Rachel Winder

AN AUTISTIC AND ADHD JOURNEY

Re-writing a New Identity Post-Discovery

Disability Studies

Collection Editor
DAMIAN MELLIFONT

LIVED PLACES
PUBLISHING

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Acknowledgments

This book is something that I thought I could never accomplish. I never saw myself as a writer, because I think in pictures, not words. However, with the unconditional support from everyone who believed that I could write, I have been able to project my thoughts onto paper, translating those pictures articulately into words.

I want to thank my beautiful Mum, who has always been, and remains still, unconditionally supportive of me. Until my discovery, my lovely mum hadn't known how best to help, yet she searched desperately for ways to guide me away from my darkness. Mum, I am so deeply sorry for all the stress and worry I caused you. I never meant for you to be hurt. Back then, I couldn't see how my self-harm was also hurting you. Now that I know who I am, I am no longer at war with myself. I can finally live my best life, and I hope you can see that now. I love you to the moon and back – and then to infinity and beyond.

Tim, my husband, my best friend and my greatest champion. Thank you for not only providing the means to create a safe space where I could recover my identity, but also for carving out the time to help me settle in. I love you with a fierceness I have never known. You love me without condition, and because of you I have learned to love myself.Something I never imagined possible.

To my children, Harry and Charlie. Thank you for teaching me how to be the parent that you need. Thank you for being the

catalysts in each one of life’s battles. With you both by my side, showing me what it means to be virtuously and unashamedly neurodivergent, I have been able to unearth my sense of self, and for that I am eternally grateful. I love you both to infinity and beyond. You both make me so very happy and proud and I feel incredibly lucky to be your mum.

If you are late-identified and still asking yourself, Am I not enough, or am I simply exhausted from trying to be “palatable”? I wrote this for you.

And if you love someone who is neurodivergent, I wrote it for you too. Because what people need most is not pity, but to be seen as they really are.

This autobiography is my attempt to tell the truth, not the polished, socially acceptable version… but the real one.

The one where I stop apologising for existing.

Auticulate™ and Autistically Blunt™: Mission statement Auticulate™ and Autistically Blunt™ were born from a lifetime of translating lived experience into understanding, blending personal insight, academic research and professional expertise to educate, empower and create belonging for neurodivergent individuals. For over forty years, I lived without the words to explain who I was or why I felt different. When I finally discovered my AuDHD identity, it was as if someone handed me both a mirror and a map. I could finally see myself clearly and begin to navigate the world on my own terms.

Auticulate™ exists to close the gap between lived neurodivergent experience and wider social understanding. Not to erase our differences, but to celebrate them. Through honest storytelling, education, and advocacy, my work helps neurodivergent people feel seen and helps others learn how to connect with understanding and respect.

This isn't about fixing or pitying. It's about recognising that difference is not deficiency, and that genuine inclusion begins with curiosity, compassion, and effective communication. By blending personal insight, professional knowledge, and academic grounding, Auticulate™ seeks to close the double empathy gap, transforming misunderstanding into mutual respect and connection.

Abstract

Rachel Winder, aka Auticulate™, shares her perspectives as a White, British, female on a pre and post Autistic and ADHD (AuDHD) journey of discovery. This book aims to bring to light the reality of being born AuDHD in the late 1970's England, but not knowing it. To then, decades later, discovering that identity, gradually unearthing the components of a unique and complex neurodivergence, buried under 40 years of societal conditioning. This unique account of one late discovered AuDHDer reaches out to those whose stories resonate, offering a sense of belonging and connection, while also challenging the harmful stereotypes that have long dehumanised neurodivergent communities. This book is not written to offend or appease but offers an intrinsically relevant, authentically raw, and always Autistically Blunt™ insight.

I may just be one neurodivergent person sharing my life, but like pixels that make up a bigger picture, each and every neurodivergent story that is seen and heard helps moves us closer to being recognised as natural and welcome human differences.

Disclaimer

This book is a reflection of my own life experiences and perspectives. While I have done my best to write truthfully and authentically, any resemblance to actual people, living or dead, outside of my immediate family, is purely coincidental. References to events and individuals are drawn from my memory and understanding, and are not intended to portray any specific person unless clearly stated.

Key words

neurodivergence, identity, discovery, relationships, parenting, teaching, lived-experience, communication, thriving, equity.

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Content warning

Some of this book's content might be upsetting for some readers. The content encompasses discussion of:

- self harm
- suicidal ideation
- suicide
- abuse in all forms
- eating disorders
- miscarriage

If this brings things up for you

Some of what I share in this book may touch on experiences that are hard to sit with – especially if you've lived through trauma, exclusion, abuse, or periods of deep distress yourself. If reading this stirs something, you don't have to carry it alone. If you're in the UK or Ireland, there are people you can reach out to, any time.

