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2022 Milestones National Autism Conference

Please be aware: Milestones has since closed, and links to its website are no longer functional.

Diagnosed at 30: What I Know Now That I Wish I Had Known Before (2022)

Presented by Carly Millis Jalowiec | https://youtu.be/qu2U04bjbtc

What does it mean to spend 30 years not knowing you're autistic? In this 2022 Milestones National Autism Conference session, Carly Millis Jalowiec shares her lived experiences as a late-diagnosed autistic adult and what she's come to understand in retrospect.

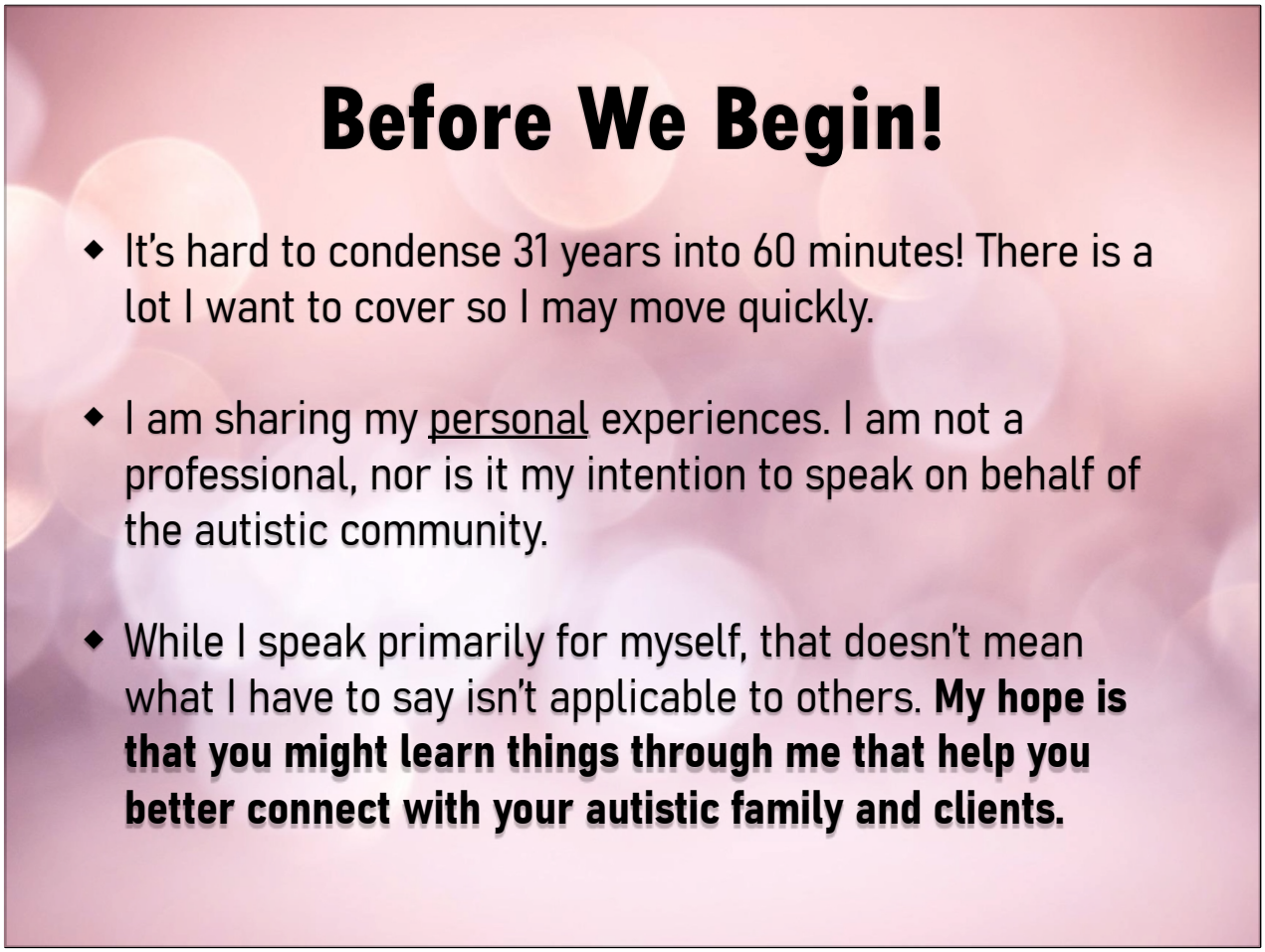
Through an in-depth look at the signs that were missed and the struggles that were misunderstood, Carly highlights why autism is so frequently overlooked in women and girls, and reflects poignantly on the years she spent feeling inherently broken. She discusses autistic masking, sensory sensitivities, emotional regulation, spoon theory, employment challenges, neurodivergent communication, and everything in between. Alongside are videos of Carly's family members sharing their own perspectives on her journey. The resulting presentation is an engaging, informative, and deeply personal look at what it means to finally understand (and celebrate!) who you've always been.

[Video Transcript] Hi. I'm Carly Millis Jalowiec and I am presenting "Diagnosed at 30: What I Know Now That I Wish I Had Known Before."

Speaker Disclosure Information

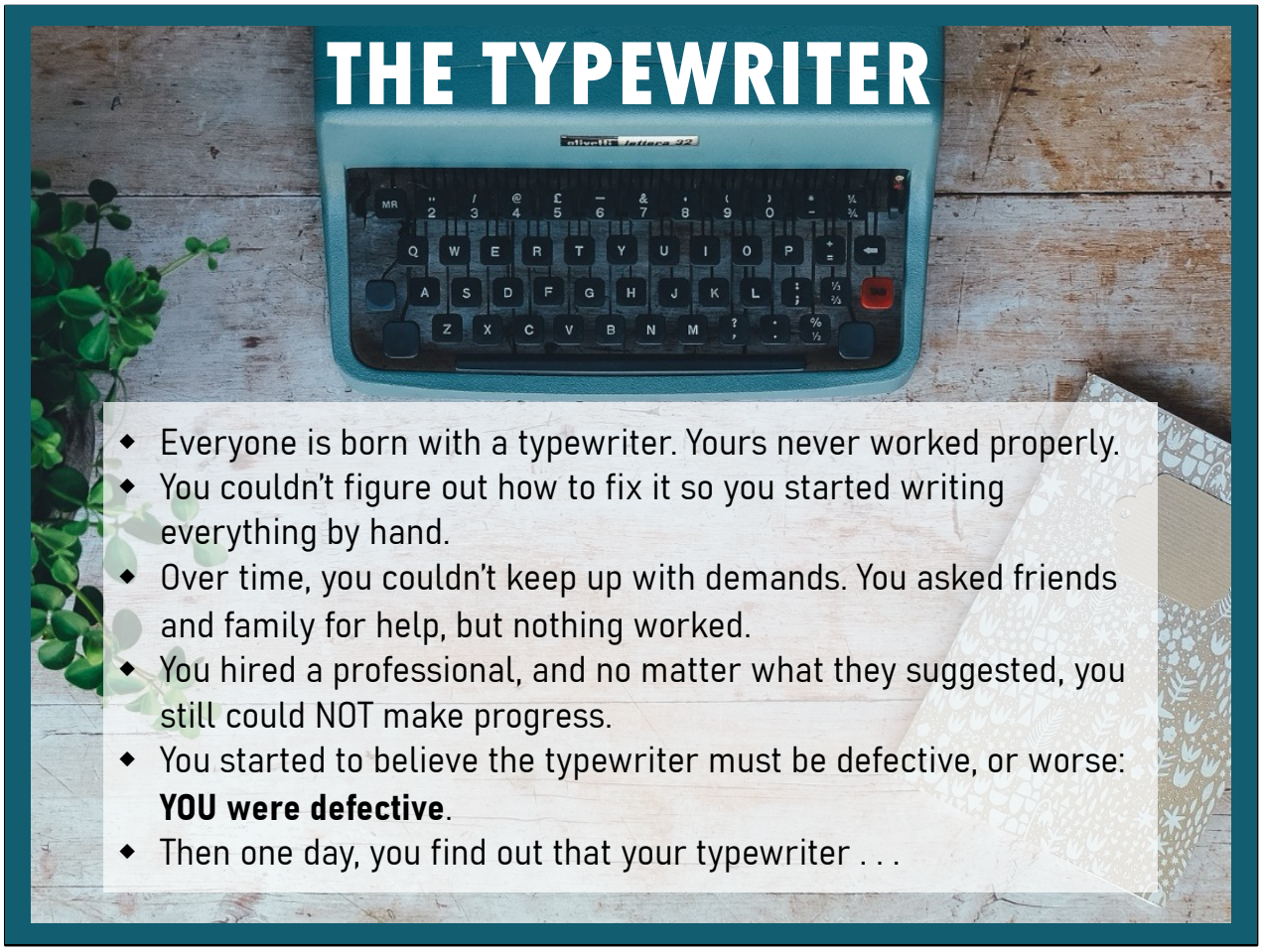
Carly Millis Jalowiec is the Education Assistant at Milestones Autism Resources, a member of the Milestones Conference Committee, and an autistic self-advocate speaking on her experiences. Carly is presenting a session for the Conference on a voluntary basis and has no other relevant financial or non-financial relationships to disclose.

[Video Transcript] Quick disclosure information: I do work for Milestones as the Education Assistant and I of course am an autistic individual.

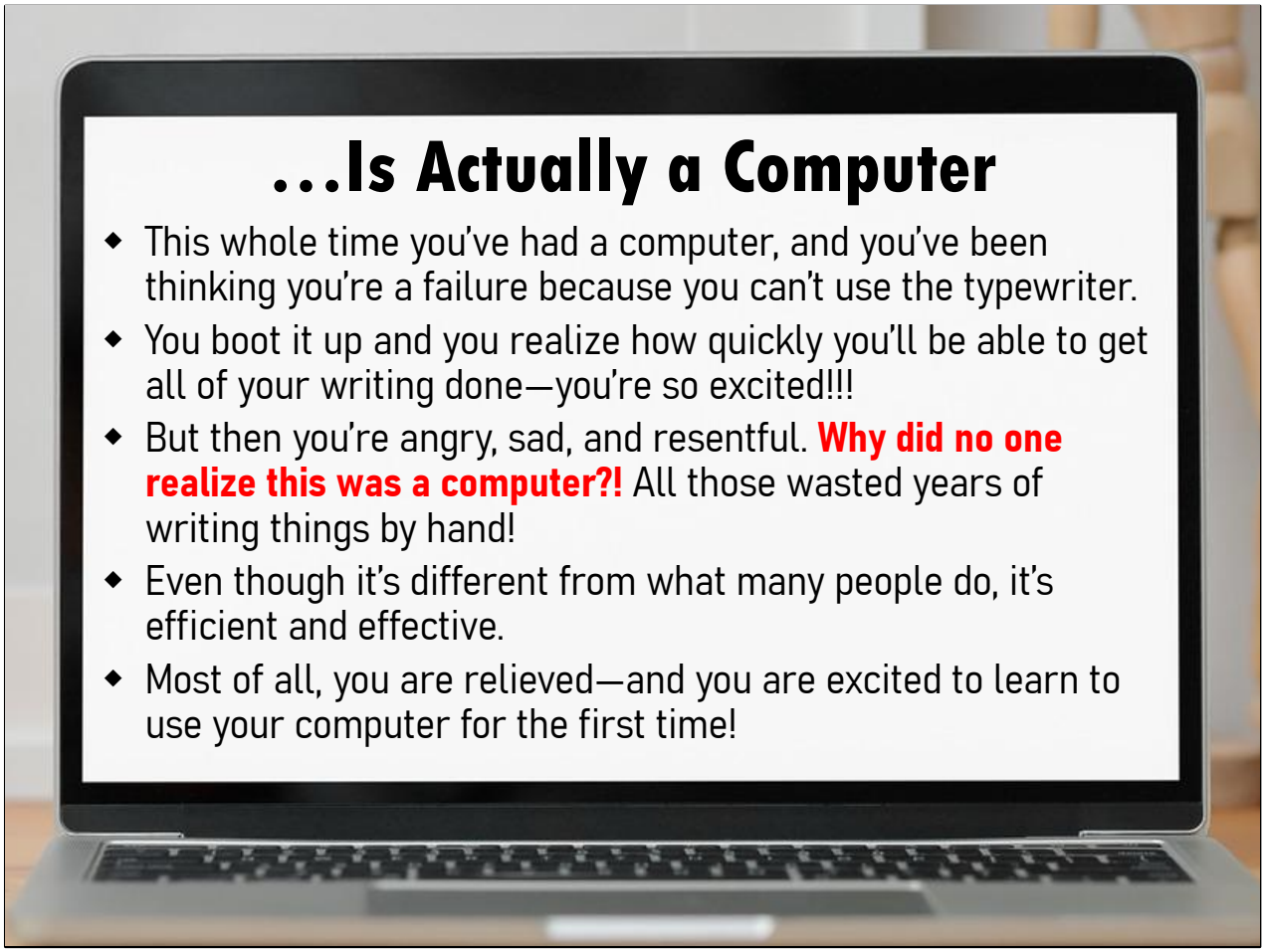


[Video Transcript] A couple housekeeping things before we begin. It's hard to fit a lifetime into a presentation, so I'm going to be broad and brief, but I definitely encourage you to download the printout of this PowerPoint. Additionally, I intend to speak only for myself, not all autistic people. But at the same time, while I know I may not present like your autistic loved ones, it doesn't mean we don't share similar experiences that hopefully you can learn from.

