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Unmasking Autism

This summary is from the book “Unmasking Autism: Discovering the New Faces of Neurodiversity” by Devon Price PhD. (In social psychology.). ISBN 978-0-593-23523-2. I found the book to be really good and useful given that several friends and family are ‘on the spectrum’ or Autistic to various degrees. A note about the book and author Dr. Price: he is trans and autistic. That is who he is and his journey. As such, he brings up gay and gender related issues a fair amount. Thinking about what I am trying to accomplish with this summary is to provide a foundation for neurotypical (i.e. ‘normal’, but sorry for using that) people to be able to have a better understanding and appreciation for Autistic people and what their challenges. I also want to provide some ideas to Autistic people and their loved ones and how to deal with and navigate the neurotypical world. (Which are both rather tall orders.)

The author uses a wide variety of example Autistics through the book. I found this helpful because as I read the book previous experiences from decades ago, triggered by the stories, came to mind. I retrospectively recognized that the people I was thinking about were probably on the spectrum. I have not included the stories in my summary. I’ve tried to just capture the key points. But I feel that there is value in reading the stories. (You may recognize yourself, friends, or loved ones.)

Given the nature of the condition, it is a very broad and complex thing. When I was young various childhood characteristics like over-active, trouble-maker, ADD, ADHD, Asperger’s, disruptive, and various behavioral issues were ultimately collected into the broader Autism spectrum. And mostly boys, almost never girls were seen in these areas (because Autism was not well understood – and, really, still isn’t). Discipline, forcing them to fit in, drugs, and institutions were the common answers.

**Introduction: Alienation**

The opening talks about the author’s experience finding out that he was Autistic. He was an intelligent and socially awkward young woman. He was looking forward to advanced degrees and living a life of mind – with not much interest in interacting with people. (Interestingly, I thought getting into technology I could just sit at my desk and do the technical stuff that I loved…. I quickly found out, damn, I have to deal with people!).

He began graduate school. And he continued to struggle with a variety of problems including eating and relationships. He felt he was broken but couldn’t figure what was broken or why. Like many people, he never asked for help. (I suspect that would have gone badly because of common reactions to Autistics.)

His life changed at a family reunion after having completed his PhD. He was talking to a cousin who asked if he knew anything about Autism. He told the cousin that he didn’t. (Which seems odd that a psychiatric PhD wouldn’t know.). The cousin described his issues which were very familiar to Devon. He also commented how he through most of their family were on the Spectrum. Some of the diagnosis that Autistics receive are: Borderline Personality Disorder, Oppositional Defiant Disorder, and Narcissistic Personality Disorder. ADHD and more are also in this constellation.

After this Devon dove into Autism. There were common (but not universal) aspects that the Autistic will avoid or develop strategies around:

* Problems with social cues
* Loud noises
* Bright lights
* Textures
* Fabrics
* Extreme focus on a topic (or multiple) of interest

According to research about 2 percent are diagnosed with Autism. But it is pretty clear to me that there is a lot of under-reporting. A lot of the work was around middle-class and upper-class white males. But there are just as many female autistics. And what most of them do is to ‘mask’ to have tools, mechanisms, processes to appear NT neurotypical (‘normal’ but the author avoids that word) and to fit in. And it is exhausting for them. The book intends to give Autistic people the tools to appropriately unmask. There are risks and issues if it done in an unconsidered fashion.

He closes the chapter with a quiz to ‘find your why’. The author will come back to this later.

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| **Values-Based Integration Process** (pg 14) | |
| Think of five moments in your life when you felt like you were FULLY ALIVE. Try to find moments from throughout your life. Some of the moments leave with a sense of awe and wonder – ‘wow, if all of life was like that, life would be amazing!” Write down each of these moments. Tell the story of each moment in as much detail as possible. Try to think specifically about why the moment stuck with you so dramatically. | |
| Moment 1 |  |
| Moment 2 |  |
| Moment 3 |  |
| Moment 4 |  |
| Moment 5 |  |

**Chapter 1: What Is Autism, Really?**

The author describes a young girl who exhibited traditional Autism traits: she lined up toys instead of playing with them, chewed on her blanket, stared at the wall, didn’t understand in jokes and teasing. Her mother wanted to get her assessed but her grandfather stopped that – probably because he thought he was protecting from labelling and the related stigma of Autism. Label avoidance is very common and it does make some sense because Autistics are viewed as less competent, even if it isn’t always the right way to go.

