Becca Lory Hector GROWING UP UNDIAGNOSED

Surviving Childhood in New York City as an Undiagnosed Autistic

Disability Studies

Collection Editors

DAMIAN MELLIFONT

&

JENNIFER SMITH-MERRY

LIVED PLACES PUBLISHING



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Dr Damian Mellifont & Dr Jennifer Smith-Merry



For you, Mom. Because we simply cannot know what we do not know.

First published in 2024 by Lived Places Publishing

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British Library Cataloguing in Publication Data A CIP record for this book is available from the British Library

ISBN: 9781915271365 (pbk) ISBN: 9781915271389 (ePDF) ISBN: 9781915271372 (ePUB)

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Cover design by Fiachra McCarthy Book design by Rachel Trolove of Twin Trail Design Typeset by Newgen Publishing UK

Lived Places Publishing Long Island New York 11789

www.livedplacespublishing.com

Abstract

What does growing up with autism truly feel like, and how can a parent best support their Autistic child? *Growing Up Undiagnosed* is a poignant, insightful guide written by Becca Lory Hector, aimed at providing neurotypical parents with a deeper understanding of the Autistic experience.

This book is a treasure trove for parents, especially for those seeking to comprehend and cater to their child's unique needs. Becca Lory Hector shares her personal journey with autism, offering an intimate glimpse into the sensory sensitivities, social intricacies, and often misunderstood aspects of living in an Autistic body. Through her experiences, she illuminates the challenges and triumphs of growing up Autistic, providing practical advice and compassionate guidance to parents.

Growing Up Undiagnosed is more than a memoir; it is a roadmap for parents who are dedicated to understanding and supporting their Autistic children. It addresses the critical question of how to ensure that an Autistic child not only copes but thrives in a world that's not always accommodating to their needs. The book empowers parents to be the best advocates for their children, ensuring they have every opportunity for a happy, successful life. It's a must-read for any parent who wonders what it's like to grow up with autism and is committed to giving their child the brightest future possible.

Keywords

Autism; sensory sensitivities; neurodiversity; parental guidance; Autistic experiences; social invalidation; emotional support; advocacy; disability; mental health; identity; empowerment; New York City

Acknowledgments

This book is a culmination of not just my efforts, but the support, guidance, and encouragement of many, many people over the years. First and foremost, my deepest gratitude goes to my husband and support person, Antonio Hector, who ensures that our entire household feels loved and cared for. Without you doing the endless list of things that you are good at, I could not do the one thing that I am good at. To my mentor, Angela Lauria from The Author Incubator, without whom this book would not exist at all, I am grateful for your insightful guidance and relentless accountability, which kept me motivated at every stage of this journey. My heartfelt thanks also go to the folks in my life who lived through life's lessons with me and those who shared their wisdom with me along the way. Last, but not least, I am grateful to the countless Autistic authors whose works came before mine and gave me the courage to add my stories to our growing voice.

About the author

Becca Lory Hector is an openly Autistic professional on a mission to close the disability gap in leadership by working with companies to attract and retain disabled talent via their diversity, equity, inclusion, and belonging (DEIB) initiatives. Becca was identified Autistic as an adult and has since become a dedicated autism and neurodiversity advocate, researcher, consultant, speaker, and author. In addition to her work in DEIB, she is focused on Autistic quality of life research and her personal development course called "Self-Defined Living: A Path to a Quality Autistic Life". All with the goal of spreading acceptance, building understanding, and encouraging self-advocacy. She is also an animal lover with a special affinity for cats who spends most of her "free" time with her many animals, her husband Antonio, and her emotional support animal, Sir Walter Underfoot.

Content warning

This book contains explicit references to, and descriptions of, situations that may cause distress.

This includes references to and descriptions of:

- Suicidal thoughts, intentions, and actions;
- Substance use and abuse, illicit drugs, and prescription medication;
- · Hospitalization and medical settings; and
- 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.