[Video Transcript] In other words, don't judge my capabilities based on my perceived competencies, and don't judge my struggles based on my ability to appear neurotypical.

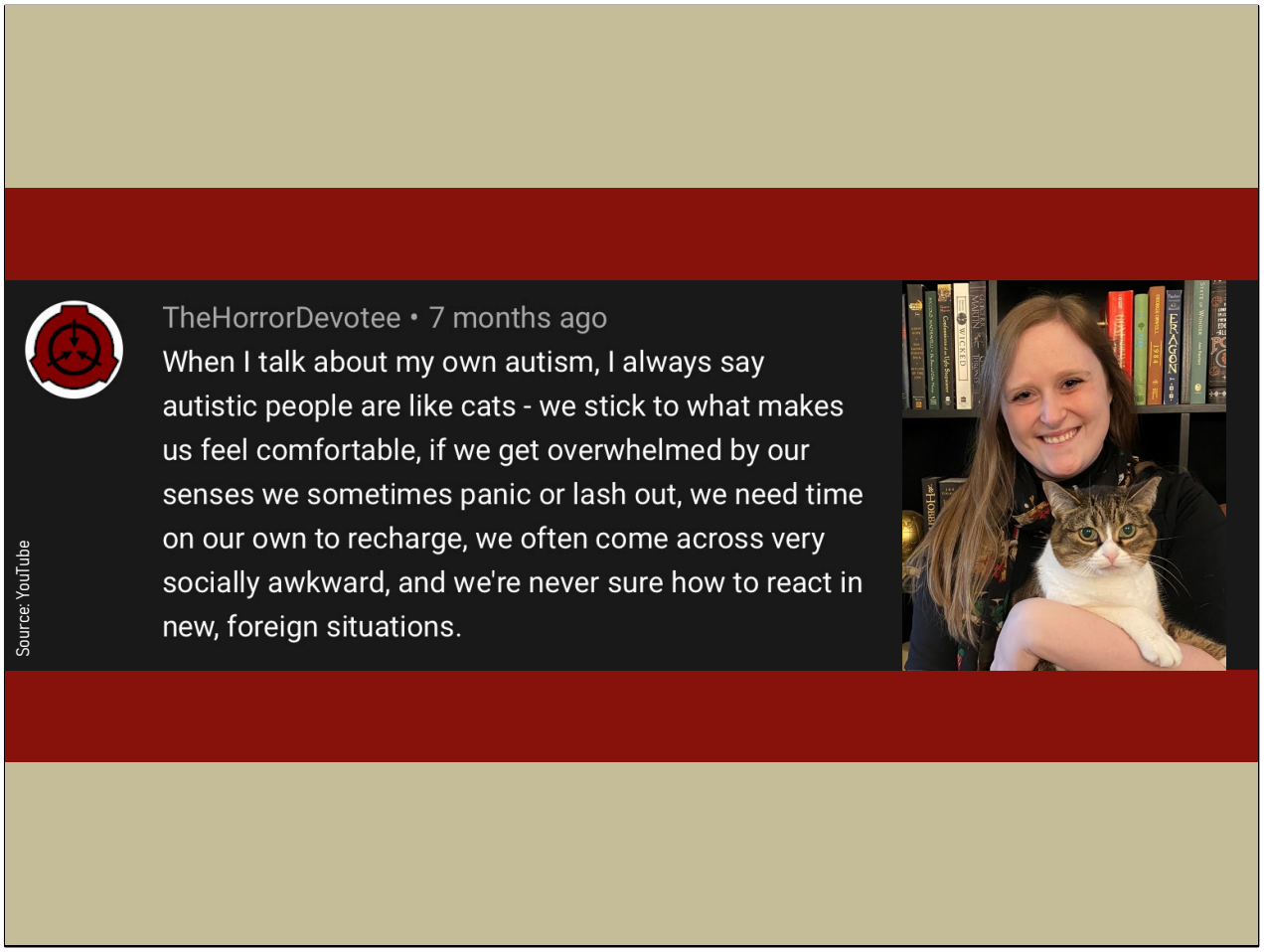


[Video Transcript] So I'm going to start with a bit of an analogy. Picture a world where everyone is born with a typewriter and yours just never worked. So you started writing everything by hand. You tried asking for help from friends and family and professionals to try to figure out what's wrong with your typewriter. But nothing worked. And over time, you started to believe that something must be wrong with the typewriter or something must be wrong with you. And it gets so frustrating and hurtful and you're about to give up until one day you discover that your typewriter...

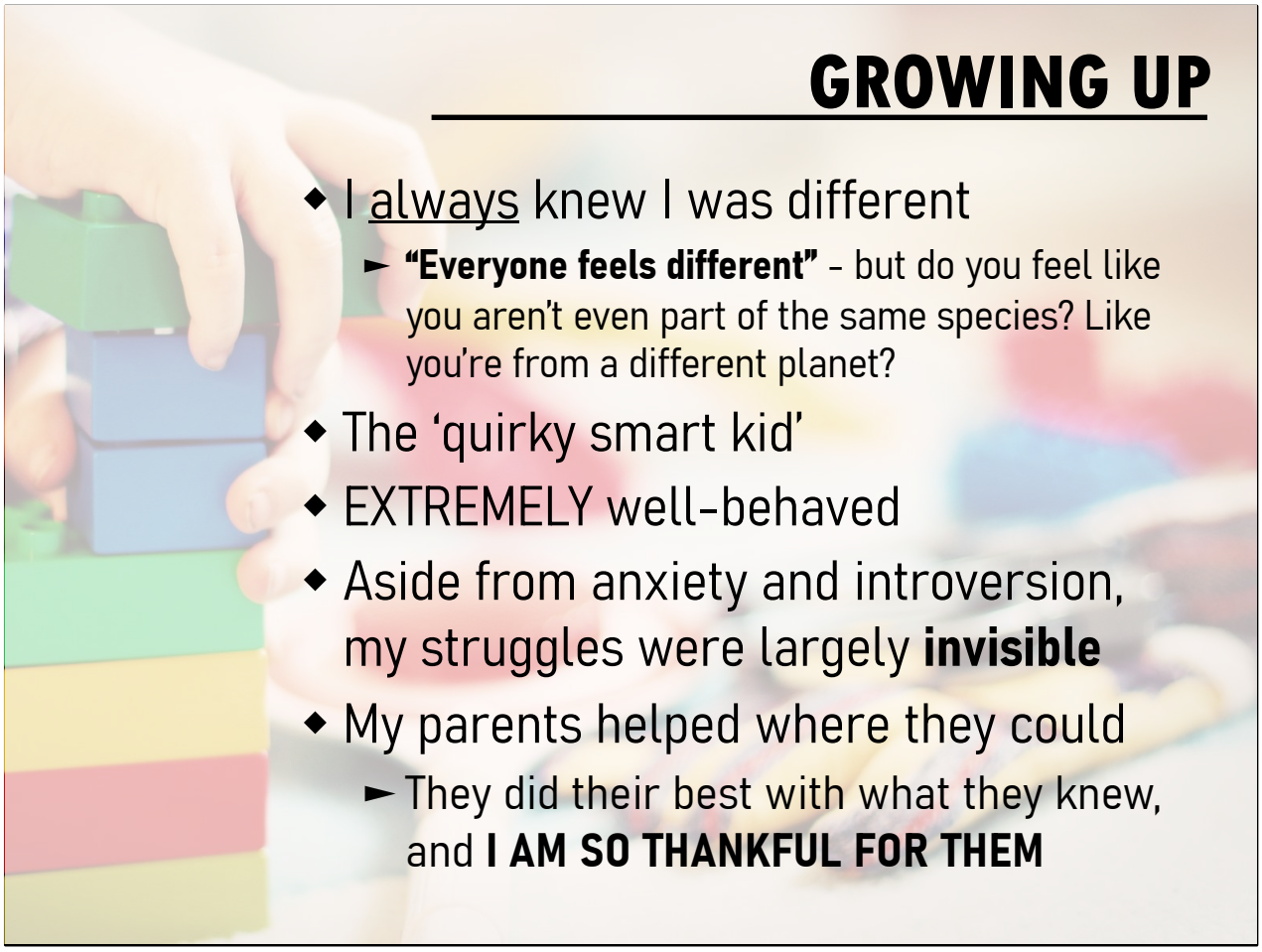


[Video Transcript] ...Is actually a computer. And you are so relieved! You don't have to write things by hand anymore. You're not bad at using a typewriter. There's nothing wrong with you. There's nothing wrong with the typewriter. But you're also hurt and you're angry that everyone missed something as huge as not realizing that this was a computer. Overall, though, you're just glad you finally get to learn to use your computer, get your writing done, and get a better understanding of who you are as a person.

[Video Transcript] Some quick background on my diagnosis. I was diagnosed in 2020 at the age of 30. I self-diagnosed the year prior when I was researching autism (because I thought my dad was autistic) and everything I read resonated with me so intensely. I knew immediately that I was autistic. So I decided to seek out a formal diagnosis, mainly for the sake of potential employment accommodations. But I also knew the amount of pushback that I would receive without having that official piece of paper that said I was autistic. I know how I present, and it's not how most people see autism. And honestly, I just did not want to constantly fight people about my lived experiences. Of course, I do have to acknowledge just how hard it is to get a diagnosis as an adult woman. That's honestly a presentation in and of itself. The disparities are enormous, but I hope that through making these kinds of presentations, we can start to fix that discrepancy.



[Video Transcript] So I found this quote online in a YouTube comment section of all places. It says, "When I talk about my own autism, I always say autistic people are like cats - we stick to what makes us feel comfortable, if we get overwhelmed by our senses, we sometimes panic or lash out, we need time on our own to recharge, we often come across very socially awkward, and we're never sure how to react in new, foreign situations." This quote resonated with me for a lot of reasons, one of which being that I love cats, and that's a picture of me with one of my four cats.



[Video Transcript] Growing up I always knew I was different. Fundamentally, profoundly different, in a way that honestly is hard to articulate. But from the outside, I looked pretty normal. I was a quirky, smart kid. I was in the gifted program. I was extremely well-behaved by all accounts, pretty much a model child. I dealt with some shyness and a decent amount of anxiety, but otherwise I was far from problematic. And while my struggles were largely invisible or misunderstood, my parents did do the best that they could do to help me. And I want to make sure I take a moment to acknowledge them because the rest of this presentation does focus a bit more on some of the negatives of my childhood, and I don't want that to be the only message received. My parents are absolutely incredible. I am unendingly appreciative and I wouldn't be where I am today without them. And speaking of my family, you will see video clips of them throughout this presentation sharing their thoughts on my journey. And here's the first one.

VIDEO CLIP: Marc Millis (Carly's Dad)