So, what is Autism?

Autism is neurological – a developmental disability that seems to be largely inherited. But there is no single cause and no single set of symptoms. Because it is developmental in nature, Autistic people tend to be delayed compared to neurotypical people. The development of an Autistic’s brain has impacts on attention, decision making, impulse control, and emotions. The author describes that infants’ brains are hyperconnected and NT people early in their life prune the connections (figuring out what’s important and what’s a nuisance) where Autistics tend not to do this pruning. This difference is where some behaviors and benefits come from (distracted by stimulus and intense focus).

Autistics tend to have these qualities:

* Hyperactive to even small stimuli
* Trouble distinguishing between environmental noise or information
* Focused on details rather than the big picture
* Deeply and deliberately analytical
* Methodical decision making (not gut-feel)
* Takes longer and more energy to process a situation

Other ways to think about these:

* Autism is associated with a deliberative processing style: Autistics tend to logic and reason rather than emotion and intuition.
* Autistic people process the world from the bottom up: Rather than coming into a new situation and ‘getting the gestalt’ they examine the minutiae.
* Autism touches every part of the Autistics life: what NT people deal with easily takes Autistics a lot of effort.
* Autism is behavioral: The author talks about ‘stimming’, the repetitive actions that calm the Autistic. Like flapping hands, listening to certain sounds, repeating words. This comforts the Autistic. Self-stimulatory behavior is not unique to Autistics and can be seen in neurotypical individuals as well. Children often engage in self-stimulating behaviors; but these behaviors decline. Even typical adults sometimes stim. For example, many people tap their foot when impatient or anxious, twirl their hair when bored, or tap their fingers when intensely thinking.
* Autistic people are at risk: Especially marginalized groups. If the Autistic is too ‘different’, they can be targets of violence, arrest, bad mental health situations.
* Autism is diverse: The ‘typical’ aspects are very different and Autistics can have some common ones or none. And some of the aspects are paradoxical.

Typical Autism is often visible from an early age. Currently, children will be diagnosed (hopefully) early in grade school. This often is in behaviors, sensory overloud, behavioral issues, non-compliance. But there really isn’t a single ‘typical’ Autistic. It occurs in all genders, races, and economic levels. What is different is that some of these rarely get diagnosed or helped. Previous understanding of Autism viewed it as technically oriented white boys.

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| **Autism Stereotypes - How have they affected You** (pg 38) |
| Think of some images of Autism that you have seen on TV or in movies. Name a few of them. |
| Pick a few of these characters and describe them in 3-5 words.  Character: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Traits:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Character: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Traits:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Character: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Traits:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| Complete the sentence:  Before I knew better, I assumed all Autistic people were. \_\_\_\_\_\_\_\_, \_\_\_\_\_\_\_\_, and \_\_\_\_\_\_\_\_\_ |
| Has anyone ever told you that you don’t look Autistic or you can’t be Autistic? What do you think they meant by that? How did hearing that feel? |

Do you think you’re autistic? The number of Autistic people is not clear because of masked Autistics (those who for a variety of reasons don’t want to know) and because some people just feel something is wrong or missing and they don’t know what it is.

The author suggests that if you want to know about getting an assessment for you or a loved one:

1. **Do you have health insurance that covers Autism assessments?**Some do, some don’t. And it’s expensive.
2. **Can you find an Autism specialist who has a proven track record?**  
   The specialists vary in quality and knowledge.
3. **What do you hope to get out of the formal assessment?**This may get you started on dealing with the disability. But it is not a guarantee of accommodations or help.