Samaritans

If you need someone to listen, without judgement.

- **116 123** (free, UK & Ireland)
- jo@samaritans.org
- samaritans.org (including online chat options)

Shout

If talking feels like too much, you can text instead.

- Text **SHOUT** to **85258** (UK)

Free, confidential, and available day and night.

PAPYRUS HOPELINE247

Support for young people, and for anyone worried about a young person.

- 0800 068 4141
- Text 07860 039967
- papyrus-uk.org

CALM (Campaign Against Living Miserably)

For anyone feeling overwhelmed, stuck, or hopeless.

- 0800 58 58 58
- thecalmzone.net/help/webchat/

If you're in immediate danger, please contact emergency services.

And if you can, please remember this: needing support doesn't mean you're failing. It means you're human.

Learning objectives

This book is developed to assist readers to:

- Understand the key differences between AuDHD and non-AuDHD identities.
- Think critically about the impacts of a late discovery on a person's mental health.
- Understand the ways in which wrongly applied labels can have negative consequences.
- Recognise and appreciate the benefits that can accompany neurodivergence.

1

Introduction

A note from the author: Before I get started with a brief history of the term Autism, I feel it's important to share with you, the reader, that while writing this book, it became apparent that I was writing in my own AuDHD style; intending to start a point and finish it, but because my brain is basically running two operating systems simultaneously, this often leads me to being easily distracted and so I start, but rarely finish.

Due to this mental chaos not being visible, people are unable to factor this into their perception of me, leaving me with the struggles of being both Autistic and ADHD, while being met with the understanding of neither.

To break this down further, for the benefit of transparency, I need stimulation, but then I get overstimulated.

I hyperfocus intensively, then abandon that task impulsively.

My brain is in a constant loop of negotiation and renegotiation (the Autism wants routine and the ADHD wants spontaneity) that nobody else can see.

I see patterns in systems that others "miss", and I see why those systems need disrupting.

And so, some few hundred mental diversions later, my friends, Penny, Laura, Charlie and Suzanna arrive, pointing out the parts where I've started but not finished. You see, my AuDHD brain assumes that the reader knows what I know, but in reality, that is definitely not the case and even though I am aware that this happens, in the moment of it happening, I am oblivious to it.

With Penny, Laura, Charlie and Suzanna's ability to see what I can't, combined with my expertise in articulating my insight in a way that others can understand, we formed the perfect partnership that enabled me to complete my autobiography in good time!

A brief background of where the term Autism has been historically

Before 1900, little research on Autism existed and many Autistic children who were perceived to demonstrate atypical social behaviours were often institutionalised. These Autistic children received residential "care"; a term I use loosely because it was not tailored to their needs, resulting in them being subjected to hostile environments and ultimately leading to lasting trauma.

Early twentieth century: Disabled people were widely perceived as a burden on society and a threat to the health of the nation. They were cast as individuals who should not be allowed to "pollute" the gene pool (Historic England, 2023).

1911: Eugen Bleuler used the term "Autism" to describe a symptom of schizophrenia, characterised by "withdrawal and self-absorption" (Bleuler, 1911). This has since been debunked because Autism, and Schizophrenia are well defined, different neurodevelopmental states (Evans, 2013).

From my perspective, the need to withdraw and re-direct my focus internally is how I would describe this characterisation, as this serves a purpose for when my social cup is full to the brim giving me the time and space to avoid going past the point of no return (burnout). This allows for the defragmentation, recalibration and recharging of my brain and body ready for the next demand.

1943: Leo Kanner described a distinct pattern of behaviour observed in eleven children that he termed as: "early infantile Autism" (Kanner, 1943). When Autism co-occurs with motor and speech apraxia, Autistic characteristics may be more openly expressed (Shriberg et al., 2011). Even when the person is aware that their differences draw unwanted attention, they may have limited ability to inhibit certain movements, vocalisations, or motor responses. This distinction highlights the difference between social awareness and motor control.

1944: Hans Asperger described what he termed a "milder" form of Autism, later recognised as Asperger's Syndrome (Wing, 1981). This being the presentation of Autistic characteristics in high-masking Autistic people who are without the above mentioned additional disabilities. The term Asperger's is no longer given as a diagnosis since the 2013 amalgamation placing it under the umbrella term "Autism Spectrum".

1950s: Bruno Bettelheim popularised the "refrigerator mother" theory, blaming Autism on poor parenting (Bettelheim, 1967). This parenting was deemed poor, by likely PNT people, who misinterpreted the differences expressed by the Autistic mothers who were, in comparison to PNT mothers, not outwardly expressing their feelings and so appearing cold. The counter argument to this is that there are AuDHD people, like me, who are very expressive and those whose faces hardly change regardless of their internal emotional fluctuations.