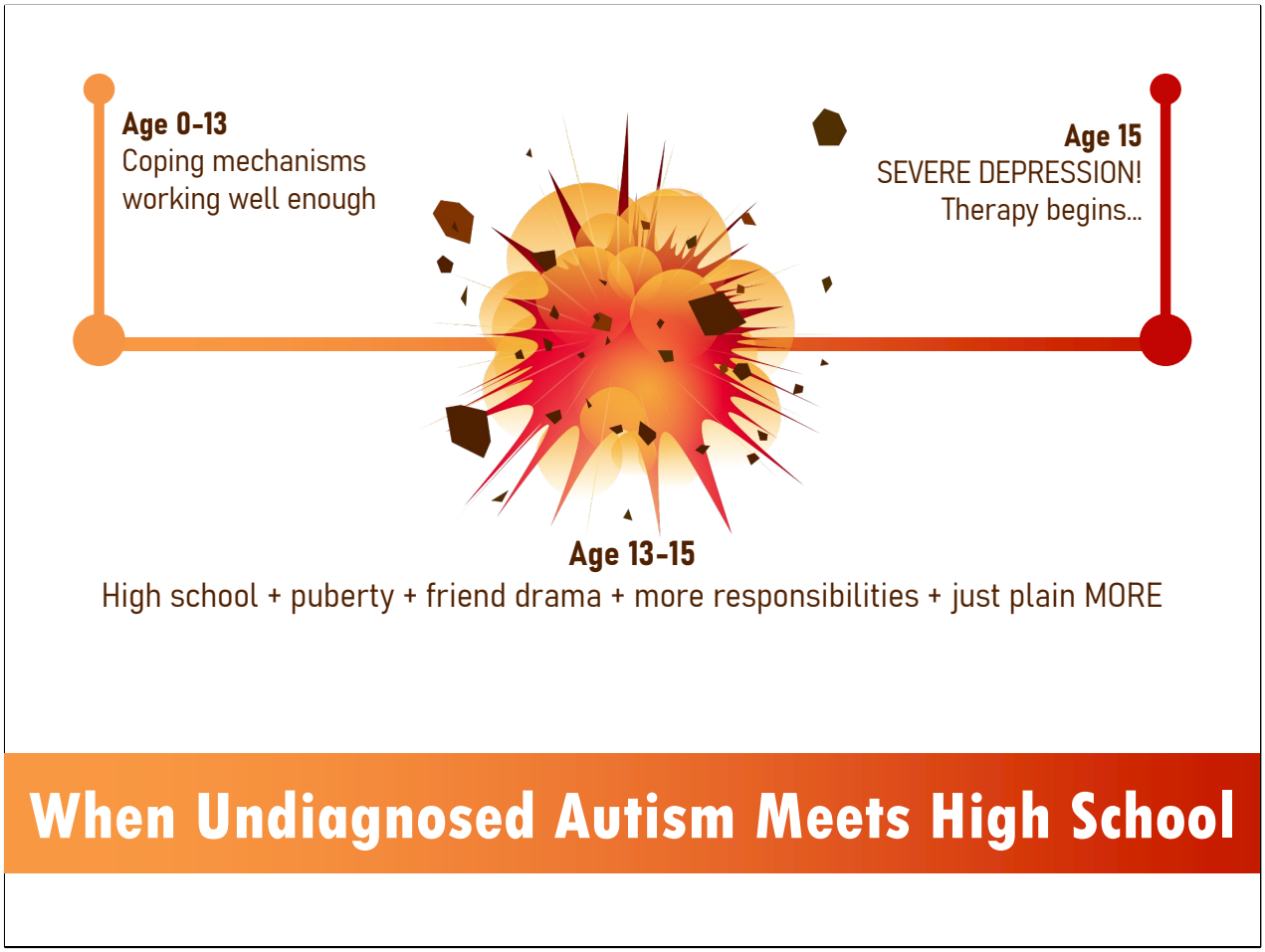
[Video Transcript] When I think back to Carly growing up...well, one thing I should say is, I recently learned that I'm also on the autistic spectrum, very similar to Carly. So a lot of things that, say, her mom would point out as being different, it was like, "well, that's normal to me!" One instance I remember. We were at a bar mitzvah and Carly got bored and wanted to go out in the lobby and read a book, and that sounded perfectly OK to me. Her mom didn't like that idea - the idea is "oh there's people and socializing!" And I'm thinking, "those people are loud! If you're into the book and need quiet around, they'll be fine without her" or whatever. So not realizing at the time that that had anything to do with just the hardwired autistic spectrum thing. I do definitely remember that her mom gave us a lot (both Carly and me), a lot of lessons on how to be more social to people, to where it got easy. And I actually appreciate that: the tidbits that you can hold on to when it does not come naturally to you. So that Carly had the benefit of having that advice on hand...I'm grateful that the situation provided that.

THEN AND NOW...

- Mom didn't want me to be "weird" or an "outcast"
  - She worked VERY HARD teaching me social skills – often to my benefit, but sometimes to my detriment
- She saw my struggles as something to "fix"
  - **If I couldn't fix them, I felt like something was wrong with me**
- My issues were foreign to her (anxiety, sensory issues, shyness, etc.) so she did not understand how to help me
- **I learned to internalize and hide a lot of my biggest struggles because they were misunderstood and often dismissed**

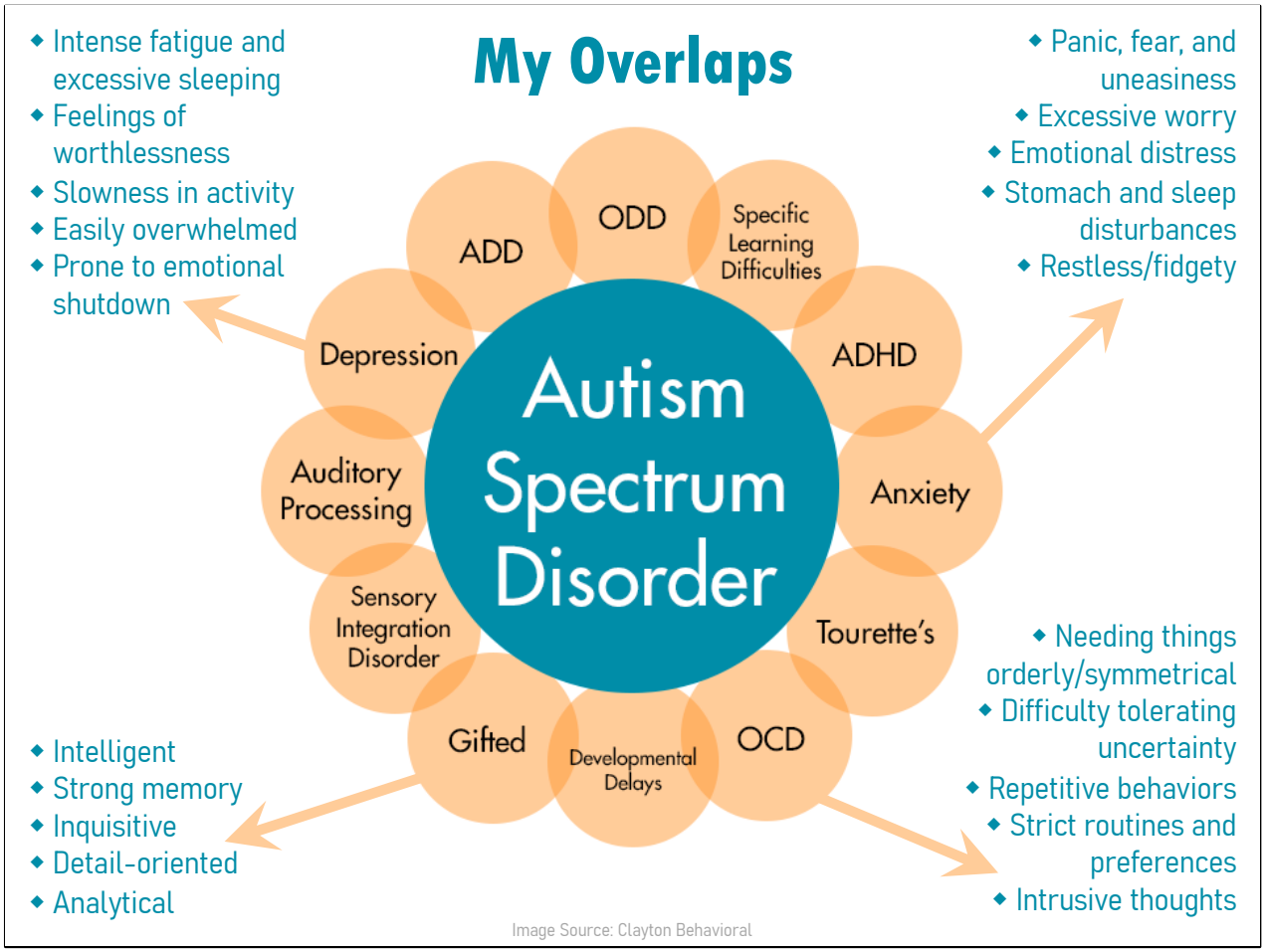
- Wanting to improve skills is a GOOD THING—but the message should be about **making a person better, not fixing a deficit**
  - Don't make it seem like someone is flawed for not naturally possessing a certain ability (even "simple" things)
- **I am THANKFUL that my mom pushed me out of my comfort zone: it taught me SO MUCH!**
  - I possess many skills that I would not have gained without "being uncomfortable" (ex: making phone calls)
  - But my mom often pushed too hard and focused on what SHE thought was important
- **Don't teach AT me, work WITH me**

[Video Transcript] As my dad just alluded to, I did get a lot of social training, which was very helpful. It's why I am as successful socially as I am today. But at the same time, it did give me some of the wrong messages. And what I heard overall was that I needed to be fixed. There was a lot of focus on my weaknesses to the point that I learned to start hiding my struggles. And what I wish had been done differently is not so much the end goal to help me be a better, more well-rounded person, but the way the messages were delivered. I wish the focus had been on leveraging my strengths and working with my limitations rather than just trying to correct all my shortcomings. And something I do appreciate is that I was put in positions where I could learn things that I might not have otherwise, but I do wish I had not been so, I guess, unceremoniously thrown into them. This led me to feeling like I was never doing enough, and that was just not helpful. So by and large, I think kind of the message here is that it's important to remember to work with the person that you have, not the person that you wish you had.



[Video Transcript] So I did OK enough through childhood, but when I reached high school, things finally really came to a head. With the combination of puberty and increased responsibilities and unfamiliar social situations, I was no longer able to maintain my makeshift coping mechanisms that had served me up until that point. So basically everything exploded and the result was a severe life-changing depression. It was just absolutely paradigm shifting in so many ways, and there was a lot of bad that came with that, but there was also a lot of good because it really shifted my perspective. And more importantly, it's when I started therapy.

[Video Transcript] I spent the next 15 years working with the same counselor on basically a weekly basis, and I received a handful of diagnoses along the way: Depression (obviously), Anxiety, OCD, PTSD, all that good stuff. And before I continue, I do specifically want to say how much I love and value therapy. It was absolutely integral to my development. I would recommend therapy to everyone, autistic or not, and I think its importance can't be understated. Additionally, even though you can't medicate autism, taking anti-anxiety medication has made a world of difference for me. I am much better at coping with my autistic struggles when I don't have anxiety on top of them. And sometimes you don't even realize how much difficulty you're having until you get on medication.



[Video Transcript] So this graphic is helpful for illustrating a lot of common comorbidities with autism. But one of the main reasons I included it is because I want to call attention to something I think is really crucial. Many self-diagnosed women go to their first therapy appointment, and they mention autism, and the counselor balks and says, "no you don't have autism, you just have anxiety, depression, OCD, etc." And when I went to get my diagnosis, I didn't have to deal with that because I had these other diagnoses on my chart already. But I think that this concept of going to the counselor and they give you 12 different diagnoses instead of the one is a good real-life example of a principle called Occam's Razor, which essentially states that if there are multiple competing theories that make exactly the same predictions, the simpler one is better. Or you might also have heard it as, "when you hear hoofbeats, think horses, not zebras." All 12 conditions on that graphic above are valid diagnoses. But if someone walks away with a laundry list like that, when one diagnosis could suffice, it's hard not to think something is missing.

THEN AND NOW...

- Because my autistic traits were similar to mental illness symptoms, there was a push to "fix" them
  - **This reinforced my childhood feelings: "if I can't fix my issues, something is wrong with me"**
- The current medical definition of autism doesn't fully include my presentation. **No one had any idea that someone like me could be autistic**
  - Because my symptoms didn't look like autism, they weren't treated like autism
- Autism, emotions, trauma, PTSD, and ways they overlap

- Being able to accept the parts of me that are hardwired has allowed me to focus on the things I CAN improve
  - **I am not wasting my time and energy fixing the "unfixable"** (although I do struggle to identify which traits I have control over)
  - I have embraced my limitations and redefined my strengths
- Some of my biggest barriers are NOT from autism, but from mental illness (anxiety and OCD are way more frustrating to me!)
- **Many of my "issues" don't actually bother ME; they bothered OTHER PEOPLE, who told me to fix them**

[Video Transcript] Because my symptoms were not recognized as autism, therapy often focused on the wrong things. And the fact that I couldn't fix things with therapy just reinforced a lot of the messages that I got from childhood where I just felt like I was just plain broken. Obviously, the outdated perception of autism is the biggest part of this conversation and as previously mentioned, deserves its own session entirely. But for now, I'll just say that having this archaic idea of autism is hurting a lot of women just like me. And what's worse is providers often don't realize what they don't know. But what I've come to understand is that there are a lot of things about me that I can't and shouldn't be expected to fix. That's not to say that I don't want to improve myself, but I want to spend my time and energy on the things I can affect. I also realized, interestingly, that many of the things that we focused on in therapy were not things that bothered or troubled me, but they were things that other people were bothered by and told me to fix. And having this information means that now I can direct my treatments to the things that actually bother me.

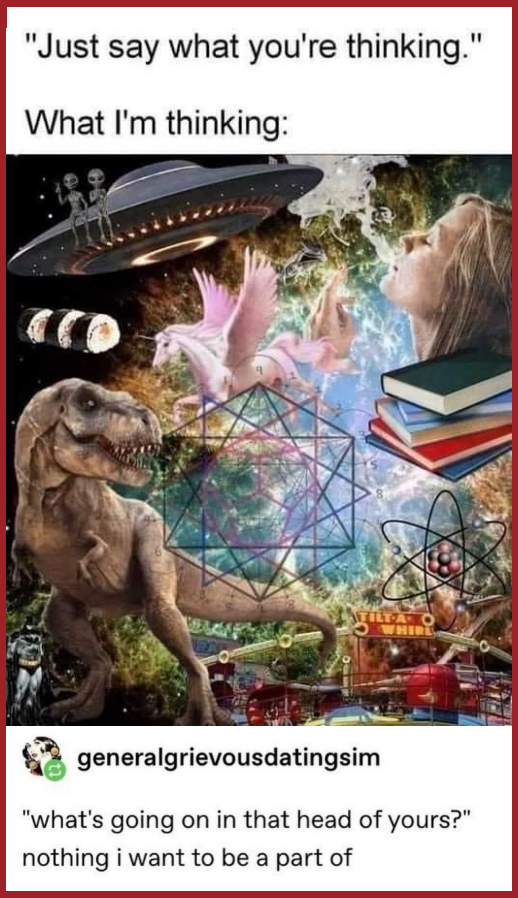
Why Yes, I *DO* Have Emotions!