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Learning objectives

This book is designed to support readers in:

- Understanding autism from a personal perspective: gain insights into the experiences and challenges faced by Autistic individuals, through the lens of the author's personal journey;
- Sensory sensitivities and social challenges: learn about the sensory sensitivities and social intricacies that come with being Autistic and understand how they impact daily living and interactions;
- 3. Support strategies for parents: acquire knowledge on practical strategies and approaches for supporting Autistic children, focusing on emotional support, advocacy, and creating accommodating environments; and
- 4. Advocacy and empowerment: understand the importance of advocacy for and with Autistic individuals, and how to empower them to lead fulfilling lives while embracing their neurodiversity.

1 The answers start here

I was identified as Autistic at the ripe old age of 36 and my diagnosis saved my life.

It was a gorgeous, sunny, spring afternoon in May when my life changed forever. I remember the weather in particular as it's been an enthusiasm of mine since childhood. As I sat in the passenger seat of my mother's Jeep digesting the news, I noted that it was an especially low-humidity day, sunny but not hot—an anomaly for the time of year in New York.

I looked over at my mother. She, too, was processing the report we had just heard. Tears brimming her eyes, she turned to me and asked, "Are you okay?"

I thought about it. For most of my 36 years, I was NOT okay. In fact, I spent a good chunk of those years angry, sad, confused, resentful, lost, and very much wishing it would all go away. Suicidal ideations became the norm for me somewhere around eight years old. The planning, wishing, and hoping for the courage to do it didn't become the norm until my 20s. For three decades, I had failure after failure, followed by deep depressive episodes, only broken by panic attacks as my anxiety raged. Was I okay?

"No, I'm not. And I haven't been," I answered, "but maybe now I will be?"

That evening, as we sat for dinner in a room filled only with the sound of forks on plates and the TV droning "Law & Order SVU" in the background, my mom voiced her regret. "I wish I had known. I'm sorry I didn't do better."

But how could she have known? Autism wasn't a conversation in the 1980s. As a child, I was just the quirky girl who read too much and struggled with change, sensory inputs, and social cues. My hyperlexia was seen as a gift, my emotional challenges as mere childhood phases. Hyperlexia refers to the condition where children show an intense early interest in letters and are capable of decoding words accurately but without understanding their meaning. The research acknowledges that children with autism and hyperlexia follow a unique pathway towards literacy. Up to 20 per cent of Autistic children demonstrate hyperlexia (Macdonald, Luk, and Quintin, 2022).

If you're reading this, maybe you're a bit like my client Penny from Brooklyn, a mother to an Autistic child who told me she is worried about her child's future and wonders if there is anything she could be doing differently. Maybe, like Penny, you discovered this book a few years after your child's autism diagnosis, seeking understanding, guidance, and perhaps solace in another's journey. Perhaps, like Penny, you've embraced your child's uniqueness but are still navigating the winding path of raising an Autistic child. If that's you, I hope my story offers you the companionship and insights I wish my mom and I could have had back then.

Born in the Bronx, NY in the late 1970s, I was to be my mom's first and only child. She and my dad were high school sweethearts who were starting a family like you are "supposed to". Yet, despite a move to the "quiet of Queens", my parents' marriage wouldn't make it past my second birthday, which left me as another 1980s kid living with divorce. Luckily for me, though, it happened before I can remember, and the lack of memories that I have of my parents together made them being apart just my normal. Nonetheless, having two homes would eventually get complicated—especially as an undiagnosed Autistic kid.

For my first five years on this planet, my differences were written off as adorable quirks. I began reading and speaking very early, a hyperverbal hyperlexic they call it, which was always met with delight by adults. "Oh look how smart she is!" "She is reading such a big book!" "She uses such big words!" "She is so advanced", well-meaning adults would coo. I had even potty-trained myself unprompted. But at the same time as folks were saying all of those things, my mom wrote this in my baby book about four-year-old me: "She may be intellectually gifted, but she is also emotionally stunted."