The author feels that the following terminology a good thing to follow:

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| **Autism Terminology - Common Dos and Don’ts** (pg 48) | |
| Use This | Avoid This |
| * Autistic person * Autist * Autistic * On the Autism spectrum | * Person with Autism |
| * Is Autistic | * Identifies as having autism |
| * Is disabled * Has a disability | * Special needs * Differently abled * Handi-capable |
| * Neurotypical (NT) * Allistic * Non-Autistic | * Normal |
| * Has high support needs * Has low support needs | * Low functioning * High functioning |
| * Masked Autism | * Female Autism * Asperger’s * High-functioning Autism |
| * Nonverbal * Loses speech | * Mute * Dumb |
| * Intellectually disabled * Developmentally disabled | * R\*traded * Stupid * Special |
| * Direct language about what a person can or can’t do, and what kind of support they need | * Euphemisms, language that minimized challenges, language that belittles or condescends |

Note that some severely disabled Autistics have, in addition to some of these other aspects, a delay in intellectual development. The author consistently refers to Autism as a disability. He capitalizes it for the same reason the Deaf community does – indicate it is a part of their identity and community. He views disability is not a bad word – being disabled is not a shameful thing - even though society at large has done that. He points out that blind people are not ‘differently sighted’ – they can’t see and it is a disability in a world that hasn’t made accommodations.

I understand what he is going for here and mostly agree. But I struggle that saying ‘disabled’ may have the same stigma as the other euphemisms. It also might be because of the time I grew up in.

**Chapter 2: Who Are the Masked Autistics?**

The author introduces you to groups of people who become ‘masked Autistics’. These are the people who for gender, family, race, economic, societal, or culture reasons were not diagnosed. These people try to adapt and fit into a neurotypical world – by masking who they really are – Autistic.

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| **Traits Commonly Associated with ‘Female Autism’** (pg 55) |
| Emotional   * Strikes others as emotionally immature and sensitive * Prone to outbursts or crying jags, sometimes over seemingly small things * Has trouble recognizing or naming one’s feelings * Ignores or suppresses emotions until the bubble up and explode * May become disturbed or overwhelmed when others are upset, but uncertain how to respond or support them * Goes blank and seems to shut down after prolonged socializing or when overstimulated |
| Psychological   * Reports a high degree of anxiety, especially social anxiety * Is perceived by others as moody and prone to bouts of depression * May have been diagnosed with mood disorders such as Borderline or Narcissistic Personality Disorder (before Autism was identified). * Fears rejection intensely and tries to manage how other people feel to avoid it * Has an unstable sense of self, perhaps highly dependent on the opinions of others |
| Behavioral   * Uses control to manage stress: follows intense self-imposed rules, despite having an otherwise unconventional personality * Is usually happiest at home or in a familiar, predictable environment * Seems youthful for their age, in looks, dress, behavior, or interests * Prone to excessive exercise, calorie restriction, or other eating disorders * Neglects physical health until it becomes impossible to ignore * Self-soothes by constantly fidgeting, listening to repetitive music, twirling hair, picking at skin or cuticles, etc. |
| Social   * Is a social chameleon, adopts the mannerisms and interests of the groups they’re in * May be highly self-educated but will have struggle with social aspects of college or career * Can be very shy or mute, yet can become very outspoken when discussing a subject they are passionate about * Struggles to know when to speak when in large groups or at parties * Does not initiate conversation but can appear outgoing and comfortable when approached * Can socialize but primarily in shallow and superficial ways that may seem like a performance. Struggles to form deeper friendships * Has trouble disappointing or disagreeing with someone during a real time conversation |

Part of the mask for Autistics is to develop rules to minimize stress like:

* Only make eye contact for x seconds
* Eat this easy to make meal this time every day
* Don’t talk about yourself for too long
* …

The author had this as ‘female Autism’ but that ignores the large percentage of Autistic people who are transgender or gender nonconforming. And in my personal opinion these can apply to any Autistic.