- From a young age, I was regularly told I was "not in touch" with my emotions
- I was seen as cold, unfeeling, and distant
- Internally, I felt things very deeply, so these comments confused me

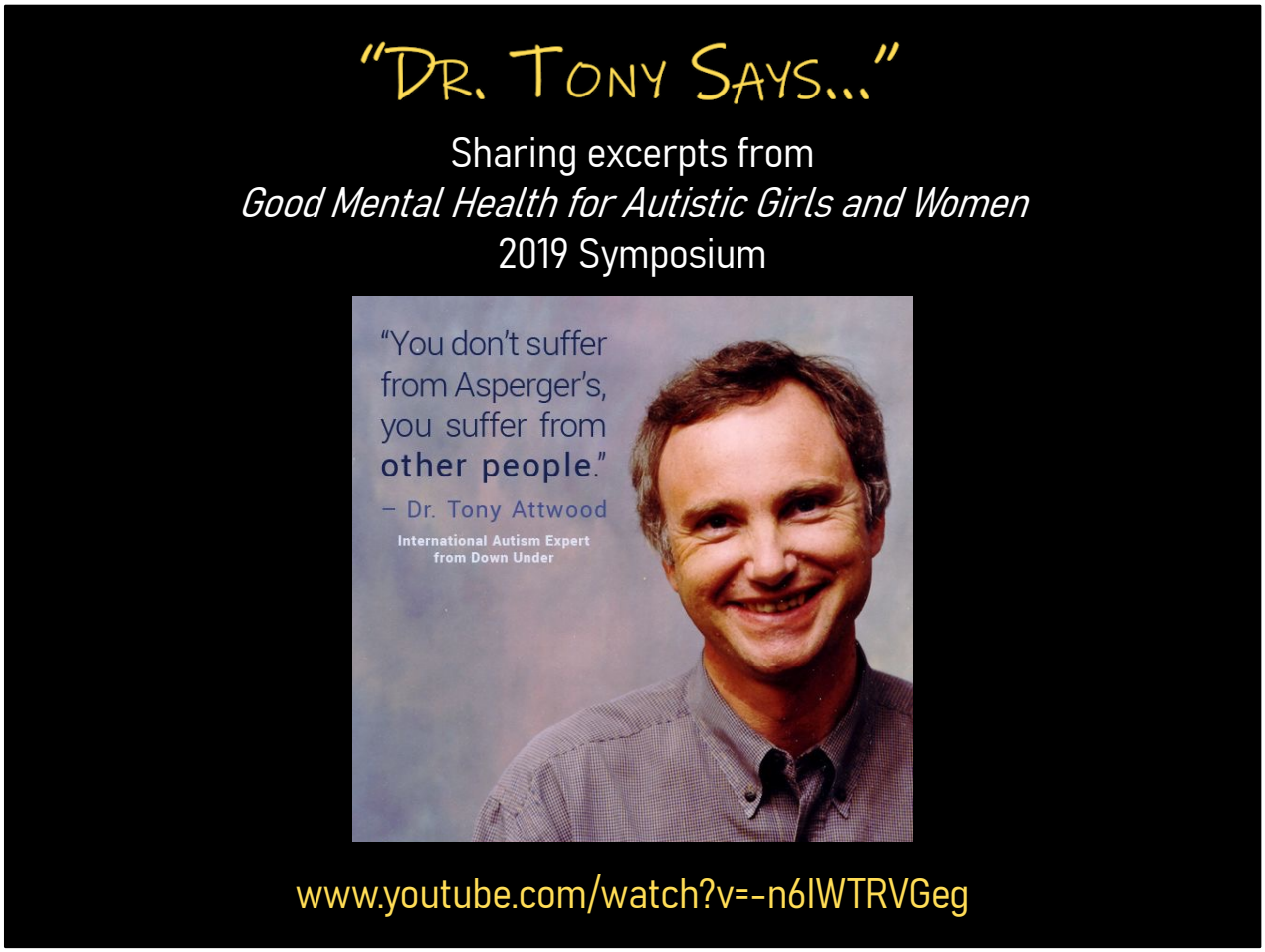
Therapist: "What are you feeling right now?"
Me: "I don't know, you tell me!"

- I didn't know how to identify my feelings—but I didn't disagree that feelings were present
- I trusted this external person to know my emotions better than I did. I had zero trust in my own experiences
- **The way I expressed emotions led others to assume I didn't have them, and I internalized this message**

I feel things incredibly profoundly even if I don't outwardly display that the same way



[Video Transcript] There is so much to say about autistic emotions. People have long misunderstood the autistic emotional experience. Ever since I was a kid, everyone always thought I was cold and distant and not in touch with my emotions, and that was extremely confusing to me because from my perspective, I felt things very deeply. And so this idea that I was not in touch with my emotions made me question, "well, what is it that I AM feeling?" I want to call attention to something that happened in my life multiple times. My therapist would ask me, "what are you feeling right now?" And my honest answer to her was, "I don't know, you tell me!" That happened on multiple occasions. And I think what's really interesting about this is two things. First, is that I didn't know how to identify my feelings, but I didn't disagree that feelings were present. I knew I was feeling something. I just couldn't put a name to it. Additionally, I think it's interesting that I trusted this external person to know my emotions better than I did. I had zero trust in my own experiences because of a lot of these conflicting messages that I received throughout my life. And I just I thought this person knew me better than I did. The main point to take away here is that just because an autistic person doesn't outwardly express emotions the way that you expect, it doesn't mean that those emotions aren't present. And while a lot of people seem to think that autistic people don't have empathy, we have an abundance - just in our own language, so to speak. There's something called the "double empathy problem," which if you boil it down, it's pretty much that focusing on this perceived lack of autistic empathy, while not having empathy for the autistic person, is a bit of a double standard. So just try to remember that what you see, and the behavior that you're witnessing, is not remotely an indicator of what is going on internally for the autistic person.



[Video Transcript] In addition to the videos from my family, I will be sharing excerpts from a presentation given by Professor Tony Attwood in 2019. I saw it on YouTube a while back and loved it so much that I made my entire family watch it. It was incredibly validating and I will be sharing a few relevant clips throughout this presentation.

Good Mental Health for Autistic Girls and Women (2019) | https://youtu.be/-n6IWTRVGeg

VIDEO CLIP: Dr. Tony Attwood

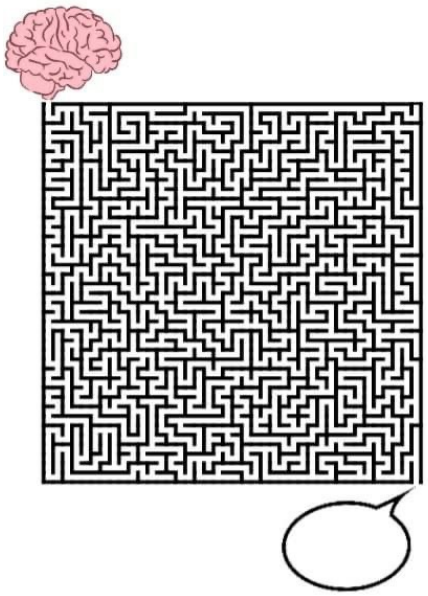
[Video Transcript] But there's another dimension and that is emotional sensitivity. There is a terrible error in understanding autism to say a lack of empathy, which is a huge insult to some of the kindest people I know. There is great caring, but I think there is a difference here that needs to be recognized, and this is being overly-sensitive to another person's negative mood - infected by it. And it's almost as though somebody is in a negative mood, an equivalent level of a cold, but the person with autism gets infected by it, but they don't get a cold, they get the flu. I'm really angry, sad, anxious. Where did this come from? What in my life has happened that will justify this emotional reaction? No, nothing's happened. You've just been with someone that is having that feeling. So it's not just simply the emotions within you, it's emotions within other people, too. And especially sensitive to negative moods of disappointment, anxiety, or agitation. And that person picks it up and it really does disrupt their day. As clinicians, we have to work on the positive emotions in autism as well: happiness. And there can be in autism a difficulty resonating with the happiness of others. It's almost as though in terms of intensity and types of emotions, if a person has negative emotions, really disliking that in other people because you pick it up, don't know how to respond, and so on. But also feeling uncomfortable with positive emotions and not knowing how to resonate with the euphoria of other people. The tragedy is, in autism, you can be infected by negative mood, but not infected by being jollied up. And "come on, yeah, look, come on, borrow my energy, yeah." No, it doesn't work. It's almost like a one-way system. The negative emotions, yeah, you get those, but not necessarily infected by the positive emotions. Neurotypicals need to realize that. Works for them, but not necessarily autism.

[Video Transcript] This graphic just really resonated with me, especially any time somebody asks you what you're feeling or what you're thinking. It's basically like, "what am I supposed to do with that question? I have just [noises] inside and you want me to put words to it?" And that's just not going to happen.

VIDEO CLIP: April Millis (Carly's Sister)

[Video Transcript] Emotionally, she doesn't get the same messages that I do. I know what anger and sadness and frustration feels like. My brain very, very straightforward says "this is the emotion you're feeling, here it is, on a silver platter." And I don't think that's how it works for Carly and works for people with autism. I think the actual neural pathways or whatever it is in the brain that tells you, here's an emotion, here's what to do with it, that's not there. And then it builds because there's so many different emotions happening at the same time. And then there's all these sensory things happening at the same time. And then this leads to meltdowns. And then it's like, "why are your...you know, you're either hot or cold emotionally." And it's like, no, the emotions are there all the time. The presentation of them and the ability to talk about them is not something that she had the skills to do it. She's learning that now, and that didn't come naturally to her. It's something that came very naturally to me. And so I'm really glad to know now and see, it makes me see her authentically and kind of how I can form a better relationship with her as a sister, how I can communicate better with her, how I can work on what her social battery needs. And I know now she's very emotional person and just doesn't know necessarily how to talk or how to do anything with it, and that's OK. And I hope that other people can understand that about people with autism, that they don't lack any emotions.

Autism, Emotions, Trauma, and PTSD: The Great Misunderstanding



- Professionals often confuse autism with PTSD: **for good reason!**
  - Arguably, all autistic people have trauma. **It is traumatic being autistic in a neurotypical world**
    - You can have PTSD and not be autistic, but you basically can't be autistic and not have PTSD
  - **The autistic relationship to, and expression of, emotions can look like dissociation, repressed trauma, etc.**
- SO MANY women in my support groups shared the EXACT same experience!
  - "You have repressed trauma"—no, I'm just autistic and "bad" at expressing emotions...
- **Treating trauma doesn't treat autism!**
  - Clutter in my house bothers me. Therapist says it's due to trauma from my perfectionist mom
  - BUT: Clutter bothers me because it's visually intrusive. No matter how much I deal with my trauma, I will still be bothered by clutter

[Video Transcript] So I wanted to call special attention to this particular issue, which ties directly into the misunderstood expression of emotions. Because of the aforementioned exchanges I had with my counselor, plus so many other things, she believed that I had severe repressed trauma, and that was why I had trouble getting in touch with my emotions or defining them. And the problem is that wasn't the problem. And this gets complicated because I DO have trauma. Essentially all autistic people have trauma, from just existing in a world that is not built for them. But there is a difference between the trauma that comes from being autistic and the way professionals see and treat trauma. This is such a common issue that gets regularly discussed in a lot of my female autism support groups, because this is a pretty universal experience for us where this confusion on how we communicate our emotions is attributed to this massive repressed trauma that just really isn't the case. And then we go and we try to find the trauma, and it's not there, and then we're even more confused than we were to begin with. I do really appreciate the weight that therapists give to trauma, but it can be argued that not properly addressing autistic trauma leads to even more trauma. So it's crucial that providers recognize these overlaps, not just for autistic people, but for people of other types of diagnoses as well.

[Video Transcript] So self-regulation is the one area where I truly feel that I missed out by not having a diagnosis early.

Because my emotions weren't understood, I was never taught how to self-regulate.
The things that overwhelm, bother, and trigger me the most are the things that were taken least seriously.

"That's not a big deal, what are you so worried about?"

"Your bookshelf looks fine already, stop messing with it"

"Don't be so mean to your sister, she just wants to play with you!"

"There's nothing wrong with your stomach, stop complaining"

I (SUBCONSCIOUSLY) LEARNED:

- Not to trust my own experiences
- To turn to other people to find out if something is "okay" or not
- **To suppress my wants and needs, especially those seen as silly or bothersome**
- That it's not okay to say "no" if other people think you should say "yes"
- To ignore my body's signals (because I thought mine were faulty)

AND NOW . . .

- I am often unable to recognize or articulate what I am feeling (physically AND mentally)
- I get overwhelmed all of a sudden **because I either don't receive, or have since learned to block out, the early signs of distress**
- I can't tell when I'm feeling anything unless it's extreme. I often have to use "external" cues instead:
  - For instance, if I notice that I am taking a long time to reply to text messages, it means I am overwhelmed

All leading to MELTDOWNS!