Sure, my interests were odd for a little girl as I preferred quietly digging in the mud and reading to playing with others. And yes, mealtimes, bathing, and dressing were fraught with anxiety and tears, but I was walking and talking on time, so all must be well. Such was the thinking of the world around me.

But at five, school begins to enter the picture and with it comes comparison. Suddenly surrounded by peers, it became clear that I was different. And, for the first time, I began to feel different.

Having to attend school meant uncomfortable clothes, not doing as I pleased, and having to stay someplace even if it smelled funny, was too bright, or too loud. Even if I had to keep my shoes on. I struggled with being without my mom, which meant her leaving me every day was a traumatic event for both of us.

On weekends, I had to pack all of my favorite things and head to my dad's apartment. He had returned to closer to the Bronx and was living in Yonkers. These weekend expeditions meant hours in the car both ways. It meant crossing two bridges, three tolls, and the endless honking of NYC traffic. These weekends also meant packing, and unpacking, all the things I could possibly need or want for two days because my dad's house was nothing like my mom's. I'm sure many kids of divorce found having two of everything fun, loved their time in the car with one parent or the other, and never gave packing a second thought, but for an unidentified little me, it was nothing short of torture; a torture I would request an end to, and be denied, at 12 years old.

At 12, I would experience my first Autistic burnout. It was triggered by the growing social expectations of that age, aka girls are so mean, and my first big transition, the move to middle school. But I was not diagnosed, and it was not called burnout, it was called "being difficult". I wasn't afforded the kind of recovery Autistics require and was instead sent to try one school after another. Some were so far from home, I had to use the NYC bus system, alone. Others were designed for "troubled kids" and other school refusers like me. None of them addressed my needs.

I ended up missing most of seventh and eighth grade. In an act of sheer desperation, my mother sent me to my dad's to go to school where he now lived in New Jersey. A smart choice on her part, as school was more comfortable than his house for me, but with that my entire world turned upside down. I was exhausted, angry, depressed, and defeated, but I was once again attending school. With my weekend trips reversed, I headed home to Queens on the weekends and eventually graduated high school and headed to college right on time at 18.

When my mom apologized for not doing better, my first thought was about all the times she must be thinking about. All the family holidays she had to make excuses for, all the times she had to go to work and leave me crying, all the times she needed a parenting partner and didn't have one, all the times she had to make painful choices because she thought it was the best option. All of the times that she hoped she was the best parent she could be. In all of the moments, she could have used some guidance or some perspective, or even just some community, but quite literally the information wasn't available and there wasn't anybody to ask

Today there is somebody to ask. There are lots of somebodies, in fact! As a dedicated advocate for our community, I end up being a resource for lots of parents like my mom. One of those moms, Penny, could be my mom. She is a single mother of an only Autistic daughter who is working her behind off to support them both. They live in Brooklyn. She is busy and stressed but also loves her daughter above all else, exactly the way she is.

Penny just wants to be the best mom she can be every single day. She has tried to learn all that she can about autism but doesn't have a ton of spare time or energy to vet what she is reading or to stay current. She tries to be patient and kind with her daughter but also finds herself frustrated with her own lack of knowledge. She feels like she is constantly putting out fires in front of her, so she cannot plan for future calm. In hopes of finding out all the right answers to her questions, Penny reached out to me.

What my mom wanted at that moment was somebody to tell her exactly what she should have done and to explain exactly why she needed to do those things. Penny is in search of this knowledge too, and she's not alone. This book is my answer to Penny, to all of the Pennys, and most importantly, it is the answer I wasn't able to give my mom on that sunny evening in May. It's a journey through my life, offering insights into the Autistic experience, practical advice, and, above all, the understanding that you're not alone in this. We may not have all the answers, but together we can find a way to embrace, support, and celebrate our Autistic children for the unique individuals they are.

