



Yenn Purkis

A LIFE LIVED WELL
AS A NON-BINARY
AND AUTISTIC
MENTAL HEALTH
ADVOCATE

Finding a Place of Hope

Disability Studies

Collection Editors

DAMIAN MELLIFONT

&

JENNIFER SMITH-MERRY

LIVED PLACES
PUBLISHING



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**Dr Damian Mellifont
& Dr Jennifer Smith-Merry**



To my parents who stood by me in the darkest of times

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Abstract

Stories and themes from the life of the author, an Autistic, ADHD, non-binary person, living with atypical schizophrenia and a range of other mental health issues. The book provides an insight into a difficult life, but a life lived well. It provides a view of mental illness and neurodivergence which will be of great value to students in clinical disciplines and medical practitioners.

The lived experience perspective is essential to the understanding of all clinicians and will help practitioners understand their clients better.

Keywords

Disability; mental health; Autism; strategies; schizophrenia; self-awareness; identity; empowerment; intersectionality

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Content warning

This book contains explicit references to, and descriptions of, situations which may cause distress. This includes references to and descriptions of:

- Suicidal thoughts, intentions, and actions
- Abuse and neglect, including in healthcare settings
- Self-harming behaviours
- Psychotic delusions and hallucinations
- Violent assault
- Sexual assault
- Substance use and abuse, illicit drugs, and prescription medication
- Incarceration
- Hospitalization
- Ableism, discrimination, and micro-aggressions

Every effort has been made to provide more specific content warnings before relevant chapters, but please be aware that references to potentially distressing topics occur **frequently** and **throughout** the book.

Learning objectives

This book is designed to support readers in:

1. Exploring the identity and experience of neurodivergent people with psychosocial disability.
2. Finding a meaningful place in society for those with an experience of neurodivergence and psychosocial disability.
3. Understanding the author's personal lived experience of Autism and mental illness.
4. Enhancing social inclusion, understanding, and respect for neurodivergent people with psychosocial disability.
5. Promoting understanding of intersectionality and mental health.

Introduction

At the time of writing, I am 47 years old. I am Autistic and have ADHD, I was diagnosed with schizophrenia at age 21, and I am both gender divergent and asexual. Now, don't get me wrong; I have what is in many ways an enviable life... but it is also a very difficult life. I have had several episodes of psychosis, each requiring intensive treatment and hospital stays. I have been a prisoner, a drug addict, a homeless person, long-term unemployed, and a bullying survivor, but I am also a published author many times over, a career public servant, a TEDx speaker, a media commentator, and a community leader. My career in these things spans almost 20 years so far; my portrait even features in a mural near my home!

All of this is to say: I am living proof that – despite the challenges posed by my illness and the poor attitudes of some – people with schizophrenia and Autism can be accomplished and can live a meaningful and positive life. In my lifetime, through the need to manage my various mental health issues and neurodivergence, I have picked up a lot of useful strategies and ideas. But it's not been easy. Neurodivergence can lead to barriers to a full and happy life, and so can mental illness – people who live with both face more than their fair share of obstacles. Because I have managed to build a fulfilling life, one in which I am happy and proud of myself, and more-or-less in control, the nurse I see to monitor my medication calls me 'an anomaly'. Sadly, I suspect he is right.

What's in the book, and who is it for?

I got the idea for this book during a recent hospital admission. In the past few years, I have developed a growing insight into the various things that are going on with my brain. This is no small feat; as we will see later. People with my diagnoses can often struggle with self-reflection, but I have worked on building an increasing level of self-awareness, and it's been so helpful. Knowing what is going on with me means that I am more able to articulate myself to doctors and other people involved in my health and life; plus I am more able to manage my own illness and navigate the world. This book is the result of all that reflection – it is my story so far, my experiences as an Autistic person who has psychotic illness, what I have learned, and what life is and has been like for me.

I particularly want to share my story and insights with clinicians and others who are supporting Autistic people with mental illness. Being Autistic and living with mental illness conditions can be very challenging, of course – but for many people, what is holding us back from a life well lived is not the conditions themselves, but the attitudes of others and of society. You will see from the chapters that follow how some of my experiences have been made harder because the people and professionals who I looked to for care, intervention, and support didn't actually understand me or my needs all that well at all. We can't 'fix' autism (and arguably shouldn't try to) and we can't 'fix' mental illness ... but we can definitely share knowledge, and try to change people's understanding.