[Video Transcript] So I struggle immensely with self-regulation. My emotions and experiences were so misunderstood growing up that not only was I never given the skills to manage myself, but I learned to distrust my own feelings. And at this point in my life, I feel like my body and my brain lack communication skills with one another. Whether this is because the emotional and the physical signs are just not present for me in the first place due to autism, or because I have since learned to block them out because I thought they were wrong or faulty (and I was like, "these signals are not helping me"), the end result is that I do not know how to listen to or trust my own body. I am just completely...I am pretty much the last to know when something's going on with me. So because I haven't been able to trust these internal cues, I've started to turn to external cues to give me an idea of what's going on. For instance, if I notice that I am not responding to text messages right away, that usually means I'm overwhelmed. A normal person would just be able to tell that they're overwhelmed. But I have to look at my external behaviors to be able to know what's going on internally.

VIDEO CLIP: Ethan Jalowiec (Carly's Husband)

[Video Transcript] When Carly gets overwhelmed with something, she has a tendency to shut down and not be able to talk. It's just something that I've had to adjust to. Like we could just be having a regular conversation. Something could trigger her and she just shuts down. Or she might be like wanting to say something to me, but not exactly sure the best way to do it. She really struggles to get those words out at times. So I do have to be very patient when that happens. And it's just kind of a, "OK, take your time, don't worry, everything's OK." And I just kind of have to like give her her space, give her her time to be able to organize her thoughts. Sometimes, and it doesn't happen too often, but, she'll have like a meltdown. She'll actually physically twitch and have a physical reaction. It's definitely difficult to see someone having a reaction like that. And I've gotten a little bit more used to it. But also, I didn't know what to do the first time that happened, and just kind of had to learn the best thing to do in those situations. She likes to be held. So when she is having that sort of outburst or meltdown or reaction, the best thing I can do is just hug her, hold her tightly, and just kind of let it pass. And that's really, it's really, you know...once I learned that, it's really made it a lot better for us when that does happen. Another thing that we kind of did more recently is we got her a weighted blanket. Whenever she feels like she's losing control or is having a meltdown, she just says, "hey, can you get my blanket for me?" And so I'll grab her weighted blanket and she'll lay down and I'll put it on top of her. And that usually works pretty well. She does like that weighted blanket. There's even been times where she's asked me to lay on top of her just for a little bit more weight. I think that's something that's really, really helped her.

VIDEO CLIP: Dr. Tony Attwood

[Video Transcript] The world of emotions is hell for those with autism. That is emotions within you and in other people. We've had descriptions of the power of the emotions within you, but it's also in other people, too. And the problem can be within the person is the strength of those emotions. So this is a quote: "If something happens to make me happy or upset, then I quickly become extremely happy or upset. I don't have many intermediate states, and I find it almost impossible to moderate my internal emotional response." Whereas neurotypicals will have "1, 2, 3, 4, 5, 6, 7, 8, 9, 10," here's "1, 2, 3 - 8, 9, 10." And it seems that anything that should have been 4/5/6 comes out as that intensity. And throughout that person's day or life, they are experiencing very intense emotions, which is absolutely exhausting.

THEN AND NOW...

- I believed that everyone else "knew better" than I did about my own experiences
  - From emotions, to physical sensations, to preferences, to behaviors
- **The ways I DID try to self-regulate were often seen as "picky" or "neurotic"**
  - Sorting things a certain way, engaging in repetitive behaviors, removing myself from overwhelming situations, and so on

- I am finally learning to focus on my body and its feelings!
- **I often don't realize WHEN I need something, let alone WHAT I need, and even less how to ASK for it**
  - Don't expect someone to ask for what they want without first ensuring they're able to KNOW what they want!
- Needing things to be "a certain way" is how I (and many autistic people) keep from feeling overwhelmed

[Video Transcript] So this is basically a follow up on the previous comments. But the lack of trust in my own body led me to think that other people knew what I felt and what I needed better than I did, just like in the example with my therapist. And on that note, I do want to gently mention that this can often lead autistic people to being taken advantage of because they are so focused on external validation. But now that I have a better idea of what's going on, I've been able to manage things a little better. An important point to make here is that the way many autistic people, myself included, are able to manage their feelings is by engaging in behaviors that others might see as neurotic, annoying, or silly, such as putting things in order a certain way of, of course, stimming behaviors. It's important to not just look at the behavior, but what purpose the behavior is serving. For example, when I was a kid, I sometimes engaged in self-injurious behavior. I hit myself on the head really hard and if someone saw me doing it, the focus would be on stopping me, not finding out what led me to do that in the first place. I was simply overwhelmed, and I didn't know how to manage those feelings. And if I had been given self-regulation tools, that behavior might have stopped entirely. So as is the theme throughout this, keep in mind that what you see is often a reflection of something much more nuanced than the behavior itself would indicate.

SENSORY ISSUES

A hard things for nonautistic people to understand!

- Sensory issues are NOT being "picky," "prissy," "difficult," etc.
- When teased about "not liking getting my hands dirty," **I internalized the message that my experiences/sensations were a character flaw**
- Recognize the unique nature of sensory issues: if you're told "I don't like taking a shower"...
  - "They must dislike being wet" (Struggle to find hygiene solutions that don't involve getting wet)
  - **"I don't hate being wet, I hate drying off my body" (Buy an absorbent bathrobe, and showers are no longer a problem)**

My Sensory "Hacks"

- Remote-controlled lights
- Buying multiple pairs of the same comfortable shoes/clothes
- Handheld showerhead
- Getting an app-controlled thermostat
- Frequently changing the bedsheets

How Nonautistic People Often See Sensory Issues

How Autistic People Feel About and Experience Sensory Issues

[Video Transcript] Sensory issues are one of those things that I think is hardest for nonautistic people to understand. And one point I like to make is that there is a broad expanse of sensations and experiences that exist that nonautistic people may never consider or know about, because they've never felt them. In other words, if you see me struggle to shower, you might think I just hate being wet, when really I hate drying off my wet body. And if you spend all of this time trying to find solutions to keep me from being wet, you're not actually solving the problem at hand. As you can see by my graphics there, there is a disconnect between the way many people think of sensory issues and the way autistic people feel about sensory issues. Because the neurotypical experiences of physical sensations are largely universal, things are generally understood to feel a certain way. So if neurotypical people think of a sunburn as a level two amount of pain, while an autistic person experiences it at a level eight, a neurotypical person may see the autistic person's response as an overreaction. And then the autistic person subconsciously recalibrates their pain scale to believe an eight is actually a two. This is how you end up with autistic people who can't accurately describe their pain, for instance. In general, the most helpful thing you can do is just trust what someone is telling you about their feelings, experiences, pain, etc., even if it doesn't make sense to you. Believe them when they tell you about things that hurt them or make them uncomfortable, especially if it's a recurring complaint. Again, just because you can't relate doesn't mean the sensations aren't there.

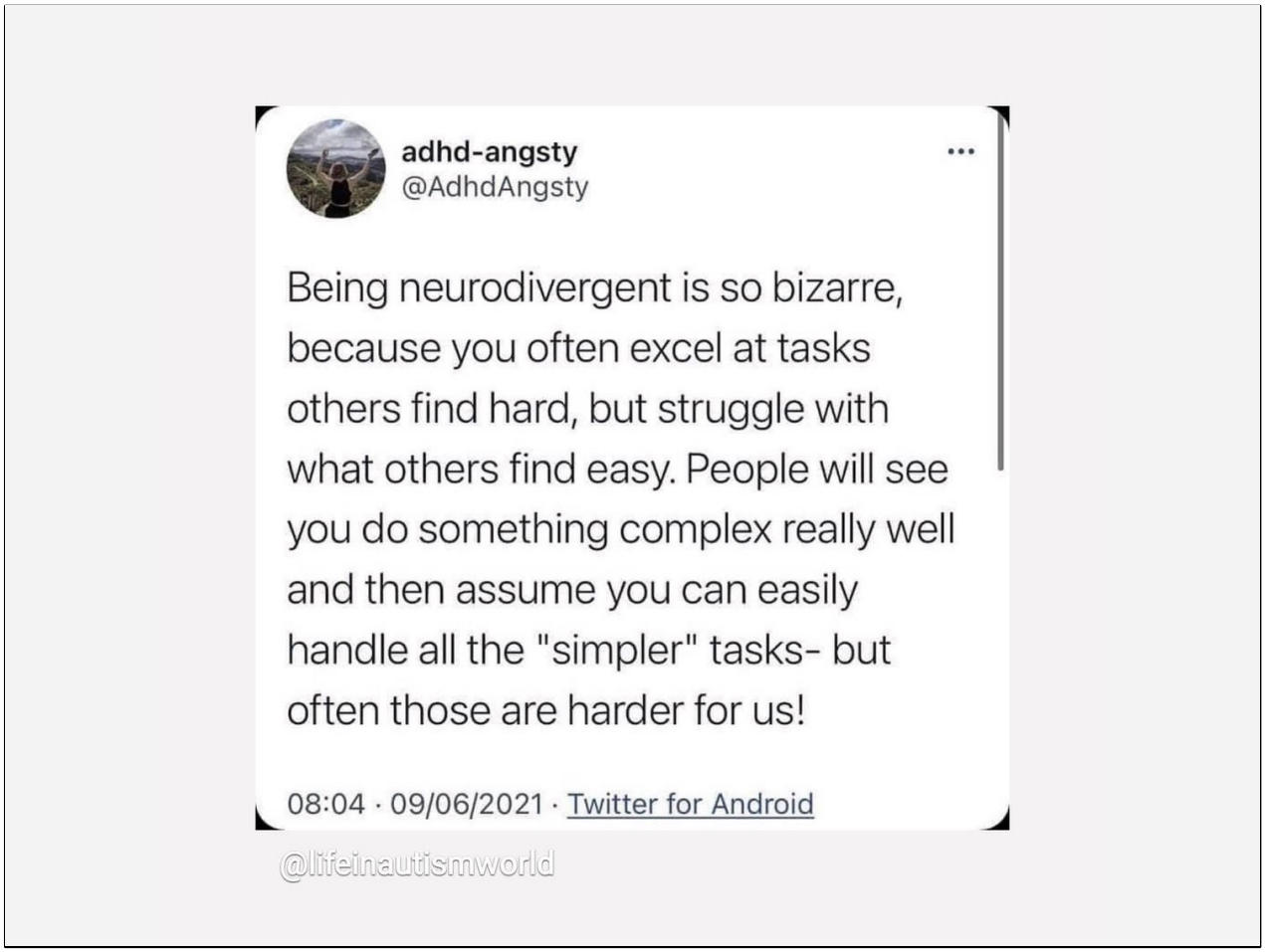
[Video Transcript] This is just another post that resonated with me a great deal when I first came across it. It says, "Overstimulation / sensory overload really is like sorry I can't hear you over the sound of my shirt tag being itchy and these two strands of hair touching my face and the TV and one of my shoelaces being undone and air touching me and the plane flying overhead and my own thoughts about remembering to buy hummus." Or in other words, "I can't talk I have socks on."

VIDEO CLIP: Marc Millis (Carly's Dad)

[Video Transcript] One that I remember that I did not grasp because it didn't happen to me (much of her other behaviors were similar to me, so it was like, "oh, she's perfectly normal, just like me!"). But tags in the back of her shirts or blouses or whatever. And I couldn't figure that out because I would check them out and there was [jumbled words]. I vaguely remember, I might be remembering wrong, that I would cut one off and it still bothered her because of what was left there. And that was one that, OK, I don't understand this is. It's like, oh, OK, now it makes sense.

VIDEO CLIP: Ethan Jalowiec (Carly's Husband)

[Video Transcript] She has a lot of these sensory type issues. The lines on socks are something that bothers her. I have never thought about the lines of socks in my life. The first time I thought it was kind of surprising to me, just like out of nowhere like, "oh, I hate these socks!" And I was like, "OK, I've never seen that reaction before, but that's cool." I think clothes in general, like fabrics, when they rub on her, they get aggravating to her and she gets frustrated by those types of things.



[Video Transcript] This post leads into the next section, which I like to call "the easy and hard things." It says, "Being neurodivergent is so bizarre, because you often excel at tasks others find hard, but struggle with what others find easy. People will see you do something complex really well and then assume you can easily handle all the 'simpler' tasks-but often those are harder for us!"

THEN AND NOW...

- I did not understand how everyone was coping with daily life so effortlessly
  - A LOT of shame from struggling with "easy" things
- **As a kid, everyone praised me for things that just came naturally, but scolded me for not excelling at "simple" things**
  - EXTREMELY CONFUSING!
  - "Wow you are amazing at brushing your teeth, have you ever thought about doing that for a living?"
  - "I don't understand why you can't finish your advanced physics homework: just DO IT, there's nothing you should need help with!"