2 Cat lover

For as long as I can remember I have been a cat-nip-carrying ailurophile, or lover of cats. Those feisty felines captured my attention before I could walk and I continue to obsess about their perfect little toeses and noses, their tornado-of-knives fearlessness, and their elegant aloofness to this day. They are such a big part of my life that as I type this, one of my six current cats is by my side with his paw on my hand ensuring that he makes these pages. Well there, Miller, my greeter cat, kitchen troll, and fabulous house panther, the folks reading know you left your pawprint on these pages.

My love of cats has also influenced how I function in the world. Watching cat behavior has taught me endless adulting skills and how to clearly express my needs. For example, cats showed me how to conserve my energy while still being alert, how to read body language better and faster to avoid consequences, and how to be clever, resilient, and brave in the face of anything bigger than you. In turn, I have learned A LOT about cats, spending decades deep-diving into all I can to understand them back. I spent decades learning about tail flicks, vocal range, and purr frequencies, and in return, I have had the pleasure of sharing my entire existence on this planet with cats. Seriously, I have NEVER lived without a cat.

8

Luckily, a little girl who loves cats never really sets off alarm bells. And even though I knew my love of animals was different and bigger than anyone else's, the response from the outside world was nothing but a nod and a smile. As far as Autistic special interests go, cats were safe. But when I began demanding enough glow-in-the-dark stars to replicate the northern hemisphere on my bedroom ceiling, eyebrows began to raise. When I moved away from memorizing dinosaur names to reading about anthropologic expeditions and fossil recovery, those eyebrows turned to stares. And, while other girls my age were collecting Barbies and Cabbage Patch Dolls, I was busy researching the tectonic plates and trying to understand how volcanoes get created. But what finally raised those red flags, and brought in the special interest police, was my unwavering interest in true crime, in particular, serial killers.

I honestly have no exact memory of how I got interested in serial killers, but if I had to venture a guess, anthropology led to psychology, which led to abnormal psychology. In other words, I was attracted to the outliers like me, those that were internally different but fit right in on the outside, until they didn't. Ted Bundy, Jeffrey Dahmer, and Ed Kemper, for example. I was fascinated by what made them tick and even more interested in the way so many of them were brilliantly deranged and living two lives. I guess I found the parallels to my reality as intriguing as they were disturbing.

In any case, by high school, I was fully engaged in this topic. I had read all of the books available to me, memorized a ton of facts, and even picked my favorite killers. So, when a history teacher asked for a report related to our unit about the 1960s, it took me

all of two seconds to choose Charles Manson and his gaggle of girls. Needless to say, though he was a valid choice for the period, Charlie and I did not find a fan in my teacher and my guidance counselor was notified.

Since I was a relatively good, if rebellious, student, I was sent off in confusion with a warning to watch my topics of interest. Nobody cared how excited I was to put the report together. Nobody cared about my attention to detail or skill with the written word. Nobody even acknowledged my perfect grammar. All they did was point out that what I found interesting, and was good at, was not okay, and I needed to change. It was not unlike all the other times when I was younger and would get excited about something, like tectonic plates, and folks would criticize my volume or flappy hands, very literally correcting my joy.

Cats, tectonic plates, and serial killers were all what we Autistic people now call SPINS or special interests. Some of you may be familiar enough with Autistics to spot a SPIN or an info dump when you see one, while others may not yet have the vocabulary to describe it. For many of us—especially as kids but even into adulthood—our SPINs are used against us, and our deep interest in a certain, very specific something sets us apart and leads to us frequently being called "weird". This is why many of us hesitate to share our SPINs.

Early work on autism discouraged SPINs, seeing them as yet another thing that makes us different, another thing to get rid of, and that is exactly what they taught our families to do. Parents followed this misguided advice and began to use their children's SPINs as part of a reward and punishment system.