Similarly, there are racial aspects that come into play for non-whites. The neurotypical American society is defined around our European background. A black or brown Autistic not only has their own cultural norms to mask, but they also have our American societal norms. They have to talk and behave in very different ways to be accepted depending on what group or environment they are in.

The psychiatrist Eugene Bleuler coined the term autism in 1911 – which means ‘isolated self’. This is in contrast to ‘allistic’ for neurotypical people – which means ‘other self’ or ‘connected self’. Most people have seen Autistics as introverted – isolated. But that is not universal. Sometimes Autistics can be very extroverted. In many cases, this is the way they put on their ‘mask’.

Autism can also occur in people with other issues or illnesses. In the 1940s psychiatrists thought Autism was a form of childhood schizophrenia. Some Autistics have PTSD from their Autism or from other events in their life. Other issues can be ADHD, Bipolar Disorder, Borderline Personality Disorder, Depression… What this boils down to is that it isn’t always possible or even helpful to untangle the constellation of disorders. And many of these issues have been misdiagnosed but should have triggered a look at Autism.

**Chapter 3: The Anatomy of the Mask**

The author describes his and a few other Autistics’ masking efforts. He then provides a exercise to try identify what were the fears or concerns that drove the mask components. When young, did people accuse you of being cruel, finicky, selfish, immature, out of touch, and the list goes on. Behind Autistic’s masks are pain and (usually wrong) beliefs about who you are and what you must avoid.

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| **Reflecting the Need to Mask: What does you mask protect you from?** (pg 95) | |
| 1. Try to recall a time early in life when you felt intense embarrassment or shame. Describe the situation: | |
| 1. When you recall this experience, what emotions do you feel? | |
| 1. Complete the sentence by checking off as many adjectives as you like: In that moment, everyone could see that I was \_\_\_\_\_\_\_\_\_    * Selfish    * Awkward    * Childish    * Self-absorbed    * Cold    * Stupid    * Weak    * Robotic | * + Robotic   + Immature   + Disgusting   + Embarrassing   + Clueless   + Cruel   + Pathetic   + Other: \_\_\_\_\_\_\_\_\_   \_\_\_\_\_ |
| 1. Of the words listed above, which one is the most painful to hear associated with you? | |
| 1. List some actions or habits that you associate with that word. | |
| 1. Complete the sentence: I pretend to be \_\_\_\_\_\_\_\_\_ so that people will tolerate me, but deep down I know that I’m not.     * Independent    * Cool    * Generous    * Mature    * Warm    * Impressive    * Helpful | * + Happy   + Confident   + Caring   + Organized   + Smart   + Powerful   + Worthy   + Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| Complete the sentence: If I want people to like me, I can’t let them find out that I \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_. | |

What is Masking? The literature classifies it as two types of behavior:

* Camouflaging: attempting to hide or obscure the Autistic traits so you ‘blend in’ and avoid detection.
* Compensation: using strategies to overcome challenges. The main goal is to maintain the appearance of high and independent functioning.

Metal health professionals have often defined Autism by how the disability impact the neurotypical people. So, the children and adults who are severely Autistic with disruptive and disturbing behaviors are the ones who get attention which hasn’t always been good. (Being well behaved will hide the person from this attention – but is that better or not?)

Some of the training that has been done is Applied Behavior Analysis (ABA) therapy. It is a series of rewards and punishments to make them ‘fit in’. About half of the Autistic adults who got ABA therapy report having PTSD as a result.