We can also take control of our view of ourselves and what we can do and achieve. Now, I have a lot of experience of successfully understanding and managing the life I have, which could benefit others. While I have some significant challenges around mental health, I also have a big repertoire of tools that I use to manage it. I could certainly have used this book myself when I was younger! So, although this book is aimed primarily at clinicians and carers who support Autistic people with mental illness, it is also for Autistic and mentally unwell people themselves, and their families.

A word about words

I want to talk about language. The language we use around disability, mental illness, and neurodivergence is extremely important. I have chosen to use what is known as 'identity-first' language in this book when talking about Autism. Identity-first language is where you put the identity – in this case, Autism – first, and then the person. Identity-first language is also used by a lot of other Autistic advocates, but I can only speak for myself when I say I feel that saying 'I am Autistic' describes the way in which Autism is an integral part of what makes me who I am. I could not remove my Autism from myself. It's not like a handbag that I can leave in a corner and pick up on my way out!

A lot of clinicians will advise people to use person-first language (i.e., 'a person with Autism'). Some Autistic people also use person-first language; some people who use this language say that it is helpful to remember that Autistic people are people – and that this comes first, before whatever conditions, neurotypes, or illnesses they may have.

Some people think that there is a 'correct' way to refer to Autistic people. I actually don't think that there is a right or wrong way. However, it is important to note that the way a person identifies themselves is correct. You cannot tell somebody how to identify. A person's identity is their own.

There are some other considerations around language in this book. I use 'mental illness', 'mental health issues', and 'psychosocial disability' interchangeably, although there are some subtle differences between these three descriptors. Mental illness describes a pathology within the more conventional, medical approach to treating people with a mental illness. Psychosocial disability, to my mind, is more related to broader society and understanding of the social model of disability (see below for a description of this). Mental health issues is a broad term for any issues or experiences around mental health which can – but does not need to be – part of a diagnosed mental illness.

'I have schizophrenia' or 'I am schizophrenic'?

I have chosen to use person-first language in relation to my schizophrenia in this book. This is a very conscious choice; while I view Autism as an integral part of me, I see schizophrenia as something additional to me. To my mind, schizophrenia is an illness. I view it as a pathology more than an identity. As such, I describe myself in this book as 'an Autistic person who has schizophrenia'. I do not describe myself as 'schizophrenic'. It is important to note that some people with schizophrenia do see it as a key part of their identity and use identity-first language.

Again, I do not think there is a right or wrong way in which people choose to identify themselves in relation to schizophrenia.

You will notice that in this book I capitalise the 'A' in 'Autism' and 'Autistic' but not in schizophrenia. Likewise, this is a very conscious choice. I see Autism as being like a different, valid culture, so it deserves capitalization just as much as my Australian identity does. On the other hand, my view of my schizophrenia is that it is an illness – not a culture or a part of my identity. In my experience, there are not a lot of positives related to my schizophrenia; but there are a lot of positives associated with my Autism and ADHD.

Without further ado...

I have written this book to support the understanding and knowledge around the intersection of Autism and mental health, through sharing my own personal experiences and journey. There are a lot of my experiences and insights in here, all of which are included in order to support your understanding of Autism and mental illness, and how they work together in a person.

Whatever your role, experience of, or interest in Autism and mental illness, I really hope you enjoy this book and find it helpful in your work. I am delighted to share some of the things which have helped me to be the 'anomaly' that I am.

1

What is Autism?

I knew from a very young age that I was different to other people, and in 1994 I got the first formal confirmation: I was diagnosed as Autistic when I was 20. Some people see Autism as a burden, a disease, or some other very negative thing, but for me, Autism is a core part of my identity. It means that I see things differently to others; I have passionate interests and prodigious skills. It also means that I have some challenges which make life hard – but then again, so does everybody else. In my view, Autism isn't really a good or bad thing: I see it more as just a way of being. Personally, I value my Autistic identity. I cannot separate myself from my Autism; It is part of me. I do not want a 'cure' or a 'fix' – in fact, I don't need one.

That's not to say it isn't hard sometimes. But I want to be clear: most of the issues I have experienced as an Autistic person come not from the Autism itself, but from other people being ableist and discriminatory. Sadly, I've experienced a lot of poor treatment from bullies and others because I am Autistic. Even so, I would not change it for anything. Autism is me, and I am Autism.

About Autism

Autism is not an illness, and it is not acquired. A person is born Autistic, and this means that their brain works differently to what is considered 'typical'.

