



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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A NON-BINARY AND  
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**Dr Damian Mellifont & Dr Jennifer Smith-  
Merry**



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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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# 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.