- **It's not that everyone is coping with life better than I am, it's that I'm dealing with things that other people AREN'T**
  - "Wow how can they tolerate that, and why can't I?" = They aren't "tolerating" anything
  - Sensory issues!!!
- Realizing just how many of the things that bother me simply don't bother other people
- Giving myself permission to ask for help with "little" things
  - **Just because something is "a lot" for me doesn't mean I'm burdening someone else by asking for help with it—they might see it as no big deal!**

[Video Transcript] As I became an adult and started comparing my progress to others, I could not understand how I was unable to manage the basics of adulthood (or really personhood). There was a lot of shame and frustration and confusion. And this is compounded by the fact that a lot of complicated things came naturally to me. When I was a kid, I was always highly praised for things that were frankly just second nature to me, and the expectation was that everything should come easy. Yet I had difficulty completing even the most basic responsibilities, and this puzzled everyone, including me. So imagine someone telling you, "you are so amazing at brushing your teeth, have you ever thought about doing that for a living?" But then also saying, "I don't know why you need help with your advanced physics homework, it's literally the easiest thing. Just do it." So you can understand why I wasn't sure what the heck was going on with me. Now I recognize that the things I thought everyone was tolerating better than I was are, in fact, things that most people aren't even aware of. I have a different set of sensitivities and vulnerabilities that don't match with the way the world is designed. Besides my own confusion, there can often be confusion from others, not just because I handle the complex things really well while I struggle with the most basic tasks. But because some days I can handle an activity that I can't handle on other days. A lot of times I subconsciously try to make it look like it comes easier to me than it does for the sake of wanting to look normal when in reality many things are incredibly challenging to me.

VIDEO CLIP: Ethan Jalowiec (Carly's Husband)

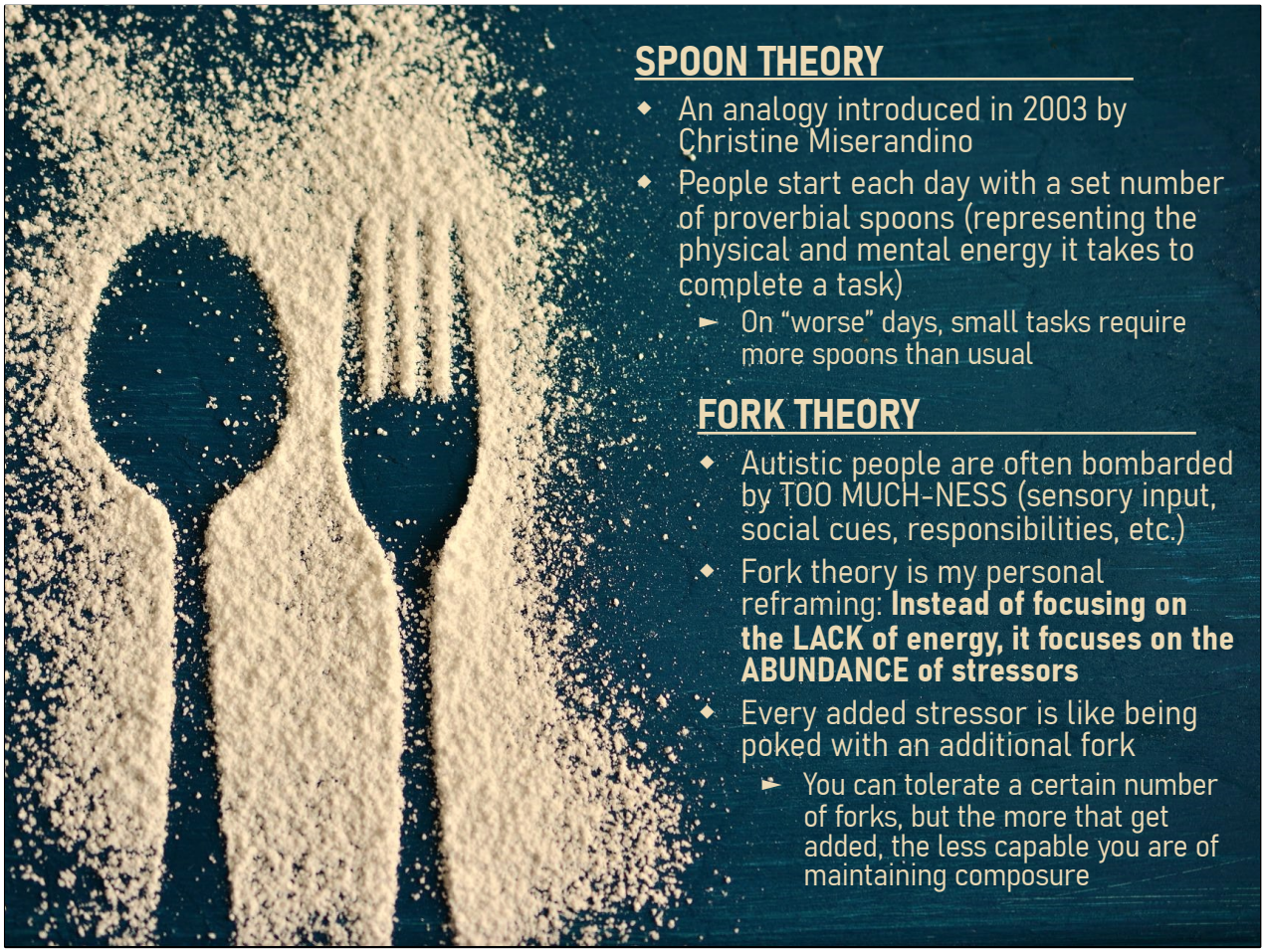
[Video Transcript] So one of the things that I've kind of had to get used to, I guess, is when I want to talk to her. If she's doing something, I can't just blurt out what I want to say. I kind of have to prepare her. She might be sitting on the couch reading something, and I can't just say, "hey, we're going to have dinner at my parents' this weekend." That would that would throw her off. She kind of has to be done with what she was doing before to be able to switch gears or switch her mind to a different topic. The way we've gotten past that is whenever I want to say something to her, if we're not already talking, I'll say, "hey, just let me know when you have a sec." And it kind of allows her to finish what she's doing and then she'll let me know, "OK, I'm ready for whatever you want to say." And then I'll be like, "OK, we're going to have dinner with my parents on Saturday." And it's never just like, "OK." It's more like, "OK, what time is that going to be?" She wants all the specifics, so it's never just a simple yes or no answer. There's definitely a lot of working things out and specifics.

VIDEO CLIP: Marc Millis (Carly's Dad)

[Video Transcript] I remember that a lot of things came really easy for Carly, so if something was a little bit hard, she would give up on it right away. And so the things that she tended to focus in on, whatever...and I was trying to wrap my brain around, "well, should I force her to do something that's difficult so that she'll learn that thing about perseverance or whatever - or what?" And by now I've kind of forgotten how that all turned out.

VIDEO CLIP: Dr. Tony Attwood

[Video Transcript] Because you may have degree of agitation from zero to ten. Neurotypical in, should we say, trying to solve a problem, their level of agitation and thinking may be, "OK, I can't do it, I'll try another way. No, it doesn't work. I'll keep going. No, no, I'll be flexible. I'll be accommodating. I'll try another way. I'll get there eventually." Level five out of ten - solved it. Great. Autism: "I can't...GET IT!!!" And I go to number ten. And then the teacher says, "come on, have another go." "Are you mad woman? That nearly killed me!" So it means in your daily life, you have a minefield that you walk through of creating intense emotion.



[Video Transcript] Some of you may have heard of Spoon Theory before, which is an analogy to explain how chronic illness impacts the ability to perform daily tasks, where people start the day with a certain number of spoons and each task takes a certain number of spoons. So once you run out of spoons, you're done for the day. While I appreciate having a term like that for the feeling of being just wholly, entirely, spent, I think a more accurate representation, especially as it relates to autistic people, is what I like to call Fork Theory, which was inspired by a post in one of my support groups. The idea here being that every added task, sensation, or stressor is like being poked within an additional fork. And instead of focusing on not having enough energy or resources, essentially seeing the person as lacking, it focuses on having an abundance of stressors, which really mirrors the autistic experience of just "too much-ness." The more forks you have, the less capable you are of maintaining composure...until eventually, you run out of forks to give.

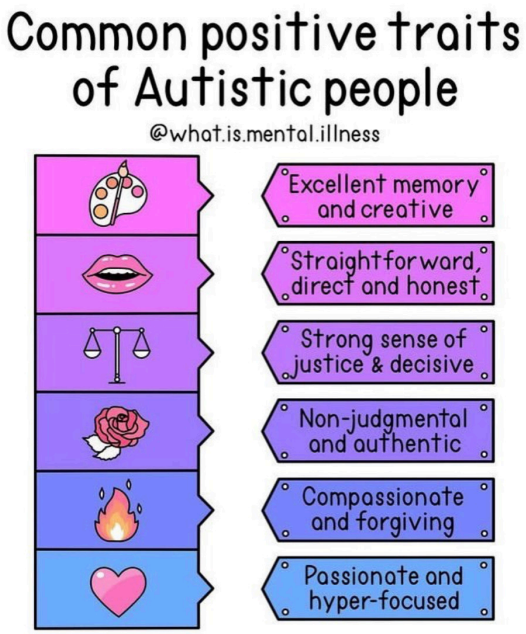
THE "HARD" THINGS ARE EASY

That which comes easiest to me is what others consider the hardest

- I LOVE complicated things!
  - Philosophy, taxes, analyzing human behavior
- **I would rather translate Latin poetry than bring groceries in from the car**
- Appreciating the different way my brain works, and learning to value things formerly seen as detriments

To me, neurotypical people do certain things "the hard way"

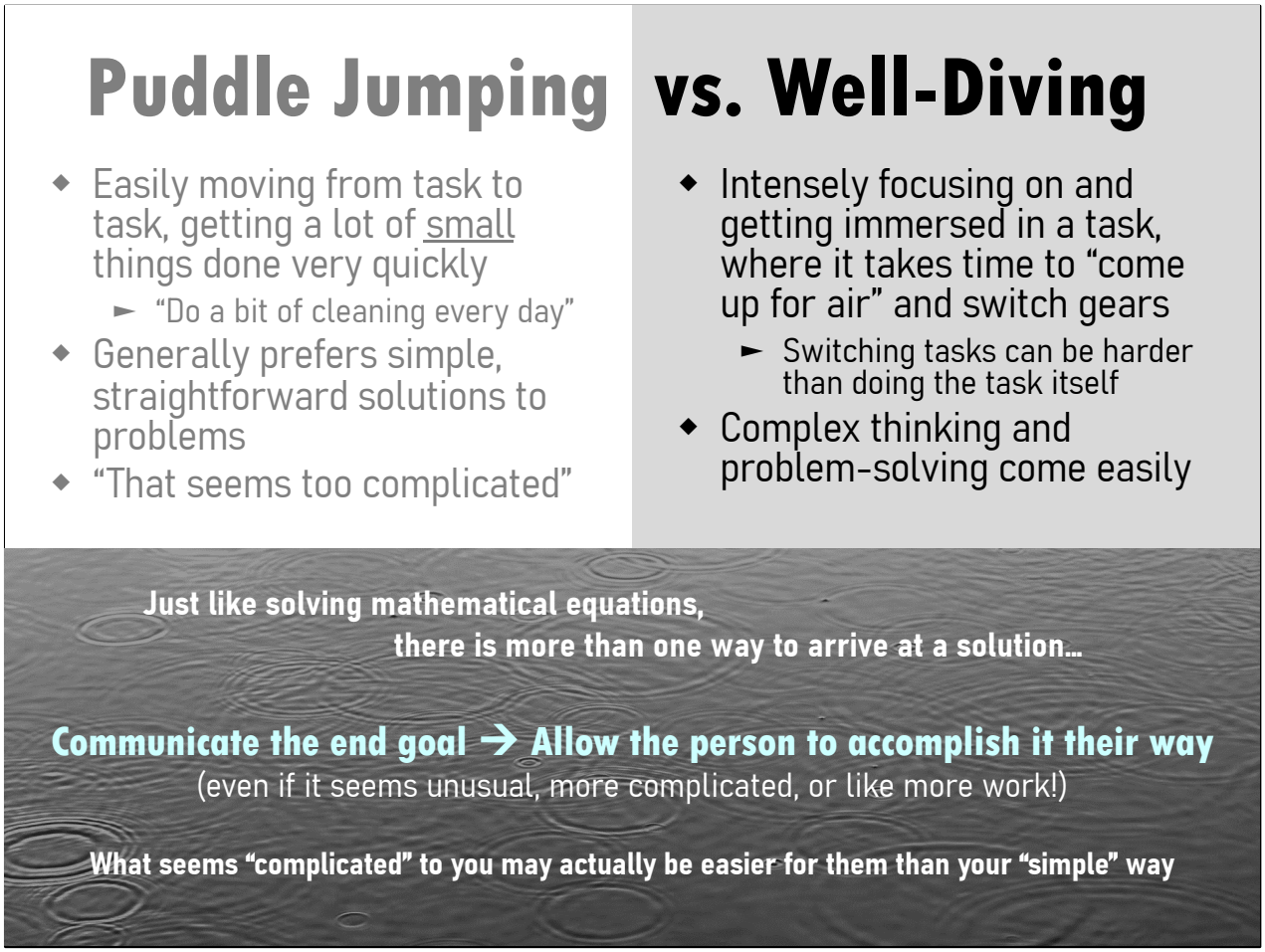
- Bringing emotions into EVERYTHING!
  - Factual information doesn't have an agenda
- Expecting people to read their minds
  - How is it easier to hint at what you want (or expect people to guess) than to just ASK?!



