as

- 'there's no treatment anyway' or 'they'll grow out of it'
- 'they can't be autistic, they have imagination' (or empathy, or humor, or theory of mind, or interest in socializing)

- their traits seem 'too mild' (but remember, that may be because adaptive strategies are masking underlying difficulties; and, as Tony Attwood writes re the threshold for diagnosis (8, p54), "it is not the severity of expression that is important but the circumstances, expectations and coping and support mechanisms.").
- they 'don't seem to fulfill enough criteria': but this may be a limitation of the experience of the clinician and / or the diagnostic system they are using: I've seen many patients, told by previous clinicians that they didn't meet the criteria for autism, who with a more comprehensive assessment such as the DISCO, turn out to fully meet the criteria. So, even though people in this group may on first impression seem not to meet the criteria for a clinical diagnosis, some do when one looks in more detail, while others, if they fully met them during their childhood, would qualify for what Tony Attwood terms 'residual Asperger's Syndrome in an adult' (10, p 26).
- 'there's no point burdening with a second label' those with autism plus another major condition they're already getting services for (like intellectual disability or mental illness) - which of course overlooks that if they're autistic as well, they're likely to have very different needs (environment, interaction style, programme, strategies, even medication dosage, etc.), a mixed or paradoxical profile of ability / disability that needs to be addressed individually, and considerable difficulty communicating any of this.

Here are some of the many conditions autism can be confused with, for one or other of the above reasons. These may be either a true misdiagnosis, or a partial diagnosis (where the person actually has two conditions but either their autism, or the accompanying condition, is overlooked):

- Psychiatric conditions
 - Depression
 - Anxiety disorders (especially social phobia, panic disorder, obsessive-compulsive disorder, post-traumatic stress disorder)
 - Eating disorders
 - Alcohol & drug problems
 - Psychosis e.g. schizophrenia, bipolar disorder
 - Personality disorders (especially schizoid, avoidant, borderline)
- Behavioral patterns such as oppositional defiant disorder, or 'attention-seeking' behavior
- Physical conditions such as chronic fatigue syndrome / fibromyalgia, celiac disease, epilepsy
- Neurodevelopmental conditions
 - intellectual disability
 - intellectual giftedness
 - specific learning disability
 - nonverbal learning disability / right hemisphere learning disability/ hyperlexia
 - attention deficit (hyperactivity) disorder
 - Tourette's syndrome
 - semantic-pragmatic language disorder
 - central auditory processing disorder
 - prosopagnosia
 - Irlen syndrome / scotopic sensitivity; eye tracking problems
 - dyspraxia (developmental coordination disorder)
 - sensory integration disorder

So, a prudent approach might be to consider autism a possibility when any of the conditions in the above list are diagnosed or suspected, especially if those conditions don't fully explain the problems, or if the usual interventions for them don't seem to work.

Other models:

The next models are not widely known or used by mainstream professionals, but I find them a tremendous help in making sense of autism and the issues autistic people present with:

Models from holistic medicine (such as 'integrative' or 'functional' medicine) show how the various body systems interact with each other, with mind and with environment, in wellness and illness. Such models help explain the likely connection between autism and a range of health issues (e.g. immune, endocrine, gut and nervous system problems), and indicate possible approaches to managing these.

Then there are 'insider' models emerging from the autistic community (6, 11-16) - and I must admit that, from my professional perspective, despite all my access to professional ideas about autism, and having to use the triad model for diagnosis, it's the knowledge coming from the autistic community that I find most useful for making sense of it all, and for helping people on the spectrum find solutions to their issues. For instance Donna Williams (6) considers the three basic underlying problems in autism to be problems of 'connection' (the processing of information, both internal & external), of 'tolerance' (hypersensitivities) and of 'control' (obsession, compulsions etc) and goes on to show how these can result in chronic stress, overload, shutdowns etc (meaning that when there's too much input coming in, parts of the mind or body 'switch off'), and how, when young children experience frequent or prolonged shutdowns, they miss key developmental opportunities, continue to function by 'sensing' rather than 'interpreting meaning' (11), and the more 'meaning' is missed, the more their development diverges from neurotypical norms. In her later writing (12, 13) Donna describes autism spectrum conditions as several different clusters of conditions (her 'fruit salad model'), and also shows how autism issues are commonly compounded by accompanying conditions ('fleas' as she calls them: mood and anxiety disorders, exposure anxiety, selective mutism, Tourette's syndrome, avoidant & other personality disorders, toxicity and nutritional factors, stress from various sources). "Very often these go completely untreated as they are put down to being part of the autism", she writes (13), and shows how treating these can make a big difference to the autistic individual's overall functioning.

So though for diagnosis, one has to make do for now with the imperfect 'deficit' model, to 'make sense' of autism, it's more useful to look beyond the 'deficit' model, to the insights of autistic people. Bearing in mind that autism is very complex, each autistic person is uniquely different, and there is no one 'insider viewpoint', these 'insights' are best taken as general pointers as to how to set about understanding the individual autistic person before you, and their issues - combined with very careful attention and an open mind as to what the individual may be trying to express.

The models we've looked at so far could be considered to be improved biomedical models. Completely different is the social model, which considers autism as a 'difference' that only become disability because of society's current response to it. As Jean Miller puts it (17) "AS is a neurological difference that often *turns clinical* in a culture that doesn't value AS strengths. Much of our survival requires us not to become better functioning, but to better function according to the cultural hegemony of NTs."

From this perspective, autism is seen as one of a cluster of conditions under the umbrella term 'neurodiversity', where the brain is thought of as 'differently wired' compared to the NT brain, and where each difference could be viewed as either

advantage or disadvantage, healthy or pathological, depending on the context and perspective. A simple shift of perspective could thus show being autistic to be an advantage, and being neurotypical a pathology: for instance (18) the 'diagnostic criteria for Asperger's Disorder' could be reframed as the 'discovery criteria for aspie', defined, not by a 'triad of deficits,' but by (a triad of) strengths. Or conversely (19) 'Neurotypical Syndrome' could be viewed as a disorder. It's a matter of perspective. Literature from the field of diversity studies, gives clues about possible benefits to our world of autism and other conditions of neurodiversity: About diversity in general, Paul Grobstein writes (20) "The biological process produces variants, as the only way to be prepared for unknown challenges, times when the environment changes in unpredictable ways. It's the variants that provide the basis for dealing with such challenges." Thomas West relating this to human culture, points out (21) that we need many kinds of ability, and no individual can have all kinds. So, he writes "we should encourage diversity not only to be civil, respectful, humane and just, but also because we have a particular stake in diversity that is rarely ... articulated. We want there to be people who have abilities we do not yet know that we need, abilities we have never tried to measure."

I personally consider that both the social model, and *improved* biomedical models, have validity and value. Perhaps, as Phil Schwartz writes (22, p.148) "the truth ... lies between the extremes: There are both intrinsically disabling factors in autism, and aspects of atypical individuality that are disabling primarily because society devalues them or fails to accommodate them."

Linked to the social model is the concept of autism as a cultural difference, with 'membership' defined not by professional diagnosis but by the 'ethnicity model', which considers a person belongs to the culture concerned, if they identify with that culture, & are accepted by that culture, as belonging. Labels commonly used in the autistic community allow for this view, with simpler more inclusive terms: NT (as defined earlier), versus 'AC' which embraces both autistic individuals (those with a formal professional diagnosis anywhere along the autism spectrum) and cousins (those with autistic features but no formal diagnosis, though they may be 'self-diagnosed peer-confirmed', meaning their self-diagnosis has been validated by autistic peers). This is really important for people in that subclinical category who may have 'fallen through the cracks' of professional diagnosis, whether through lack of access to assessment or misdiagnosis / missed diagnosis, but who nevertheless find they have much more in common with autistics than with NTs. These folk are included (as cousins) in the autistic community, where both autistics and cousins can find ideas that help them make sense of their lives, and strategies that actually work for them.