Neurodiversity

One way to view Autism is through the lens of neurodiversity. Neurodiversity is the concept that everyone's brains work slightly differently – that just as humans are diverse when it comes to skin colours, languages, genders, and so on, we are also diverse when it comes to our 'neurotypes' (the ways in which our brains function). Accepting that there is no one way that human brains 'should' be means that Autistic people can be considered 'different not less.' This also means that Autistic people are not broken or in need of 'fixing.' Historically, Autism has been viewed as primarily a deficit, and a problem, and Autistic people have been viewed as a burden on their parents and carers. This is highly offensive to Autistic people and, in my view, not really true.

Autism is not an illness; it is a description for one way that the human brain can work. It is considered a neurodivergent condition – which means that it is a condition that diverges from the 'norm.' People whose brains work in the way which is considered 'the norm' are called 'neurotypical' – so a neurodivergent condition is any condition in which someone's brain diverges from the neurotypical. Other neurodivergent conditions include AD(H)D, dyslexia, dyspraxia, and synaesthesia. Some people include mental health conditions in the neurodiversity umbrella, but I don't like to lump them together; to me, schizophrenia is a mental illness that I have, and Autistic is something that I am, a

part of who I am and how my brain works. So it's helpful to me to keep neurodiversity and mental illness as separate categories. 'The challenge to the neurodiversity paradigm will be greater insofar as its claims are taken to apply not only to autism but to other neurodivergent conditions such as attention deficit hyperactivity disorder (ADHD), Tourette's syndrome and dyslexia' (Hughes, 2021, p. 48).

Neurodiversity aligns with the concept of Autistic pride – something that many Autistic people find empowering and validating. Neurodiversity promotes inclusion and respect for Autistic people. The use of identity-first language ('I am Autistic' as opposed to 'I have Autism') is tied in with the Neurodiversity approach. The traditional approach to Autism sees Autistic people as having no agency in our lives. Conversely, Neurodiversity and Autistic pride is empowering and inclusive of Autistic experiences. Neurodiversity is a very helpful way of viewing Autism and other neurodivergent conditions. The neurodiversity model sees us as valid just as we are.

Common Autistic characteristics

Autism is different for each person who is Autistic. However, many Autistic people share common attributes. Here is a non-exhaustive list of characteristics that Autistic people may have, based on my observations from my own life and the experiences of other Autistic people I have known in my life and work.

- **Differences in communication:** This is a key difference between Autistic and neurotypical people. In my experience,

Autistic communication tends to be more direct and interested in facts than neurotypical communication.

- **Logical approach to life:** Autistic people often share a logical approach to life that is different to the logic that is held by most neurotypical people, meaning that each group can view the other as irrational.
- **Honesty and a literal approach:** Autistic people tend to be honest to a fault and see some neurotypical communication as being 'dishonest' or tricky. This is an area where there is a clear difference between Autistic and allistic people. What is clear and honest to an Autistic person may be received as blunt and cruel by an allistic person.
- **High anxiety:** Autistic people often experience high levels of anxiety and find uncertainty very challenging.
- **'Stimming' and repetitive behaviour:** 'Stimming' is self-stimulatory behaviour; things like flapping hands or clapping. Stimming is a great way to manage anxiety and demonstrate excitement or happiness too. Most people – including neurotypical people – have stims of one kind or another, it's just that Autistic people's stims can be more noticeable. Twirling hair or playing with jewellery are examples of stims that are more common to neurotypical people, and that may not be immediately recognised as the stims that they are. Some clinicians discourage stimming, but in my experience, this is not a good approach. As long as a stim is not destructive, then people should not be discouraged from doing it. A lot of people have reservations about stimming because it looks odd or atypical – but odd or atypical is not a good reason to stop something that is helpful. The problem there is not the Autistic person stimming at all, but the fact that someone is being bothered by it even though it's causing no real harm.

- **Routine** is a way that many Autistic people manage their life. If the routine is broken, then we can struggle. Autistic people can benefit from having a 'map' of future activities that they have not done before which can address their concerns around new things. This can include photos or instructions. Many Autistic people benefit from lists and calendars setting out their daily activities.
- **Sensory processing issues:** These can be significant and make life challenging. This means that sensory experiences can be heightened for many Autistic people. We might find lights too bright, or sounds distracting and unpleasant, or we might absolutely love shiny things. People can have positive and negative sensory experiences. Sensory issues can mean some Autistic people are unable to participate in activities, including education or employment. Autistic people benefit when accessibility includes consideration of sensory access as well as physical access.
- **Overload, meltdown, and shutdown:** This happens when Autistic people have too much input in terms of sensory, social, or emotional experiences. A meltdown or shutdown is a response to this, and this response can manifest in different ways for each person. Autistic people almost always do not want to have a meltdown or shutdown, and often feel guilty or upset when one happens. However, a meltdown or shutdown is not a temper tantrum or poor behaviour; when a person gets to the point of meltdown or shutdown, they are usually not in charge of what happens. The best strategy for managing meltdowns and shutdowns is learning to spot the early warning signs and build in some de-escalation strategies. These strategies might include removing

themselves from the situation, or listening to relaxing music. Each person will have different strategies that work for them.