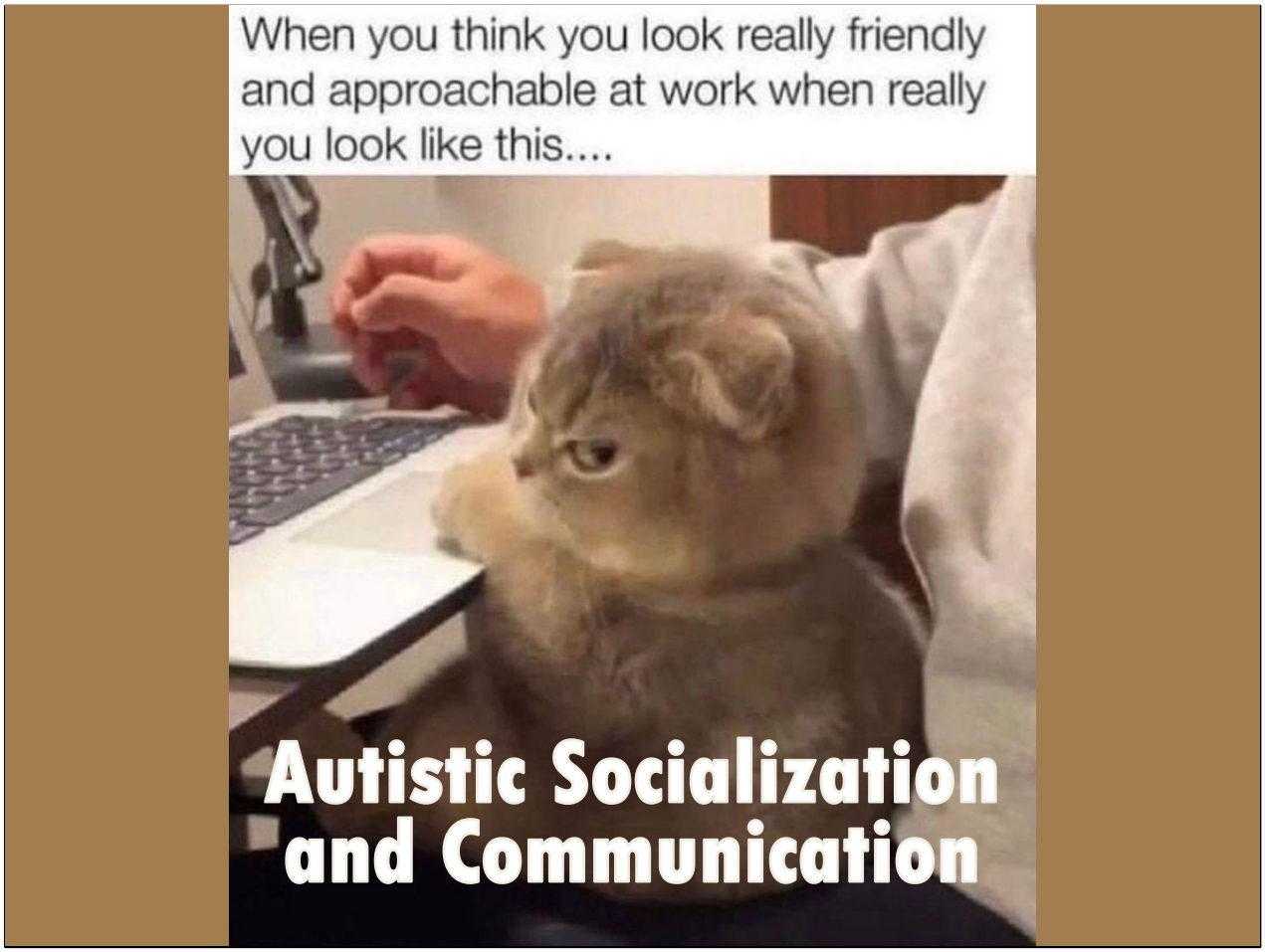
[Video Transcript] On the flip side of everything, I seem to excel at what others consider difficult tasks. I love complex, intricate, multi-level thinking. It's honestly more like breathing to me than breathing is. And I have really learned to value the ways that autism affects my thinking. The things that I love most about myself are from my autism. And as you can see from the graphic up there, there's a list of common positive traits of autistic people that are always fun to highlight. But also just for fun, I figured I'd mention the ways that I think neurotypical people complicate things. For instance, if someone invites you out and you don't feel like going, you lie and say, "I already have plans." And I don't understand how dishonesty is somehow kinder than honesty. I'm lucky to have friends that I can just be honest with and say, "I'm not feeling up to it." Frankly, sometimes I wonder how many autistic social conventions would actually be preferable to neurotypicals if it weren't for so much societal pressure. But I digress.

VIDEO CLIP: Ethan Jalowiec (Carly's Husband)

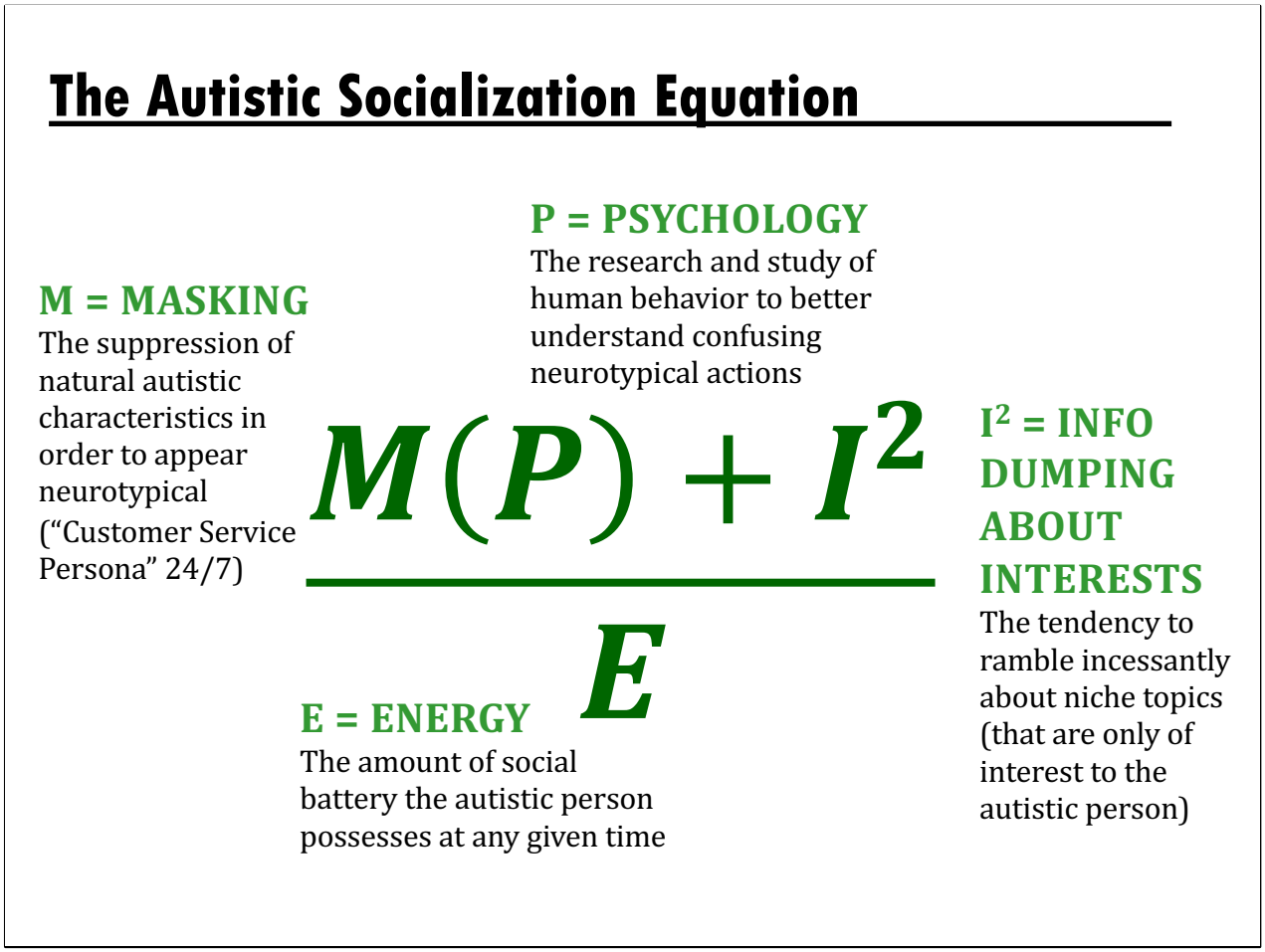
[Video Transcript] She's very, very organized and very planful in the way she operates. She creates spreadsheets for everything. She has a spreadsheet for all of the books in what we call our library. She has a spreadsheet that organizes all of these (fiction and nonfiction). The nonfiction books are organized by Dewey Decimal Number, the fiction ones are organized by author. And I just think that's really cute, and I appreciate something like that. When we went to Vegas last year, she created a spreadsheet for all of the restaurants that we were thinking of trying out, and kind of narrowing it down by location and cuisine and all of these different categories. I just think things like that, it really made it really nice and easy to plan a vacation. Planning a vacation can be stressful at times. And the way that she's organized has made it really nice and easy to do a lot of things



[Video Transcript] "Puddle jumping versus well-diving" is an analogy I came up with during a conversation with my mom. She was trying to help me get better about taking out the trash and suggested to just do a little bit every day. But that's not how my brain works. She would rather (and I think many people would rather) take one bag of trash out every day, which takes two minutes each time. While I would rather take it all out one time at the end of the week, even if it took longer than the individual days combined. In many ways, the duration of the task is inconsequential, it's having to start a new task in the first place. In the analogy, my mom has what I call a "puddle jumping brain." She can easily move from one task to another and get a lot of little things done very quickly. However, she struggles and has difficulty staying focused on one thing for a long period of time. My brain is a "well-diving brain." I focus so intensely on the task at hand that I can complete virtually anything in one sitting, even if it takes hours (and in fact, that's how I prefer to work). Yet because I dive so deeply into a task, it takes time for me to "come up for air" and switch to something else. So having this understanding of different thinking styles and the way that they translate into actions has allowed me to not only better structure my day, especially when it comes to my workday, but it has allowed my mom and I to better understand each other. And one takeaway here pretty much is to let people complete a task the way they prefer to. It might seem unconventional the way that they like to do it, but as long as it gets done, why does it matter how?



[Video Transcript] And now we move on to the topic of autistic socialization and communication, where you think you look really friendly and approachable when you actually look like that.



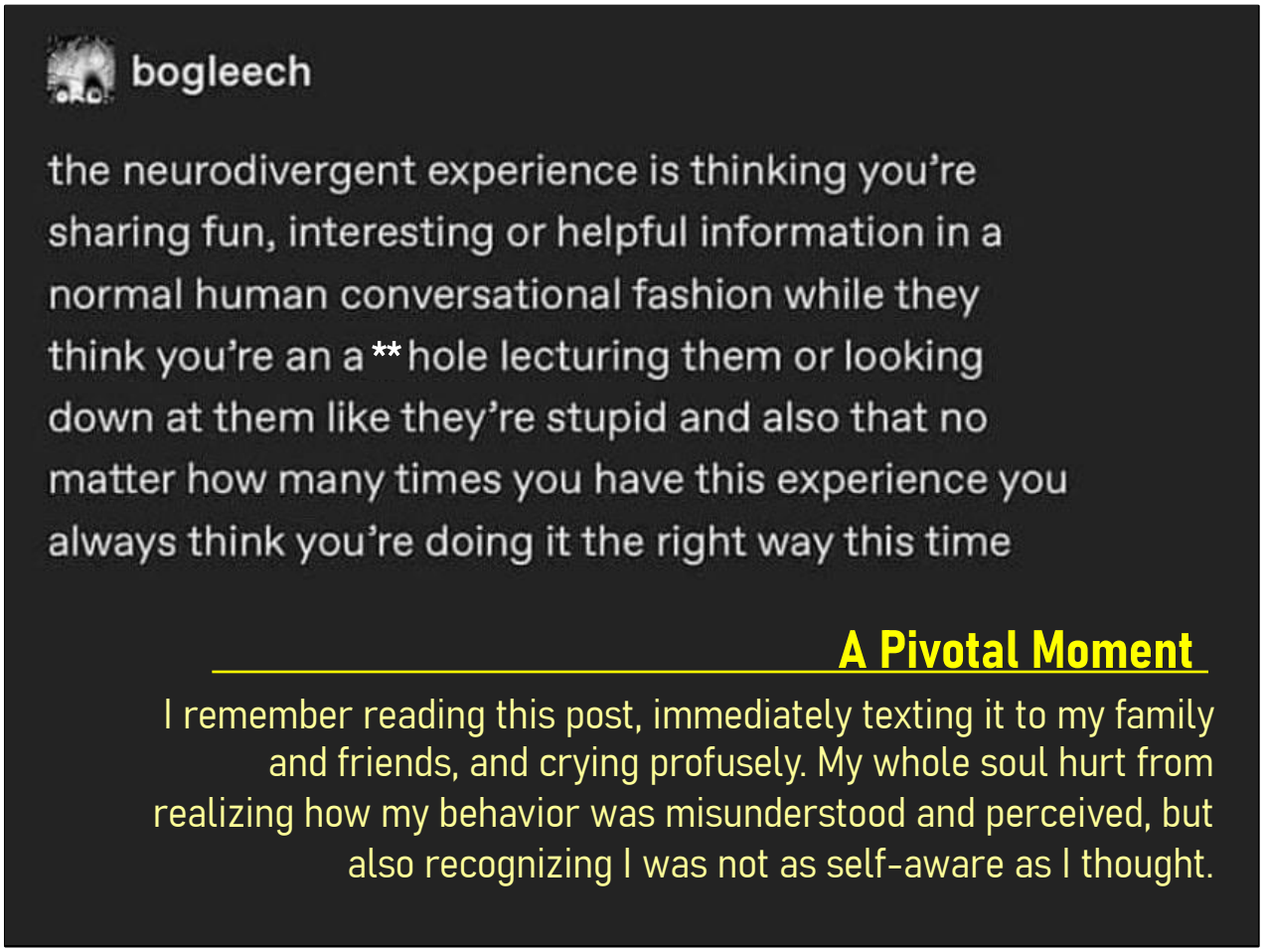
[Video Transcript] This is my tongue-in-cheek attempt at humor. Here, I have developed the "autistic socialization equation" where M stands for masking, or the conscious attempt to appear neurotypical by suppressing autistic traits. I like to call this "customer service persona on steroids." P stands for psychology, wherein the autistic person studies human behavior, and the more they learn about neurotypical social constructs, the better they can mask. I squared stands for info dumping about interests. This is where the autistic person attempts to share fun information, yet is often oblivious to the lack of interest from their audience. And finally, E stands for energy, or the cost of performing all the above actions.