Advantages of identifying autism

Sharing personal experience of AS can help. As a newly diagnosed AS adult wrote (1) "Though therapy was helpful, I think I learnt a lot more from autobiographies, & other peoples' experience with AS, & 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-judgments that were making me very depressed about myself."

Having a label that cognitively explains rather than morally blames one's differences, 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 modified, which can be compensated for and which must be accepted and coped with. Such approaches are, as one autistic adult writes,

“working with autism, instead of against it” (23), or as another puts it (24) “Instead of failing to succeed at what you’re not, you can start learning how to succeed at what you are”. And there are many ideas about how to do this, which are brainstormed within the autistic community: something the autistic community has become skilled at, with its on-line and real-life support groups, range of personal insights, and the dearth of relevant ideas from ‘outsider’ perspectives. This accumulating wealth of ‘insider knowledge’ is now coming out increasingly in published books by adults on the spectrum: as well as autobiographies, insightful books ‘about’ autism from the ‘inside’ perspective for both autistic and non-autistic readers (2, 6, 11-15, 28) and books of general or specific strategies for autistic individuals (29-41).

A professional diagnosis has the added advantage of providing access to funded services and supports (usually the only pathway to funding at the present time).

Having at last an appropriate label or signpost, whether from a professional or the autistic community, helps indicate where to look for solutions for the many challenges of life on the spectrum. Of course, there’s no ‘magic pill’ for autism itself, but there are

- general measures that help, like attending to the sensory & social environment, to the interaction style, providing structure, visual supports, reducing stress and overload, etc
- general books about autism: among the myriad of titles, the most useful generally being either those by AS individuals (2, 6, 11-15, 28) or those by professionals quoting or drawing extensively on the experiences of AS individuals (3, 8, 10, 25-27)
- specific ideas & strategies from the autistic community, for a wide range of important issues that have unique nuances for autistic people – such as
 - employment issues (5, 31-34): some 90% of autistic adults being unemployed or under-employed despite their capabilities – whereas coming to understand autism, along with individual strengths and weaknesses, and possible accommodations, can result in successful study and employment for many more
 - activities of daily living: rarely covered in professional advice, but covered in detail by AS authors (34-35) e.g. shopping, budgeting, running a home, travel, safety
 - autistic-style friendships, relationships, and ‘making sense of’ / managing social life in general (34, 36-40)
 - self-advocacy (40)
 - disclosure (1, 5, 31, 34, 40-41) - a huge topic in itself, and a potential minefield, given the misunderstanding and stigma around autism that persist in society: Tragic outcomes have occurred when someone has been diagnosed without being informed about, or helped with, all the issues surrounding when and how to disclose.
- autistic-friendly approaches to counseling (1, 43-5): adapting communication, advice & therapy in accordance with the AS client’s unique perspective, style (of thinking, feeling, relating, learning) and focusing on the specific issues & dilemmas the AS client is seeking help with. This of course should apply to *all* professionals working with autistic people: in the health, education and social welfare services, and also in the workplace. It’s not uncommon for autistic adults ((46, p 75) to avoid accessing the health and social services they need, because of their social and communication differences not being understood, anxieties and fears, often arising from previous negative experiences: for instance in counseling (before, and sometimes even after, their autism was identified) experiences like the therapist disbelieving the autistic client’s story or trying to

- change the autistic client's innate style (1). One approach that may be particularly useful is 'solution focused' counseling (45), which focuses on the autistic individual's own goals, & helps apply their existing strengths to reach those goals.
- a range of therapies & medicines, which may be used for autism itself, or for what Donna Williams calls the 'fleas': conditions that accompany autism, like mental health or developmental conditions, or an assortment of physical health problems that aren't unique to autism but may be more common and complex in autistic people (like headaches, 'chronic fatigue syndrome', or other conditions affecting gut, immune, endocrine or nervous system – for which there are treatments derived from the models we looked at earlier, from Donna Williams and from integrative medicine, like diet, supplements, limiting exposure to chemicals etc.). Firstly, mainstream therapies (like speech-language therapy) and medications (e.g. see recent summaries in (46) & (47): note that autistic people may respond to medications unpredictably, for instance often needing much lower doses than neurotypical people do). And then a host of alternative or complementary therapies. One newly published book (48) provides a comprehensive overview of the latter. Most of these therapies, and even many orthodox medications, are regarded by mainstream professionals as unproven in autism. However, quantitative research (controlled double-blind trials etc.) in something as complex and variable as autism is difficult, so being unproven doesn't mean they shouldn't be used, just chosen with care. Guidelines to help decide which if any to use, include asking about the goal of the treatment (I'd urge that this be improving functioning and well-being, living as fulfilling a life as possible, *not* the controversial goal of 'cure' promoted by some), treatment details (method, time and cost, suggested trial period, how treatment is adapted to the individual, effectiveness and how this is evaluated, adverse effects, risks and safeguards) the experience and qualifications of the therapist, and the opportunity to discuss with clients who've already undergone this treatment. Treatments that claim to be the only solution or the best one, to 'cure', to work for all autistic people, and / or that are not tailored to the individual, should be considered with particular scepticism. It is prudent to seek, where possible, the opinions of autistic adults who have undergone the therapy in question, as they may describe adverse effects and longterm consequences overlooked by those evaluating from an 'outsider' perspective (as has been the case, for example, with ABA therapy).
 - approaches to understanding and solving many 'peculiar' problems that affect autistic people, hardly mentioned in the professional literature, but explainable by 'insider' models. For these problems, one often needs to work out unique individualized solutions from a thorough knowledge of both autism in general, and the individual seeking help. For example, 'inertia': the difficulty getting from intention to action (or according to the dictionary 'the tendency to stay in the same situation if no one or nothing intervenes', which in autism may mean getting 'stuck' on one thought pattern or focus, making it hard to get started on something else). This is *not* an 'attitude' problem as observers usually think: it's not because the individual dislikes or is refusing to do the task. It's also not just a matter of lack of motivation or depression, though these may make it worse. Inertia is a real inability, at least at that point in time, and despite all the (usually unseen) effort, thought and energy the individual may be expending to overcome this. Finding a solution (16) is likely to involve a detailed individualized analysis of such things as every smallest step of the task, the skills needed for each step, the individual's existing strengths and strategies and patterns, effective prompts, environment, fluctuations in energy through the day, etc – often using tasks with which the individual is successful, as a model for mastering the task in question. Inertia is just one example of the seemingly odd, misunderstood phenomena that tend to happen in autism, little documented professionally but well documented within the autistic community (in fact 'Inertia' is the central topic for Autscope

2008, a four-day retreat / conference for autistic people, to be held in UK next week). Such phenomena put the autistic person at risk of more labels (e.g. 'lazy' or 'stubborn' in the case of inertia), prevents them from living out their potential, but *can* be helped with individually tailored strategies, to the extent that a person labelled so-called 'low-functioning' might even become quite 'high-functioning'.

Disadvantages of identifying autism

What about the disadvantages of seeking and / or receiving an autism diagnosis?

Firstly, there's the risks of misdiagnosis or missed diagnosis, leaving the undiagnosed autistic stuck with the wrong kind of help or no help, moral labels, and issues of identity and self-esteem, instead of access to the autism knowledge they need to make sense of their lives.

Seeking an assessment can in itself evoke guilt, embarrassment and so on from fears of being seen as greedy (if seeking the diagnosis to get services), or self-indulgent (if not needing services).

Then, even if the individual is correctly diagnosed as autistic, if this new diagnosis isn't accompanied by a positive model and insider insights, there's the danger that they will lack the resources needed to work constructively through the inevitable adjustment process that follows (coming to terms with the diagnosis, disclosure, finding helpful solutions and strategies, etc.). The diagnosis may even seem like a death-sentence, with restrictive advice that can needlessly shatter their dreams (about careers, relationships, marriage, having children, etc.) and shackle them to negative stereotypes ('lacking imagination, feelings and empathy' etc.). Disclosure of the diagnosis may then bring them face-to-face with the misunderstanding and stigma around autism that still exist in society at large.

So the disadvantages of assessment and diagnosis arise mainly from inadequacies in the nature and quality of autism assessment, of the information and support provided with the diagnosis, and of the response of others. In other words, from shortcomings in the knowledge and attitudes of all involved.

Conclusions

Thus, there's a need for both shifts in the understanding of autism by society (professional and lay), as well as specific solutions for some very real autism-related issues: issues extending far beyond the triad, and solutions guided by the insights of autistic people themselves. That way, labels can become signposts, to help each autistic individual achieve a fulfilling life journey. How each of you assists a person through this crossroad, can profoundly influence that person's future.

Moral labels and misdiagnosis are clearly dead-ends for an autistic person. Finding identity through the autistic community is a pathway of potential self-discovery and success, that also welcomes 'cousins' who 'fall through the cracks' (or chasms!) of the professional pathway with its imperfect biomedical foundation. The 'professional diagnosis' route can be hazardous: not always easy to get onto, and once on it the trip may be a good or a bad one. This route is usually, however, the only access to funded services and supports. Depending on how the autistic individual is met along the way by professionals, support people and society, this route may be experienced as either a 'death-sentence', or a life-affirming key to creating a future that works: most likely to be achieved through connections with the autistic community, and guidance by autistic trailblazers who've walked the pathways themselves.

This journey could be so much easier if there was better understanding of, and respect for, the autistic way of being, and if AS and NS people could work together towards this. There are some beginnings of such AS-NS collaboration:

For instance, the New Zealand government has just published, this year, a comprehensive ASD Guideline, developed out of several years of collaboration among professionals, autistic adults, parents, and others, and described as a 'world first' in terms of the breadth of its scope. Of course it only describes what *should be* available, not what *is* available, but it's a start, and there are now steering groups (comprising both AS and NS members) working on *how* to implement these guidelines. The Preface states (46, p 11): "I look forward to, and work towards, the day when all individuals who would benefit from an ASD diagnosis can get one ... to a time when all professionals in all fields upskill themselves to at least a basic level of autism-friendliness, and can also admit when they don't know everything about ASD; and when ASD is not automatically seen as a problem, but is valued for its contribution to a resource pool or people thinking outside the square."

So perhaps there is hope for greater understanding of autism, more working together of AS and NS people, and a brighter future for all. That all might have the opportunity to experience what one woman (1) describes (after being diagnosed in her 50s): "The deepest hunger of the human heart is to *feel* understood, valued and respected. My recent [autism spectrum] diagnosis has helped me to feel these three things for myself, and about myself, which I had never been able to before."

References

1. Baker, A. *Invisible at the end of the spectrum*. In *Proceedings of the Conference Autism: Unlocking the Potential*; Autism NZ, PO Box 7305 Christchurch, New Zealand, **2003**.
2. Miller, J. K. (ed), *Women from another planet?: Our lives in the universe of autism*; Dancing Mind Press, **2003**
3. Biklen, Douglas, with Richard Attfield, Larry Bissonnette Lucy Blackman, Jamie Burke, Alberto Frugone, Tito Rajarshi Mukhopadhyay, & Sue Rubin. *Autism and the myth of the person alone*; New York University Press: New York, **2005**
4. Baker, A. Differences. In J. Kearns Miller (ed), *Women from another planet?: Our lives in the universe of autism*. Dancing Mind, pp 19-60, **2003**
5. Baker, A. *Autism and careers requiring empathy: Are they compatible?* Paper presented at World Autism Congress, Cape Town, August **2006**
6. Williams, Donna. *Autism -- An Inside-Out Approach: An Innovative look at the mechanics of 'autism' and its developmental 'cousins'*; Jessica Kingsley Publishers: Pennsylvania, **1996**.
7. Wing, Lorna, *Diagnostic interview for social and communication disorders: eleventh revision*; National Autistic Society, London, **2003**.
8. Attwood, Tony. *The complete guide to Asperger's syndrome*; Jessica Kingsley Publishers: London & Philadelphia, **2007**.
9. Tantam, D. Adolescence and adulthood of individuals with Asperger Syndrome. In A. Klin, F. Volkmar & S. Sparrow (eds) *Asperger Syndrome*, pp 367-402; Guilford Press: New York, **2000**.

10. Attwood, Tony. *Asperger's Syndrome: A guide for parents and professionals*. Jessica Kingsley Publishers: London & Philadelphia, **1998**.
11. Williams, Donna. *Autism and sensing: The unlost instinct*; Jessica Kingsley Publishers: London, **1998**.
12. Williams, Donna. *The jumbled jigsaw: An insider's approach to the treatment of autistic spectrum 'fruit salads'*; Jessica Kingsley Publishers: London and Philadelphia, **2006**.
13. Williams, Donna. *Acting 'normal' whilst having 'fleas': Addressing the 'fleas' of co-morbid mood, anxiety and compulsive disorders as part of an autism-spectrum condition*. Workshop presented to Autism NZ, **2006**.
14. Lawson, Wendy. *Understanding and working with the spectrum of autism: An insider's view*; Jessica Kingsley Publishers: London, **2001**
15. O'Neill, Jasmine Lee. *Through the eyes of aliens: A book about autistic people*; Jessica Kingsley Publishers: London and Philadelphia, **1999**.
16. Sullivan, Anna. *Inertia: From theory to praxis*. www.autistics.us/library
17. Miller, J. Introduction. In J. Kearns Miller (ed), *Women from another planet?: Our lives in the universe of autism*. Dancing Mind, xvii-xxiii, **2003**.
18. Gray, C. and Attwood, T. *The discovery of "Aspie" criteria by Attwood and Gray*; The Morning News 11, **1998**
19. Institute for the Study of the Neurologically Typical. *Neurotypical Syndrome*; <http://isnt.autistics.org>.
20. Grobstein, P. *Diversity and deviance: A biological perspective*; Bryn Mawr Alumnae Bulletin, **1989**.
21. West, T. *In the Mind's Eye: Visual People with Dyslexia & other Learning Difficulties, Computer Images & the Ironies of Creativity*; Prometheus Books New York, **1997**.
22. Schwartz, P. Building alliances: Community identity and the role of allies in autistic self-advocacy. In S. Shore (Ed.). *Ask & tell: Self-advocacy & disclosure for people on the autism spectrum*, pp 143-176; Autism Asperger Publishing Company: Shawnee Mission KS **2004**
23. Sinclair, J. What does being different mean? In *Our Voice: The newsletter of Autism Network International*, Issue 1, **1992**.
24. Meyerding, Jane. *Thoughts on finding myself differently brained*. <http://www.inlv.demon.nl/> (Articles), **1998**.
25. Faherty, Catherine, *What does it mean me? A workbook explaining self awareness and life lessons to the child or youth with High Functioning Autism or Asperger's*; Future Horizons: Arlington, Texas, **2000**.
26. Stone, Florida. *Autism – the eighth colour or the rainbow: Learn to speak autistic*; Jessica Kingsley Publishers: London, **2004**.
27. Bogdashina, Olga. *Sensory perceptual issues in autism and Asperger Syndrome: Different sensory experiences, different perceptual worlds*; Jessica Kingsley Publishers: London, **2003**.
28. Stillman, W. *Demystifying the autistic experience: A humanistic introduction for parents, caregivers and educators*. Jessica Kingsley Publishers London & Philadelphia, **2003**.
29. Fleischer, Mark. *Survival strategies for people on the autism spectrum*; Jessica Kingsley Publishers: London and Philadelphia, **2005**.
30. Edmonds, Genevieve and Worton, Dean. *The Asperger personal guide: Raising self-esteem and making the most of yourself as an adult with Asperger's Syndrome*; Sage Publications Company: London, Thousand Oaks and New Delhi, **2006**
31. Meyer, R. N. *Asperger Syndrome Employment Workbook*; Jessica Kingsley Publishers: London, **2001**.