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| **Masking Overcorrection** (pg 106) | | |
| **I was taught it was bad to be:** | **So I had to pretend to be:** | **I did this by behaving this way:** |
| Arrogant | Humble | * Pretending I didn’t know answers to questions * Keeping silent when people said things that weren’t true * Softening statements with phrases like ‘maybe’ or ‘if that makes sense’ |
| Cold and Unfeeling | Warm and Friendly | * Smiling all the time no matter how I felt * Asking people their feelings and not talking about myself * Taking care of others when they were upset |
| Annoying and Loud | Agreeable and Quiet | * Only experiencing big emotions in private * Solving problems by myself * Not getting ‘too excited’ about anything, including good things. |
| Childish | Mature | * Serving as a confidant for adults and authority figures * Carrying myself in restrained and ‘proper’ way * Acting like a ‘teacher’s pet’ or ‘little professor’ and distancing myself from my peers |
| Awkward | Cool | * Withdrawing from any activity I wasn’t instantly good at * Pretending to be aloof and uncaring * Rehearsing fake conversations in my mind so I could make talking to people seem effortless |
| Clueless/Pathetic | Independent | * Nodding or laughing even when I have no idea what’s going on * Developing unique, private habits and hacks that make it possible for me to hold my life together * Making sure my looks ‘put together’ on paper, even at the expense of my health or happiness |
| Sensitive | Strong | * Not voicing my needs * Feeling ashamed whenever I wanted to cry or express anger * Fighting internally with every ‘disruptive’ emotion I felt. |
| Weak | Rough | * Mocking or being aggressive with other people * Thinking of myself as superior to others * Showing distaste for anything society considers feminine, soft, or tender |
| Weird | Normal | * Studying what other people like in a systematic, analytical way * Imitating people or characters’ mannerisms, style of dress, tone of voice, etc. * Mocking those who are more obviously ‘weird’ |

**Chapter 4: The Cost of Masking**

The cost of masking is very high and exhausting.

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| **Propping Up the Mask:** (pg 111)  **Problematic Coping Strategies and Why Autistics Use Them** |
| Problem Drinking or Substance Abuse   * Dulls sensory sensitivities * Provides ‘courage’ for intimidating social situations * Relaxes inhibitions and filters * Provide energy to get through the demanding world * Stimulates the senses * Entertains an anxious or preoccupied mind * Silences the inner critic |
| Eating Disorder Behavior   * Grounds life in daily goals and rituals * Provides physical stimulation via hunger, exercise, purging, etc. * Distracts from social struggles by focusing on the body * Defines goodness and worthiness in terms of behavior or appearance * Gives the Autistic person a sense of self-control or discipline * Explains away feelings of gender dysphoria or physical dissociation |
| Detachment and Dissociation   * Prevents rejection by disengaging first * Blunts painful emotions such as grief, sorrow, regret * Allows the Autistic to focus on what they’re naturally good at * Removes the pressure to learn challenging emotion or social skills * Silences needs and emotions others find bothersome * Preserves limited energy |
| Adherence to Rigid Rules and Belief Systems   * Makes a confusing reality feel more understandable and concrete * Translates vague social norms in to specific expectations * Creates an in-group to which the Autistic can belong * Soothes self-doubt and fears about being a bad person * Promises salvation from the present unjust world |
| Fawning and Compulsive People-Pleasing   * Earns the Autistic praise * Offers a false promise of acceptance * Simplifies complicated relation dynamics * Flattens social interactions into one easy rule: always say yes * Validates the Autistic’s belief they should ignore their feelings and needs * Minimizes conflict and reduces anger |

The table really summarizes the main point of the chapter. ‘High-control’ sorts of groups are often high-risk for Autistics because they play to the Autistic’s masking behavior and give the Autistic person a place to ‘belong’ or ‘fit in’. But Autistics end up being easy to control and are taken advantage of. The warning signs of a high-control group:

1. The group promotes an antagonistic view of the outside world and non-members. “It’s us versus the world.”
2. Group members constantly feel insecure about their position within the group. Members may be punished or ostracized for any small mistake or failure.
3. Personal boundaries are discouraged. People are expected view the group as a ‘family’ and sacrifice as much as they can for it.
4. Any perspective challenges the group’s orthodoxy is unspeakable. Members feel shame about thinking or feeling the wrong things.
5. Repetitive language and group jargon are used to dismiss criticism. Group members repeat cliches in order to silence difficult conversations.

For the Fawning and People-pleasing the author has this tool. Consider each statement and reflect on huw true each one is for you:

1. It doesn’t feel like anyone knows the real me
2. I don’t know how to say no to people
3. I feel responsible for managing other people’s feelings, even when they don’t involve me
4. I sometimes feel like I’m betraying myself by going along with things I don’t agree with
5. I closely monitor social situations to see when conflict is brewing and try to stop it before it starts

**Chapter 5: Rethinking Autism**

Starting at the beginning, the first of unmasking process is recognizing that you are Autistic. It may not feel great, but it is an active step towards self-acceptance and to understand yourself and starting to re-frame your life. The point is to rethink the beliefs and behaviors and put them in this new context.

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| **Relabeling Autism Stigmas (pg 144)** | |
| **Old Label** | **New Label** |
| Stubborn | Assertive, Persistent |
| Wild | Energetic |
| Distractible | Perceptive |
| Demanding | Knows what they want |
| Inflexible | Traditional, does not like change |
| Manipulative | Knows how to get needs met |
| Anxious | Cautious |
| Nosy | Inquisitive, Curious |
| Loud | Enthusiastic |
| Argumentative | Committed |

So, to reframe these stereotypes, how do you understand the value you get from them?

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| **Reframing Autistic Stereotypes** (pg 147) | | |
| **I was told I was:** | **But actually, I am:** | **I value this quality in myself because:** |
| Arrogant | * Confident * Principled * Independent | * It helps me stand up for what’s right * I’m often the first person to speak out about a problem * I can set a positive example for others |
| Cold and Unfeeling | * Analytical * Rational * Thoughtful | * I notice things others miss * I don’t get swept away in the heat of the moment like others * I’m good at noticing connections and systems that others don’t see |
| Annoying and Loud | * Enthusiastic * Alive * Outspoken | * I am my own best advocate * I raise other people’s energy levels * I experience intense happiness and recognize beauty |
| Childish | * Curious * Open Minded * Joyful | * I’m great at learning and growing * I experience the full range of human emotion * I take pleasure from the small things |
| Awkward | * Authentic * Unique * Don’t blend in with the crowd | * If something is hard for me, others probably need help too * My way of moving through the world is entirely its own * I don’t conform to unfair standards |
| Clueless/Pathetic | * Reflective * Unassuming * Open about vulnerability | * I recognize we all need each other * I know how to ask for the help I need * I value my connections to other people |
| Sensitive | * Perceptive * Emotionally attuned * Compassionate | * I recognize mistreatment very well * I’m good at sensing the emotional level * I’m in touch with my feelings and with the feelings of others |
| Weird | * One of a kind * A trailblazer * Unconventional | * I make the world a bigger/broader place * I challenge old conventions and unfair rules * I’m the ultimate authority on how my life should be |

Another part of being Autistic is special interests.

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| **Special Interest Week** (pg 154)  **Seven Prompts to help you reflect on Autistic Joy** | |
| Instructions: Every day for a week, set aside some time to reflect on one of the prompts below and think about and write about the Special Interest | |
| Day 1: Your oldest special interest |  |
| Day 2: Your most recent special interest |  |
| Day 3: A special interest that’s changed or grown |  |
| Day 4: A special interest that is a collection |  |
| Day 5: The special interest that has shaped most of your life |  |
| Day 6: A special interest you share with someone |  |
| Day 7: What are the special interests that have been positive in your life |  |

A lot of times, Autistics will say things like ‘that’s not allowed’ or ‘the rules are different for me’. The author is suggesting that the Autistic stop thinking about what neurotypical people wanted (or what they think NT people wanted) and shifting to look at what is appropriate to drive the Autistic’s actions and behaviors – their values.

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| **Values-Based Integration**  (pg 156) | |
| Go back to the five moments in your life when you felt like you were FULLY ALIVE. Review those memories and why it was special to you. Think about key words that apply | |
| Moment 1 | (keywords why this moment was special) |
| Moment 2 | (keywords why this moment was special) |
| Moment 3 | (keywords why this moment was special) |
| Moment 4 | (keywords why this moment was special) |
| Moment 5 | (keywords why this moment was special) |
| Try to identify which of the words are the most important resonant. If possible, group them together and identify threads or key areas: | |

At the end of this chapter, the author suggests thinking about what meaningful things have come from the Autism. Things like:

1. Because of hyperfocus, I have developed these skills.
2. With special interests, I know a lot about these subjects.
3. I would never have met these people who are important to me.
4. I would never have developed my personality traits.
5. I wouldn’t be as resilient in these various ways.

**Chapter 6: Building an Autistic Life**

This chapter is mostly stories about Autistics who made changes by unmasking and being truer to their basic nature. Examples could be adapting their life to best suit their personal needs: 1) stop showering with the lights on to help with sensory overwhelm. 2) giving yourself permission to eat the same 5 foods every day and so on. An interesting story had to do with ‘divergent design’ – making structure, things, and spaces for Autistics.  Some questions that can enable the design of your environment:

1. What textures comfort or ground you?
2. Do you prefer minimalist or cozy?
3. Do smells make you relaxed or invigorated?
4. What sort of light do you like (and for what): dim, colorful, bright?
5. What objects do you enjoy holding or having close-by?
6. Do you need background noise to focus or is there ambient noise you need to block?

The author goes on to talk about reimagining multiple things:

1. Success
2. Time
3. How you dress

Some ideas for being visible as an Autistic:

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| **Everyday Unmasking**  (pg 189)  **Daily Challenges for Being Radically Visible** |
| Disappoint someone: Practice saying ‘no’, ‘I’m not available to do that’, ‘I’m uncomfortable with that’ without any explanation or apology |
| Express disagreement in a situation where you’d normally just nod along to keep the peace. |
| Notice when you feel pressured to do something you don’t wish to do. Practice observing this aloud: ‘I’m not sure why you are pushing this because I already said no.’ |
| Try to go an entire day without guessing or anticipating anyone’s emotions. |
| Try to go an entire day without controlling what messages your facial expressions or body language is giving off. |
| Ask for something you usually feel too guilty to request. |
| Go through an entire conversation without faking any reactions or emotions. |
| Sing along to your favorite music while walking down the street. |
| Bring a stim toy with you to a social gathering or public space, and use it without shame. |
| Wear a fancy outfit or costume you absolutely love instead of waiting for an event or excuse to wear it. |
| When a friend asks you how you doing, give them an honest answer. |
| Take action without running it past anyone for approval. |
| Share big emotions with safe people. |
| Tell someone you trust about your neurodiversity and what it means to you. |

I found this list very informative…. Because it shows the things that Autistics have in their head that they worry about and impact them.

**Chapter 7: Cultivating Autistic Relationships**

Self-disclosing has benefits and risks. Neurotypical people might understand or they don’t. You need to think carefully when it makes sense. Also, it is helpful having a supporter or fellow Autistic that can back you up. Some people just won’t believe you or take it as an opportunity to belittle you. One mechanism for self-disclosure is social media – it can be safer that in real life (IRL). If you want to come out as Autistic, it is good to consider why:

1. Who do I want to come out to as Autistic?
2. Why do I want to come out? What do I hope will happen?
3. What do I wish people understood better about me?
4. How much energy am I willing to put into educating this person about what Autism really is?
5. Do I have a specific ‘ask’ that I’d like to make? Like requesting accommodation or different treatment?
6. Who ‘gets’ me and can help advocate for me?

The author and several of the people mentioned in the book found huge benefit when they connected to or developed friends and acquaintances who were also on the spectrum or supportive Autistics. Essentially this is about cultivating unmasked friendships. This can be hard because some of the Autistic behaviors are at odds with having a solid ‘inner circle’:

1. When someone gives you a compliment, do you feel you have to downplay it?
2. Are there people in your life who seem ‘too nice’?
3. Are you afraid of trusting people because they might abandon you?
4. When someone gives you positive attention, do you feel creeped out?
5. Are you afraid that kind, loving people deserve ‘better’ than to be friends with you?
6. When someone gets vulnerable with you do find ways to downplay it?
7. Do have a hard time showing people that you like them?

Autistic people have some specific needs in communication:

|  |  |
| --- | --- |
| **Common Autistic Communication Needs** (pg 208) | |
| **Overall Need** | **Accommodations you might request** |
| Clear Expectations | Specific plans with details about time, place, and what is going to happen  A clear yes or no – no euphemisms  Meeting agendas handed out in advance and adhered to  Reading materials, questions, and discussion topics provided in advance or a high stress event  Step by step detailed instructions on how to complete the task  Specific and measurable outcomes or goals |
| Explicit Messaging | Not assuming people can use facials expression, tone of voice, posture, …. As indicators of emotion  Giving direct explanations of feelings  Recognition and respect of boundaries  Not punishing or judging people for failing to read between the lines  Using clarifying questions |
| Reduced Sensory / Social Load | Having no expectation of eye contact  Giving space to talk about challenging topics while walking, using hands  Allowing people to express emotions via text, email, or handwritten note  Giving people time alone to reflect on their feelings  Learning to recognize fawning signs of meltdown  Providing frequent breaks from socializing or quiet retreat locations |

**Chapter 8: Creating a Neurodiverse World**

Again, the author approaches Autism as a disability. Most of the world use the medical model of disability. This model focuses on identification, diagnosis, and treatment or cure. It focuses on the individual not on society at large. This causes various issues for something like Autism.

In the recent past, there was a social model of disability. The author refers to Deaf people. There are specific schools for the Deaf community. In this context the Deaf person is not disabled. The hearing person who doesn’t know sign language is the one marginalized.

The author lists several things that society could do to help Autistics:

* Expanded legal protection
* Public space accommodation (visual, auditory, tactile, olfactory)
* Broadened social norms
* Expanded public and professional education on Neurodiversity
* Universal Health Care
* Basic income
* Revamping/removal of criminalization / mental health systems

I think many of these are good ideas. However, given the current partisan split in the nation, I don’t think many of these have much of a chance to gain wide acceptance. The things that I think could happen are: legal protection, limit public space accommodation along the lines of ADA, and expanded education on Neurodiversity. As much as I think Universal Health care should happen for everyone, not just Autistic, I don’t see it happening yet (even though it is cheaper than what we have). The others, I’m afraid, are non-starters.

**Conclusion: Integration**

In closing, the author talks about his journey of self-discover and shifting from his unconscious alienation to being aware person integrated in his environment. It wasn’t a perfect or easy transition.

He talks about some research on post-traumatic growth that happens to people who have been this and other trauma:

|  |  |
| --- | --- |
| **Key qualities of the Redemptive Self** (pg 255) | |
| Generative | Works to improve the world or benefit future generations |
| Sensitive | Cares about the needs of others and is concerned by social injustice |
| Committed to Values | Develops their own set of core beliefs and values, which guide their behavior throughout their lifetime |
| Balances Independence with Connection | Has a strong sense of one’s own agency and power, but also connects meaningfully with other people and recognizes we are all independent |

**Tim’s thoughts and summary**

The book helped me a great deal to recognize Autism in a broader context. I am trying to put away the old stereotypes about Autism. My general awareness is better than it used to be, but not perfect by any means. Entertainment and public opinions seem to continue to go to classic stereotypes and tropes.

My personal observation here is that I suspect that very few people are NT. The author talks later about ‘neurotypical’ as a societal and industrial construct to make sure people are productive. This feels about right to me. So, I think that everybody is different in some way. In other words, ‘nobody is normal’. For Autistic people the differences are greater and less appreciated, valued, and accepted. I still believe that we all need to be more accepting and try to understand people and who they are. The old adage of listen and observe before talking or acting. And in our frantic and frenetic world that has gotten so much harder.