For Autistics, a special interest, or SPIN, is an area of intense focus, interest, and knowledge, while also being an essential component of our quality of life (Grove et al., 2018). Autistics usually spend a good deal of our time (and brain space) on our SPINs, and we often feel emotionally attached to them in much the same way non-Autistics feel attached to family members, some of which they don't know well or see often. In addition, Autistics often feel so attached to our SPINS that there is a period of grief, much like losing a loved one, when we move on from one. It is super important that people understand that SPINs are necessary and valuable to Autistics and should not ever be minimized as an "intense hobby".

Sometimes our SPINs are lifelong, like my reverence for felines, while other times, one will slowly extinguish and we wait, in grief and dysregulation, for another to ignite. Some of us boast a library of interests, while others of us only require one or two at a time. For most of us, the pursuit of our interests is a private event that is often done in "hyper-focus mode", which is our way of decompressing, turning off the world, and regulating ourselves.

Our SPINs are a necessity, not an indulgence. We don't just want them; we NEED them to regulate and thrive. Studies carried out in the last 15 years are validating what many Autistics have always known: apart from their potential to establish a profession, they consistently boost self-esteem and assist individuals in managing their emotions. Research indicates that they may also aid in the socialization and education of Autistic kids (Kapp et al., 2013; Milton, 2012). Special interests are beginning to be embraced by educators and physicians rather than being suppressed or erased. Teachers are incorporating them into their lesson plans.

"There's been a lot of negative language used around special interests, things like 'inflexible' and 'obsessions'", says psychologist Rachel Grove, a research fellow at the University of Technology Sydney in Australia. "The real paradigm shift is thinking about special interests as more positive" (Kapp et al., 2013).

In the book *What I Want to Talk About*, popular autism advocate Pete Wharmby takes readers on a journey through his special interests, explaining how they gave him energy and focus (Wharmby, 2022). In this book he explains that special interests are the results of monotropic focus, but that focus can lead to forgetting to eat, sleep, or use the bathroom for hours when tuned into his passion. If you love an Autistic person, it's important to know that SPINs are essential and to treat them with respect and reverence, while also bringing us a snack and reminding us to take a nap from time to time.

Fortunately (and unfortunately) for me, my mom had no information about SPINs either way. There was nobody to tell her she needed to stop me, and as a single mom in Queens, I'm sure she appreciated that I was silently, and safely, keeping myself occupied, albeit with some strange topics instead of with other kids. What she did instead is revolutionary by modern parenting standards, but she quite simply trusted her gut and supported my passions without judgment. And whatever my current enthusiasm was, it was never used as a reward or punishment for unrelated actions. Meaning that, in the confines of our home, I was allowed to pursue my interests to my heart's delight, and on most days, she would entertain me by pretending to be interested in them too. It was in those moments that I loved my mom the most. Because in those moments, I felt wholly loved and completely understood.

In addition to providing a means to regulation, Autistic SPINs feed directly into our natural strengths in both our capacity for memorizing details and our naturally sophisticated logical reasoning. And in return for our dedication, we often find ourselves experts on a huge variety of topics, starting at a very young age. Thus, lending to the colloquial term for young Autistics like me, twice exceptional.

3 Twice exceptional

Before identifying as Autistic, I identified as an Information Seeker. My brain is simply happiest when it is drowned in new data, and as such, I am happiest when learning something new or layering deeper knowledge onto an existing base. And for as long as I can remember, my motivation for doing anything has always been to understand all that I can about everything that I can. This has also always meant that the most frequently used word in my vocabulary is "why".

While in general being a curious child is often met with positivity, in the pre-Google world, my preoccupation with why was as much of a nuisance as it was something to marvel at. Because, of course, once my singular focus was drawn to a topic, it would mean unending hours of me talking endlessly about everything I learned along the way; the classic Autistic info dump.