- **Hyper-empathy or a misconceived lack of empathy:** Many Autistic people pick up on the emotions of those around us as if by osmosis. This can mean we are very thoughtful, but it can also make life challenging and even exacerbate mental health issues. There is a pervasive myth that Autistic people lack empathy. This may be due to us responding in an atypical way to the emotions of others, rather than us lacking empathy.
- **Difficulties reading facial expressions, body language, and other non-verbal communication:** This can contribute to difficulties around communication between Autistic and allistic people.
- **Difficulties recognising people:** Many Autistic people have a condition called prosopagnosia which makes recognising faces very difficult.
- **Passionate/'special' interests:** Autistic people often have a topic or topics that they are very passionate about. Autistic passions can drive activities and even careers. Autistic passionate interests may be the only pleasurable and engaging thing in an Autistic person's life. However, sometimes Autistic people are discouraged from using or pursuing their interests. As long as the interest isn't destructive or damaging, my feeling is that it is a much better approach to foster involvement in interests and fandoms, as they spark joy for Autistic people and can result in some amazing outcomes.
- **Pathological demand avoidance (PDA):** PDA is a condition that means requests or questions are experienced as traumatic and demanding. PDA is what's known as a

profile of Autism, which means that some – but not all – Autistic people will present with PDA. The PDA Society of the UK describes the PDA profile as:

...often anxiety related, are driven to avoid everyday demands and expectations (including things that they want to do or enjoy) to an extreme extent, tend to use approaches that are 'social in nature' in order to avoid demands, tend not to respond to conventional parenting, teaching or support approaches.

(PDA Society, 2021)

- **Gender divergence:** Many Autistic people identify as being trans, non-binary, and other divergent gender identities. Some people see the intersection of Autism and gender diversity as being its own distinct neurotype which is often called 'Autigender'.
- **Issues with eye contact:** Autistic people often find eye contact painful and invasive, and will struggle with making or sustaining eye contact. Sometimes people – such as teachers, family, or clinicians – force them to make eye contact despite it being stressful and perceived as invasive or even painful. In fact, eye contact is not necessary for communication – if it was, then nobody would be able to communicate using a telephone! This is an area where it is extremely important to have understanding and the ability to see things from an Autistic perspective.
- Many Autistic people have **co-occurring mental illness conditions**.

Autism and functioning labels

Many people ascribe levels of functioning to Autism. This reflects the levels for Autism set out in the DSM5, but the language of levels has been around for longer than the DSM5. The labels are usually 'high functioning' and 'low functioning'. High functioning is often used to describe a person with verbal speech who manages to navigate the world well and (apparently) doesn't need much support. 'Low functioning' is often used to describe a person who doesn't have verbal speech and who requires a lot of support. However, this structure doesn't reflect most Autistic experience: many Autistic people will fit the 'high functioning' criteria one day and the 'low functioning' one the next. This means that many Autistic people struggle with the functioning labels and find them unhelpful. Often, a person will mask or camouflage in order to be socially accepted. This makes them look like they are functioning at a higher level than they are, even though they may be really struggling. Because of this, the functioning labels can result in people missing out on much-needed support. Conversely, the 'low functioning' label can result in people missing out on accessing anything challenging, and they can be seen as being incapable of doing anything.

Autism as a foreign culture

It's my experience that Autistic people often get along well with other Autistic or neurodivergent people – better, in my view, than with neurotypical people. This is, of course, a bit of a generalisation – but it is certainly a trend that I have noticed in my life and in the neurodivergent people I know and meet. So why is this? Well, taking into account all of the characteristics in

this chapter, and noting how so many are to do with different ways of thinking, understanding, or behaving, it is possible to think of Autistic experience by viewing it in terms of cultural or national differences.

