

**but you don't  
look autistic  
at all**

**bianca toeps**

© 2020 Bianca Toeps  
All rights reserved

This book is an adaptation of the original Dutch version *Maar je ziet er helemaal niet autistisch uit*, published by Blossom Books, 2019

Cover design and photography: Bianca Toeps  
Cover hair and makeup: Charlotte van Beusekom  
Graphic design text: Studio L.E.O.  
Translation: Fay MacCorquodale-Smith, Translate This  
Proofreading: Natasha Ziada  
Final checks: Maria van Loosdrecht, Iris van Hal and Jorrit Bosma

butyoudontlookautisticatall.com  
@biancatoeps  
#ButYouDontLookAutisticAtAll  
#BYDLAAA

For interviews, speaking events or comments, reach out via  
info@butyoudontlookautisticatall.com

*If I had a chance to go back in time  
I'd tell the younger me to breathe  
Cause you'll be fine  
Trust the path you're on and dream  
Write down the words on your mind*

Maria Mena, 'Interesting'



I would like to thank dad for his incredible bravery to work with me on this book. I would also like to thank Monique for letting me call her 'stepmother' in the interest of readability, even though she hates that word. I thank Riemer for his endless patience with me every time I was just done with writing. Thanks to Aafke for her encouragement and corrections, and for being my Big Example because she has written a book before. I would like to thank Blossom Books for their trust, because there's nothing better than a publisher who gets you and sometimes just writes "hahaha!" in the corrections. Thanks to Charlotte for the beautiful makeup on my cover and author photos. Thanks to all the people who I interviewed for this book, or who gave me snippets through Twitter.

A very special thanks for the English edition goes out to these generous supporters: Sven Hilbrants, Aisha Sie, Paul Rispen, The Young Family, Sander Begeer, Mark Sleper, Renske & Andreas, Gwen Landes, Dimitar Nedev, Josephiene Westdorp, Quinte Marijnissen, Annette, Owen Stock, Karin Claudemans, Fumiko Miura, Javier Miranda Perez and Mariko Horioka.

ありがとうございます!

# Table of contents

Preface	7
Intro: Invisibly different	11
<b>1. An alien in Tokyo</b>	<b>13</b>
Circus horse	16
Autism according to the DSM-5	18
The Theory of Mind (and why it's shit)	23
A double empathy problem	27
The Intense World Theory (and why it is <i>the</i> shit)	30
<b>2. The DSM and I</b>	<b>35</b>
Social stuff	37
Is everything alright?!	37
Look at me when I'm talking to you!	41
I'm not here to make friends	45
Behaviour and overstimulation	49
Echo! Echo!	49
Rituals and patterns	51
Trains vs. ponies	55
Stimuli	57
A list of sensory stimuli	58
Thoughts	65
Understimulation	67
Executive functions	69

Masking and the autistic burn-out	73
Significant limitations	75
It's not secretly something else	76
<b>3. Let's get chronological</b>	<b>77</b>
The Pink Tower and my parents' divorce	79
From first grade to Disneyland	84
Toeps the accountant	91
The eating disorder era	96
Take two	100
A conversation with my father	102
Toeps the fashion photographer	108
<b>4. The diagnosis</b>	<b>115</b>
Out of a cereal box	117
The questionable history of Dr Asperger	119
After the diagnosis	124
Daniëlle's story: a late diagnosis	126
Sander's story: looking for help	131
Ups and downs	135
<b>5. Boundaries and limitations</b>	<b>137</b>
Melissa's story: Concrete	
jungle where dreams are made of	140
Pushing boundaries	142
Plans versus options	146

Stomach aches	149
According to the norm	152
About coaching	157
<b>6. Nothing about us, without us</b>	173
Autism mums	175
#ActuallyAutistic	181
Zjos' story:	
The Perks Of Having A Dead Brother	186
Christina's story:	
growing up in the spotlight	188
<b>7. Eight things we don't want to hear anymore</b>	191
But you don't look autistic at all!	193
Are you sure you're not an Indigo child?	197
Didn't your mother love you enough?	201
I always colour coordinate the shirts in my closet; I'm so autistic!	203
Everybody wants a label nowadays	205
I don't believe in labels, you're just you!	209
You're not autistic, you have au-tis-m	211
It's probably because of the vaccinations	215
Epilogue: Pick your battles	217



## Intro: Invisibly different

---

You walk out of the aeroplane via the jet bridge. For the past ten hours, you've been sitting in a cramped seat, eating an undefinable meal and watching *Kung Fu Panda* because you didn't have anything better to do anyway. You wanted to sleep, but thanks to the baby three seats down that was only a partial success. Now you're here, on the other side of the world. Billboards are calling out incomprehensible messages and even the bathroom is something to behold with its thousands of buttons, bells and whistles. The musical note produces a noise that vaguely resembles cascading water and what you thought was the flush button turned out to be the setting to wash your bottom. A lukewarm trickle sprays upwards. Eew.

Past customs you're being picked up. You hold out your hand, but the person in front of you doesn't take it. Instead, he bows. You try to make eye contact, but the man in uniform merely looks down. Just as you're about to open the taxi door, it opens by itself. From the back seat you look out the window covered in stickers, past the blaring television screen at the back of the headrest of the seat in front of you.

There are neon billboards everywhere. "Nihon e yokoso!", the driver says. Silence. The driver thinks for a second and then says, "Werukomu tsu Djapan!"

Within thirty minutes, you've probably broken dozens of social rules. You feel like an alien, like a bull in a proverbial china shop. You're tired and overstimulated because of all the signals that are fired at you. Signals you don't

*But you don't look autistic at all*

understand most of the time. Your saving grace: you're a foreigner. You're clearly not Japanese, so nobody blames you for your mistakes.

But what if you do look Japanese? Ah, different story.

That's what autism feels like to me.

Autism, that's what I have.<sup>1</sup> You can't tell from the outside. So when I tell people about it, that's what I hear all the time: "But... you don't look autistic at all!"

---

<sup>1</sup> More about the use of 'autistic' versus 'with autism' in chapter 7, part 7, on page 211.



Chapter 1

# An alien in Tokyo

---



There I am, in Tokyo. The reason *you* feel like an alien here, is probably the exact reason why I feel so at ease. I'm an alien everywhere, but in Tokyo I have an excuse. A visible excuse for why I'm different – my 1.83 meter tall Western appearance. No one notices that my awkwardness usually isn't caused by my gaijin-ness (*gaijin* is the Japanese word for stranger, foreigner). It also helps that my autistic quirks – such as not looking people in the eye, my aversion to touch, and my love for trains that run on time (and have Quiet Zones that are actually quiet!) – are the most normal thing in the world here. The three months a year that I spend among the neon billboards in Japan are a period of well-deserved rest for me.

Now, it's not my intention to write a rhapsody on how amazing Japan is. I could go on about it for hours (because hey, autistic), but as far as I'm concerned you could just pick up a good old travel guide or look up the *Abroad in Japan, Only in Japan* and *Begin Japanology* videos on YouTube. This book is about autism.