By about six or seven years old, thanks to my very own complete World Book encyclopedia set, my interest had moved from baby animals to volcanoes. With nobody else to share the learning burden, at some point my poor mom had heard enough about the difference between lava and magma and sent me back to my room, my very favorite place to be. My room was my sanctuary. It was where I carefully displayed that World Book and the giant dictionaries that went with it. It was where I lined up all my

furry plush toys and hid all the hard-faced plastic dolls that dared to invade. It was where I could safely disappear into a book and the only place my brain could find silence from the cacophony that is living in NYC. And, perhaps most importantly, it was where I was most free to indulge in being my authentic Autistic self. Naturally, this had to be where I would hold my very first class on volcanoes. And let's be very clear, I felt called to teach a class, a group versus an individual.

I mean, here I was still in single digits, being rejected for my desire to pass on the information that I learned, and my response was to turn around and not only keep doing it but to do so with even more people at one time. Back then, my resilience was just beginning to show, but my innate desire to teach others would be one I would come to rely on as the foundation for my advocacy work and my career.

Each day after school, my new favorite thing to do was to create my classroom. My plush toys would make excellent students, and that would be an easy solution to filling the class. So, instead of setting them down in "seats", I began with writing and creating our textbook and eventually the workbook that went with it.

My mom would often brag to folks that I was her "Encyclopedia". At family gatherings, I would hear her proudly announce that folks could ask the "Encyclopedia". On her phone calls, I would hear her say things like, "I don't know where she gets it from, but she is a genius." And, honestly, I loved my encyclopedia, and I loved making her proud. It was pretty okay to hear my mom say with a smile, "She is just like a walking encyclopedia. She takes in

everything, and she retains it all." Which was all fine and well until the "everything" I was taking in became too much.

You see, this magnificent ability to take in all the details had some unfortunate side effects. To begin with, overwhelm is never too far away. It feels like my brain is always collecting information from around me, but it is unable to sift through and decide what is most important. Instead, it takes in all the details as though they are equally important. So, while some folks can be in a room full of different noises, smells, and colors, and still carry on a conversation, I become so quickly overwhelmed by taking in all of the details that I often lose the ability to speak. Sometimes in these scenarios, I can maintain one- or two-word sentences, while at other times I cannot even make my lips move.

Historically, the autism spectrum has been understood as a linear continuum from "low functioning" to "high functioning". This framework utilizes functioning labels like "high-functioning autism" and "profound autism" to indicate a person's support needs and capacities as perceived by the observer. However, our ability to function is something that fluctuates. It tends to ebb and flow throughout the course of our lives, often changing from year to year, if not day to day, as a result of how especially complicated it can be to be an Autistic in today's world.

Because of these fixed, and often not so helpful or accurate functioning labels, my autism went unrecognized and my need for support in these areas also went unrecognized, as I masked distress behind academic achievement. The resulting trauma still impacts me decades later.

What my experience with twice exceptionality and my reputation as the Encyclopedia taught me was that there is a danger in thinking that Autistic people like me can appear like we don't need a lot of supports to function. My mom was doing her best to support me by bragging about my strengths, but what that encouraged me to cover up were the areas where I did need help as they were what was leading to situational mutism, exhaustion, shut-down, and burnout at the early age of 12.

It is essential that we understand that static and linear functioning labels are not helpful in accommodating our fluctuating needs. When we use functioning labels, we minimize the internal realities and unseen vulnerabilities of so-called "highfunctioning" Autistics. The intense world theory helps explain why. Many Autistics sense stimuli more acutely than the neuromajority, while simultaneously missing the innate ability to filter inputs and edit responses. As a result, those of us with high aptitudes in some areas, like data collection and pattern recognition, may also experience debilitating repercussions from sensory overload, chronic pain and physical exhaustion, and cooccurring mental health issues. Brilliance in one area often coincides with extensive support needs in others, with the former, in some cases, eclipsing the latter to the detriment of the Autistic person themselves.

So, not only were my needs being missed and not met, but I was learning that my value and worth very much relied upon my twice exceptionality. I got so much positive reinforcement for these aspects of who I was that I began to act this way even when I didn't feel this way. This inauthentic persona is what we