1970s: Bettelheim's theory of poor parenting was debunked when research on monozygotic twins (identical twins – from the same fertilised egg rather than two separate eggs) suggested a strong genetic link to Autism (Hallmayer et al., 2011). I can see how this information allowed for a better understanding of the differences in the love language of Autistic mothers towards their offspring, which initially, to PNT people, appeared cold, but seen through the lens of an Autistic mother was just expressed differently, and yet still served as a maternal connection. One person's love language could be interpreted as another person's pain. Hugs, for example, are commonly associated as an expression of appreciation and warmth but there are those of us who feel an intense disliking of being hugged because it is experienced as painful, unexpected, restrictive or too intimate. My expression of love is through hugs and randomly making things for people I like to show my appreciation of their existence. This is referred to amongst the neurodivergent communities as "Penguin Pebbling".

1970s: Lorna Wing and Judith Gould identified the "triad of impairments" as a diagnostic tool (Wing and Gould, 1979). The "triad of impairments" included "deficits" in social interaction, social imagination and social communication.

During the 1960s and 1970s, a theory of learning called behaviourism became popular. One of those behaviourist approaches being Operant Conditioning, which focused on encouraging "desired" or "socially acceptable" behaviours and shutting down "socially unacceptable behaviours" (Skinner, 1938). This method was conducted without the consideration of any potential suffering, the sole focus was to strip the individual of their "undesirable" but innate response to their environment, and replacing it with a contrived synthetic response, considered "ideal". Behaviourism may have been applied with the intent of protecting the individual from teasing, rejection or reputational damage but the failure to consider potential harm resulted in irreversible trauma. This was due to the methods aimed at encouraging compliance and conformity causing distress because the assumed unnecessary innate behaviours served as self-regulatory mechanisms, essential for the maintenance of the body's sensory equilibrium, which must stay within the optimal range of homeostasis. Basically, if your senses are out of balance and you are prevented from stimming, then your body experiences an increase in anxiety, which if left unresolved, leads to a fight/flight/freeze response resulting in the inhibition of being able to reason and rationalise.

1980s: The movie Rain Man, brought Autism into the public spotlight, and appeared to trigger an increase in the reported ratio of Autistic to PNT people. However, this apparent rise was not evidence that more people were becoming Autistic. Rather, the film helped bring Autistic characteristics into the public eye, enabling caregivers and clinicians to recognise and label "behaviours" that had previously gone unnamed. Many of these expressions of self closely mirrored those of the Autistic character Raymond Babbitt, played by Dustin Hoffman, making them more visible and relatable to a broader audience.

1990s: The MMR vaccine myth emerges, falsely linking Autism to the vaccine. If I apply Rajendran and Mitchell's criteria for critiquing this: I was not vaccinated as a child due to allergies, but

I am Autistic-ADHD, and Autistic, AuDHD people who lived during times where vaccines were not yet discovered or available, were still Autistic/AuDHD. Let's be clear, Autistic people have existed long before the term Autism was ever used. Long before it was forged in the fires of "Mount Doom" (Tolkien, 1954).

It is worth noting that all humans face some potential risk of harm from being vaccinated – just as they do when they are not vaccinated. The deeper question is one of ethics: choosing not to vaccinate, risks exposing a child to diseases that historically cut short infant lives with brutal swiftness, all in the hope of avoiding having an Autistic child.

1994: The DSM-4 defined Autism by a Triad of impairments. Social interaction, Communication, Restricted and repetitive behaviours.

2000s: Sensory differences were recognised as a key aspect of Autism. I didn't want to have to say this, but if only all researchers thought to ask Autistic people what their experiences were like, then they might have figured this out much sooner.

2007: Saw the challenging of the triad of impairments with the application of criteria, which critiques each of the mentioned "impairments" by looking into the universality, uniqueness and specificity. The criteria used at this time was formulated by Rajendrun and Mitchell (Rajendran and Mitchell, 2007) and asks:

- Universality: Are these differences present in all Autistic individuals?
- Uniqueness: Are these differences unique to Autism?
- Specificity: Are these differences present only with Autistic people or are they observed in all humans?

This set of criteria (universality, uniqueness, and specificity) enables researchers to critically assess whether their hypotheses genuinely reflect characteristics that are core to the Autistic experience, or whether they are simply observing human "traits" seen across the worldwide population.

Many behaviours often labelled "autistic" can also be found in the PNT population. That is not surprising, we are all human. But similarity at the surface does not mean sameness at the core. Not all humans are autistic, even though all autistic people are human. The distinction lies in the underlying neurology – in how experiences are processed, how environments are filtered, and how the nervous system responds.

For me personally, I see me being single-focused (monotropic), where I direct intense attention and cognitive energy into specific interests, often to the subconscious exclusion of other stimuli, as being distinctively an AuDHD characteristic. Something not commonly shared by non-AuDHD people.

In my experience of cognitive empathy inhibition and emotional empathy, I can share deep emotional empathy with others, but primarily when we have shared lived experience. Without that shared reference point, I have no internal frame of reference to draw on, and so the emotional connection does not arrive instinctively. In these moments, I can find it difficult to intuitively understand what someone else is thinking, feeling, or expecting; particularly in fast-paced or socially ambiguous situations where non-AuDHD social etiquette takes precedence over AuDHD social communication.

At times, I forget that not everyone experiences the world in the same way I do. Not because I lack care or compassion, but because I assume shared capacity before I assume difference. In those moments, my thinking is simply: *I can do this, so you probably can too*. The empathy is not absent; it just arrives a step later, once context catches up.

These aspects, I feel, help illustrate how individual Autistic experiences may diverge from, what is assumed, broader human behaviours. This, in my opinion, is something that rigid diagnostic models often fail to capture. The irony!

2010s: Autism Spectrum Disorder (ASD) is officially recognised as a developmental disorder in the DSM-5 (American Psychiatric Association, 2013). Can you remember what the letters D.S.M. stand for? Please don't worry if you can't. If you're like me and have already forgotten, then here's a reminder: The Diagnostic and Statistical Manual of Mental Disorders.

2013: The above-mentioned triad of impairments is renamed in the DSM-5 as the Dyad of impairments. Social communication and interaction deficits (the first two were merged together), restricted, repetitive patterns of behaviour, interests, or activities. I'm not really sure why it was renamed, because all they did was merge the first two, but hey-ho.

In the last century, society's understanding of Autism and ADHD has shown a glimmer of movement towards a more accurate perception. This has driven some interventions with Autistic and ADHD people to change from eliminating self-stimulatory behaviours to positively supporting their need to self-stimulate. However, there is still much to be done to increase the quality and consistency of support. I feel this can only be achieved with the authentic inclusion of Autistic and ADHD people. Not just as token representatives, but as equal partners, actively shaping decisions, research, and practices that affect our lives. Knowledge does not sit solely within professional frameworks. When we combine the insights of neurodivergent practitioners with the lived, unmasked experiences of neurodivergent individuals in wider society, our understanding becomes richer, more nuanced, and more truthful.

There are so many social platforms, rich in shared neurodivergent experiences – readily available, moment to moment, cutting edge, first-hand data. What more could any potential researcher ask for! If Sir David Attenborough spoke the same language as the animals he observed, would he have ignored their input and instead insisted that his observations alone were enough to build an accurate understanding of their true nature? I'm assuming not, because it's very likely that by ignoring those cues, someone would have been gobbled up or trampled on, or both!

Autism, as it appears to stand today

Today, in clinical settings, Autism is often defined as a "neurodevelopmental disorder" within the DSM-5 (see appendix 2. DSM-5 Criteria). It's described as a "spectrum condition" because of the way individuals vary in presentation. In order to be diagnosed, "deficits" in at least two out of four types of "restricted" "repetitive" behaviours must be recorded.

However, within wider society, Autism is slowly becoming more readily accepted as a natural neurological difference rather than solely a clinical “disorder”. This shift is often supported by visual representations of the brain, such as images of neurons viewed under a microscope. Images like these, offer a snapshot comparison between Autistic and PNT neurology enabling us to see that congenital neurodivergence occurs naturally and intentionally, rather than as a defect or failure.

For many people, seeing difference makes it easier to believe it exists. When internal experiences are invisible, they are often doubted or dismissed; visual evidence can act as a bridge between lived experience and understanding.

On the left side, there is a pale branch-like shape against a dark background. It has a main stem with only a couple of smaller offshoots. Along its length are a few tiny bumps, but they are quite sparse. Overall, it looks simple and not very detailed. On the right side, there is another branch-like shape, but this one is much more complex. It has several offshoots splitting away from the main stem, and it is covered with many more tiny bumps, which are much denser and closer together. This makes it look busier and more intricate compared to the left side.

Figure 1 shows the PNT neuron as having gone through a more thorough pruning, compared to that of an Autistic neuron.

From findings like this, and the shared insight of actual Autistic people, the focus seems to be moving towards a re-evaluation of current approaches, such as no longer being obsessed with searching for cures for Autism, to a more holistic and person-centred approach. This allows for the introduction and expansion of more accurately supported environments, which include the people and policies within it.