Imagine that Autistic people are like people from a different culture living in a foreign nation. As an Autistic expatriate, you have learned the language and the customs of your new home; but it never really felt like home. If someone from your homeland visits, though, you'll likely feel understood in a way that you don't by people in the country where you live. They speak your language, and understand the customs you know which nobody in your adopted country understands. How well you would get on with this person!

Now that I have accepted and learned about my Autism, this is very similar to how I feel amongst other Autistic people. My Autistic peers speak my 'language', and often will share knowledge and experiences that I have had. Of course, we're all human, and it's not a rule that all Autistic people will be friends – just like no human is guaranteed to be friends with any other human – but it is certainly a tendency that I have noticed.

The Medical Model vs. The Social Model

This is why I find the concept of neurodiversity so important. To me, this way of understanding Autism really emphasises my belief that we are different, but we are not less. The concept of neurodiversity fits into what is known as the social model of disability.

There are two main ways in which to understand disability, including psychosocial disability: the social model and the medical model. The social model of disability states that a person is not disabled by their own body, but by the society around that person. For example, the social model would argue that a person who uses mobility devices such as a wheelchair is not limited by their body, but by our society's failure to make things accessible to bodies that work in different ways (e.g. by installing ramps and lifts). This is how I see my own Autism. I think my Autism is not a deficit. I think my Autism is a difference. There are many elements of my character related to my Autism that are incredibly helpful and positive. I think a lot of the issues I come up against – as with fellow Autistics – are related to people not understanding what Autism is or how Autistic people are different.

The medical model of disability is structured around the idea that disability is rooted in something being medically wrong, and that disability is something to be cured rather than accommodated. I think the medical model can disable people and lead to people doubting their capability and buying into negative messaging around themselves. As an Autistic person, being told I am broken and in need of fixing actually strikes at the heart of my identity and makes me feel inadequate. I don't need to be 'fixed' and when people suggest that, it upsets me. I am a very proud and bolshy advocate so I can respond to those negative statements. What really upsets me is that many other Autistic people are not as bolshy or proud as me, and may be negatively impacted by messaging around them needing to be 'fixed.'

I definitely find the social model of disability preferable to the medical one and feel it is more closely aligned to my experience

of life. But it doesn't have to be either/or: in terms of my own set of attributes, I view Autism and ADHD a lot more clearly through the lens of the social model, while I see my schizophrenia possibly more through the medical model. (This is not the only way to view schizophrenia though – we will look at different ways of viewing psychosis in a later chapter.)

My story: Autism

I was just 20 when I was diagnosed as Autistic, and memories of my high school experiences were still fresh in my mind. I had been the target of what felt like every bully in the place, and the most common theme in the bullying I experienced was that I was seen as weird and a 'nerd'. When I got my diagnosis, then, I thought it was a diagnosis of 'nerd' and that it justified the taunts by the bullies at school. Partly because of this, it took me a further seven years to really accept my Autism.

Even when I did accept this part of myself, though, there wasn't a lot of information available. To be honest, I still kind of believed that I had been medically diagnosed as a 'nerd' ... it's just that I minded being a nerd less than I had in the mid-1990s! Now, I have access to more helpful information on Autism, and a much better understanding of what it means. I do wonder, though, if there are others out there who think that their Autism validates the mistreatment they have received. There's a lot of stigma still around Autism, and these negative views can come from all quarters – not just from bullies. A diagnosis can make a big difference to a person's life and self-image, but societal attitudes can sadly mean that it takes time to accept and assimilate before

it can be seen as a good thing, or even just accepted as part of oneself.

The journey to accepting my Autism

I was always very reluctant to talk about my Autism, even after I accepted the diagnosis. I felt like it was a shameful secret, and felt happier talking to people about my having been in prison than about being Autistic!

I finally properly embraced my Autism in 2005. I met Autistic author and advocate Polly Samuel, who later became my mentor. Polly was an out loud and proud Autistic advocate. I spent many days in her home, stimming and talking about Autistic identity. Polly encouraged me to write my life story; this became my first published book. With all the publicity for the book, I was thrust into the world of Autism advocacy. I felt like I knew nothing about Autism, but I actually had a wealth of lived experience to share in presentations and media interviews. This experience was the final piece in the puzzle for me; I became a very proud Autistic person and an advocate myself. It is now almost 20 years since I wrote that first book, and I am now a very visible Autistic advocate. I am extremely grateful to Polly for her part in my journey; I can finally say that I like being Autistic.

My Autistic characteristics

I have a number of characteristics and personality traits which I understand to be related to my Autism. These attributes are not necessarily good or bad. They just are. These include: