

**Identifying autism: Limiting or liberating?** - Dr. Ava Ruth Baker  
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[Note: 'autism' and 'autistic' in this article refer to the whole autism spectrum, including Asperger's.]

A common barrier to seeking or making an autism diagnosis, is concern about the stigma of a label, as I have encountered from diverse perspectives over my decades of giving and interpreting autism diagnoses, receiving my own, and accompanying others as they discover their autistic identity within the autistic community. Unfortunately the reality for undiagnosed autistics is that today's society usually 'labels' them anyway - if not with a formal autism diagnosis, or self-identifying via the autistic community, then with misdiagnoses or moral labels. Let's take a closer look.

Most undiagnosed autistics are already burdened with *moral labels*: weirdo, stupid, lazy, rude, arrogant, selfish, control-freak, over-anxious etc. Witnesses to our social blunders, disbelieving anyone could be so ignorant of basic social know-how while so capable in other areas of life, assume we're either being deliberately difficult, or just don't care. "Just try harder" we're told, when we're already trying our utmost. Or "Just relax, be yourself" – but 'being ourselves' brings even more criticism. We take this to heart, going all-out to change these alleged character defects – unsuccessfully, given such labels are usually inaccurate and miss our core issues.

The outcome of a diagnostic assessment for an undiagnosed autistic might be a *professional label* of autism spectrum disorder (ASD), a misdiagnosis, or no diagnosis at all (missed diagnosis), this last often bringing further moral judgments: An adult seeking assessment might be labeled malingerer or hypochondriac, while a parent seeking diagnosis for their child might be labeled an inadequate parent. I have detailed elsewhere (1, 2) tips on navigating the diagnostic process, the many developmental or mental health conditions an autistic might be *misdiagnosed* with, a helpful approach for those dismissed as having 'autistic traits' but not ASD, and how such missed diagnosis or misdiagnosis can occur. For instance only the 'outer layers' of an individual's issues and coping strategies may be seen, not their underlying core autistic profile.

While professional labels are products of the '*biomedical deficit model*' (1), an alternative view is the *social model*, which considers a 'condition' only becomes 'disability' because of society's current response to it. Thus for autism spectrum conditions "AS is a neurological difference that often *turns clinical* in a culture that doesn't value AS strengths" (3, page xix). The medical and social models are not necessarily mutually exclusive - perhaps "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" (4, page148). The umbrella term 'neurodiversity' includes autism as one of a cluster of conditions where the brain is considered 'differently wired' compared to the NT (neurotypical) brain, and where each difference (such as autistic focus on details) could be viewed as either advantage or disadvantage, healthy or pathological, depending on the context and perspective. A simple shift of perspective can show being autistic as an advantage, and neurotypical a pathology. Look how 'Neurotypical Syndrome' is formulated as a disorder on one website (5); and how Carol Gray and Tony Attwood reframe the 'diagnostic criteria for Asperger's Disorder' as the 'discovery criteria for aspie' (6), defined not by a 'triad of deficits,' but by strengths.

Those on the spectrum often use informal *self-labels* such as ‘aspie’ / ‘spectrumite’ / ‘autist’: as individual preferences vary, having others assign such labels to an individual or group may be unwelcome. Within the autistic community, autism is commonly considered a cultural difference, with membership defined not by professional diagnosis but by the ‘ethnicity model’: one belongs to the culture concerned, if one identifies with that culture and is accepted by that culture as belonging. Accordingly, the *autistic community label* ‘AC’ embraces both autistics (those with a formal diagnosis anywhere along the autism spectrum) and ‘cousins’ (those with autistic features but no formal diagnosis, who are ‘self-diagnosed peer-confirmed’ i.e. their self-diagnosis has been validated by autistic peers). Thus, the autistic community can be a place of validation and welcome for not only the formally diagnosed, but also those autistics who’ve ‘fallen through the cracks’ of the professional system.

Enough of ‘labels’ - I would urge a shift in thinking around diagnoses from ‘labels’ to ‘sign-posts’. While the word ‘label’ suggests a fixed, limiting concept, a ‘sign-post’ helps find one’s way along a journey - a dynamic process, rich in future possibilities.

A diagnosis / identity that finally ‘fits’ helps us not only make sense of the many perplexing situations that have happened in our lives to date, but also make more realistic plans from getting to know our strengths and challenges, which traits can be modified, which compensated for, and which must be accepted and lived with. Autistic adults call such approaches (2) “working with autism, instead of against it” (Jim Sinclair) - “Instead of failing to succeed at what you’re not, you can start learning how to succeed at what you are” (Jane Meyerding). Ideas about how to do this are brainstormed within the autistic community, and available in the growing literature *by* adults on the spectrum: books for not only autistic peers but also parents, professionals and the wider public. Insights and strategies from the autistic community include aspects of autism as yet little explored in professional literature – like the three days we spent brainstorming ‘inertia’ at one of the annual ‘Autescape’ conferences ([www.autescape.org](http://www.autescape.org)). For the newly diagnosed adult, the autistic community can be a place to share with like-minded peers, and to learn from those autistic trailblazers and community-builders who forged a path towards autistic self-determination and autistic community in an era when such goals seemed ludicrous.

Conversely, even a correct diagnosis of autism may resound like a death-sentence, if not accompanied by a positive model and supports to work constructively through the inevitable adjustment process following diagnosis (7, 8): the stages of coming to terms with the diagnosis, disclosure, finding helpful solutions and strategies, etc. Overly-restrictive advice needlessly shatters dreams (careers, relationships, parenthood etc.) and shackles the newly diagnosed to outdated stereotypes (‘lacking imagination, feelings and empathy’ etc.), while haphazard disclosure of the diagnosis brings them face-to-face with, and unprepared for, the misunderstanding and stigma around autism that still persist in society. The book *Aspies on Mental health* (9) – recommended reading for all professionals in autism or mental health fields – shows, through often-harrowing personal accounts, the links between how autism diagnosis and support are provided, the misdiagnosis that’s prevalent, and autistic mental health.

Such extremes in the process and outcome of identifying / diagnosing autism were among the drivers behind ASK Trust ([www.asknz.net](http://www.asknz.net)) producing the booklet featured in this Journal, through which autistic peers can welcome the newly diagnosed to their place on the spectrum in a positive and informative way.

It takes courage for a parent or individual to consider seeking a diagnosis or self-identifying as autistic. Standing vulnerable at a crucial cross-road, how they are met by professionals, support people and wider society can make a profound difference. Will the process limit or liberate? Be experienced like a death-sentence or a life-affirming key? My hope is that one day, all can experience what one woman (8) expressed after being diagnosed in her fifties: "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."

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