32. Fast, Y. & others. *Employment for individuals with Asperger syndrome or Non-verbal learning disability: Stories and strategies*; Jessica Kingsley Publishers: London & Philadelphia, **2004**.
33. Grandin, Temple & Duffy, Kate. *Developing talents: Careers for individuals with Asperger syndrome and high-functioning autism*; Autism Asperger Publishing Company: Shawnee Mission, KS, **2004**.
34. Zaks, Zosia. *Life and love: Positive strategies for autistic adults*; Autism Asperger publishing Company: Shawnee Mission, KS, **2006**.
35. Lawson, Wendy. *Build your own life: A self-help guide for individuals with Asperger's syndrome*; Jessica Kingsley Publishers: London, **2003**.
36. Lawson, Wendy, *Friendships: the aspie way*; Jessica Kingsley Publishers: London & Philadelphia, **2006**.
37. Lawson, Wendy. *Sex, sexuality and the autism spectrum*; Jessica Kingsley Publishers: London & Philadelphia, **2005**.
38. Grandin, Temple & Barron, Sean. *Unwritten rules of social relationships: decoding social mysteries through the unique perspectives of autism*; Future Horizons Inc.: Arlington, Texas, **2005**.
39. Stanford, Ashley. *Asperger syndrome and long-term relationships*; Jessica Kingsley Publishers: London, **2003**.
40. Shore, Stephen (Ed.). *Ask and tell: Self-advocacy and disclosure for people on the autism spectrum*; Autism Asperger publishing Company: Shawnee Mission, KS, **2004**.
41. Murray, D. (ed). *Coming out Asperger: Diagnosis, disclosure & self-confidence*; Jessica Kingsley Publishers London & Philadelphia, **2006**.
42. Ghaziuddin, Mohammad. *Mental health aspects of autism and Asperger Syndrome*; Jessica Kingsley Publishers: London, **2005**.
43. Paxton, Katherine and Estay, Irene A. *Counselling people on the autism spectrum: A practical manual*; Jessica Kingsley Publishers: London and Philadelphia, **2007**.
44. Forrester-Jones, Rachel and Broadhurst, Sarah. *Autism and loss*; Jessica Kingsley Publishers: London and Philadelphia, **2007**.
45. Bliss, E. Veronica and Edmonds, Genevieve. *A self-determined future with Asperger syndrome: Solution focused approaches*; Jessica Kingsley Publishers: London and Philadelphia, **2008**.
46. Ministries of Health and Education. *New Zealand Autism spectrum disorder guideline*; Ministry of Health: PO Box 5013, Wellington, New Zealand, **2008**. Also available online at www.moh.govt.nz/autismspectrumdisorder.
47. Chez, Michael G. *Autism and its medical management: A guide for parents and professionals*; Jessica Kingsley Publishers: London and Philadelphia, **2008**.
48. Kurtz, Lisa A. *Understanding controversial therapies for children with autism, attention deficit disorder & other learning disabilities: A guide to complementary and alternative therapies*; Jessica Kingsley Publishers: London and Philadelphia, **2008**.