VIDEO CLIP: Dr. Tony Attwood

[Video Transcript] Because one of the characteristics of autism in girls can be to observe, analyze, and imitate, to look for patterns, that they became a psychologist at three years old. And they discovered patterns and interactions that aren't in the psychology textbooks because they're written by neurotypicals. "I am able to distinguish very subtle cues that others would not see, or it might be a feeling I pick up from them." What neurotypicals do is they tend to use the visual and auditory. The visual is the facial expression and gesture. The auditory is the tone of voice. Now in autism, you have a different sensory profile, and I think this is in a six sense sensitivity. And it's able to pick up emotions in other people using channels that neurotypicals aren't aware of that are accurate, definitely accurate (trust your intuition there), but can be overpowering. It's a sixth sense. So you avoid some social situations due to being sensitive to negative vibes.

VIDEO CLIP: Marc Millis (Carly's Dad)

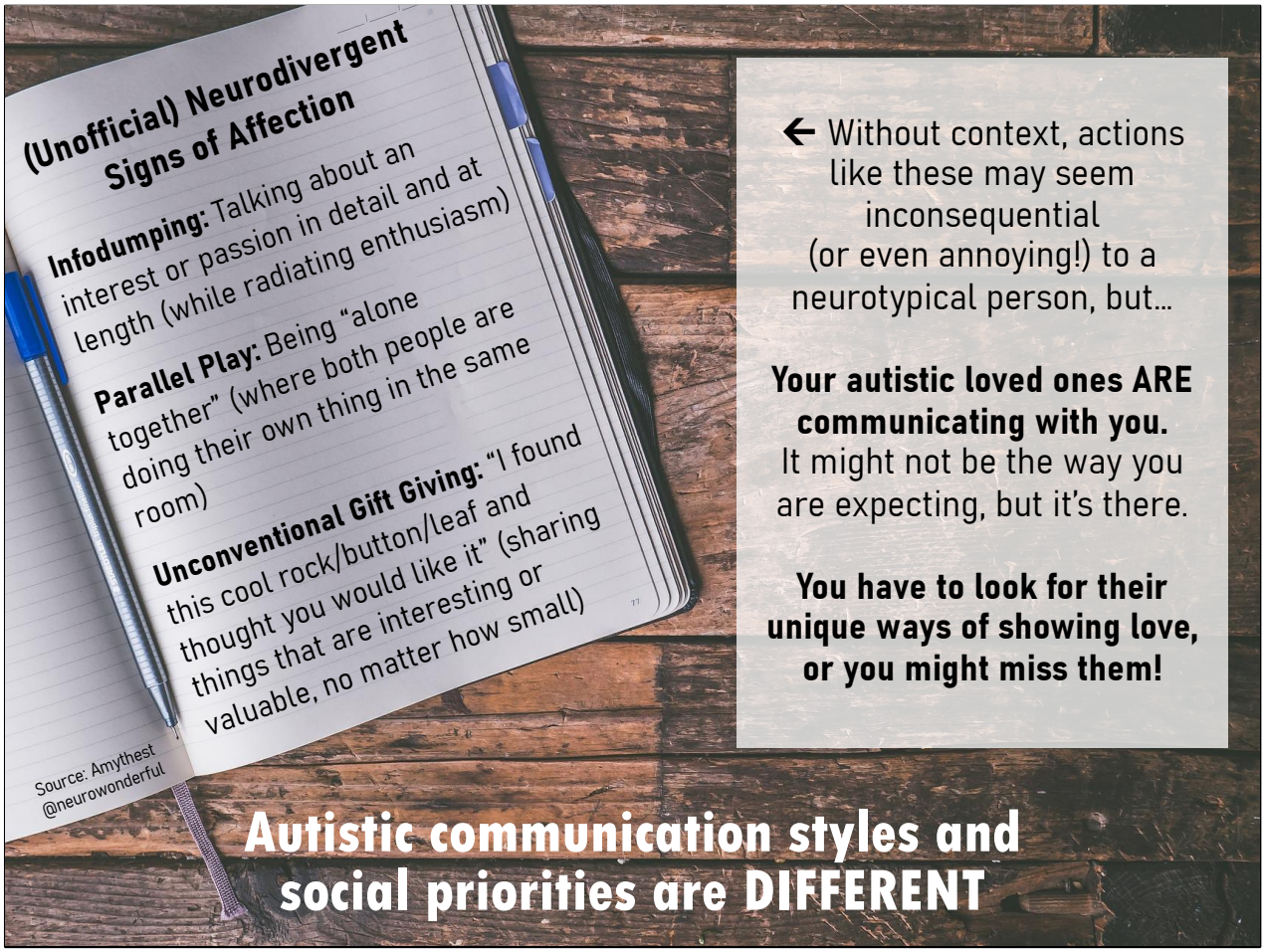
[Video Transcript] One of the things that was kind of maybe a little bit surprising in retrospect: in high school, Carly had a lot of friends, and they would come over frequently. And I mean, the socialization around them seemed very natural. Of course, in retrospect too, a lot of those people were very smart and attentive, in other words a very similar personality thing. So the socializing aspect, but with her friends (a decent group of people that matched with her). So when I think back, it's like, "well, she socialized just fine!" OK, but that was with a certain group of people.



[Video Transcript] I want to share a particularly pivotal moment for me. This post was particularly crushing and it jarringly shifted my perception. It says, "the neurodivergent experience is thinking you're sharing fun, interesting, or helpful information in a normal human conversational fashion while they think you're an a**hole lecturing them or looking down at them like they're stupid, and also that no matter how many times you have this experience, you always think you're doing it the right way this time." I remember crying upon first reading this and sending it to my friends and family, not only for context on my intentions in those past conversations, but to acknowledge that my words likely didn't have the impact I thought they did. I love sharing information, and I do it constantly. I knew in a general sense that I might look like a know-it-all, but I thought I was articulating things kindly. And this truly encapsulates a lot of the autistic experience. No matter how close you think you are to getting things right, you manage to still unknowingly rub people the wrong way. And I worry about it all the time. Another way this plays out is in people thinking I'm angry when I'm just really passionate. There have been so many instances where the response to my just normal talking has been, "there's no need to get angry!" And that throws me for a loop every time. And this happens with my husband and I as well. We love to debate and discuss (it's part of what makes our relationship great) and the amount of people that thought we were fighting is ridiculous.

VIDEO CLIP: April Millis (Carly's Sister)

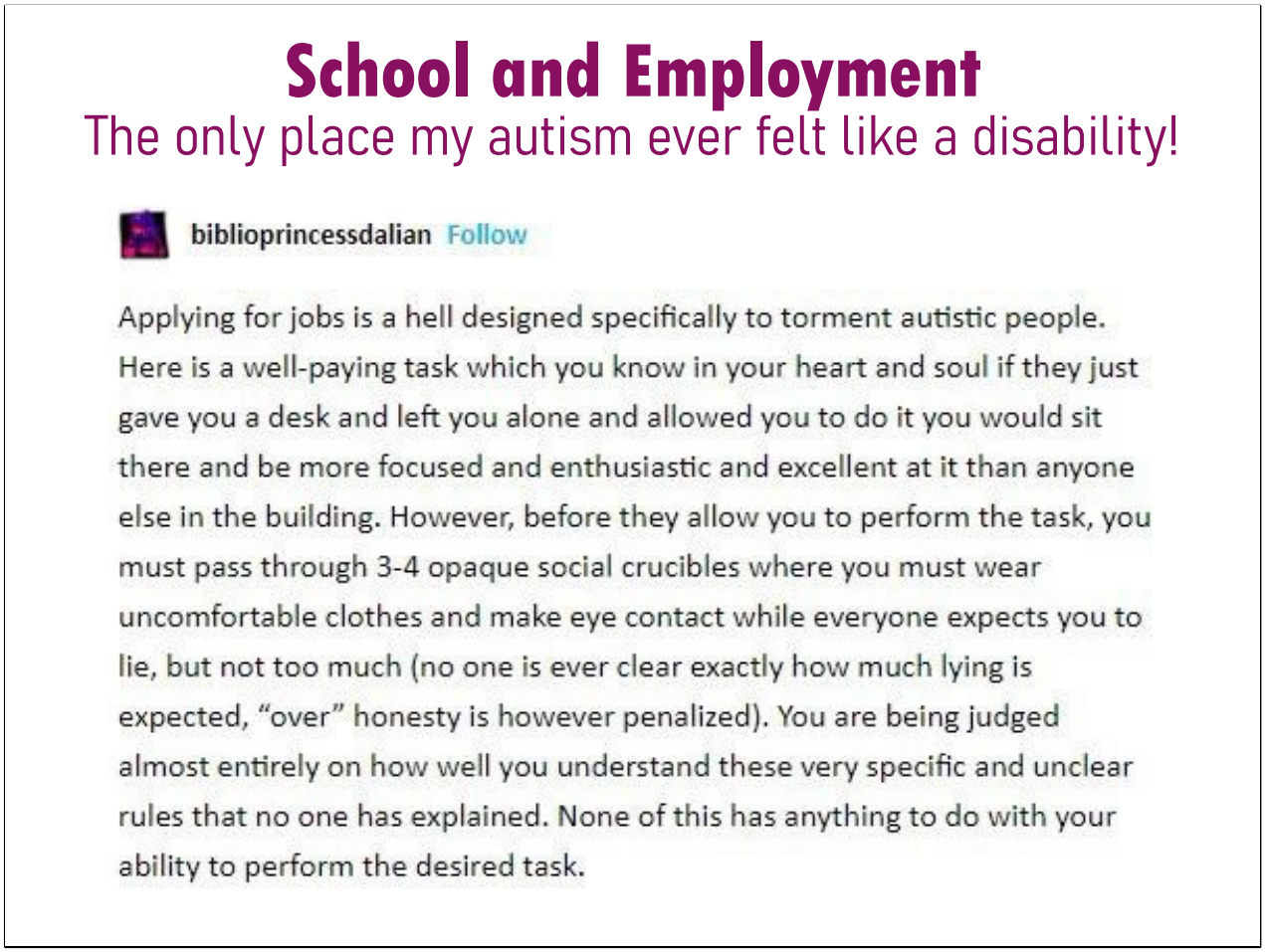
[Video Transcript] I used to think Carly was very emotionally detached. I struggled to feel like an emotional connection to her growing up and I used to just think she didn't have any feelings towards me and she was too intellectual to have feelings and she always had to be right. I thought the intellectualism was this sense of ego, like she knew so much, like she was trying to prove herself. And autism as a diagnosis, now knowing that she has it, tells me that none of that is true. That she doesn't say what she says and what she knows to sound better, or be better than anyone else. It's just...it's it, it's black and white, you are or you aren't. So knowing that kind of makes me feel better about her being right. Also coming to terms with the fact that she just knows a lot more about things than I do. And that's great because now I know how to learn from it, and not take it so personally.



[Video Transcript] If it isn't already painfully clear, autistic communication styles and social priorities are different. In the graphic, you see a list of neurodivergent signs of affection like infodumping and parallel play. You might have been on the receiving end of some of these behaviors and not thought anything of them, or might have even been annoyed by them. But it's important to recognize that these actions, as inconsequential as they may seem, can often carry meaning. One thing I like to explicitly call out is that your autistic loved ones may be expressing affection for you on such a different frequency than you're expecting that you're missing the signs entirely. So the more that you can be open to different forms of affection, the more you'll realize just how loving your autistic companion has been this whole time. On the flip side, using your ideas of social success to define that for autistic people may fall flat. For instance, at my wedding, my mom told me just how thrilled she was to see me having such fun dancing. And I was like, "Mom, I hate dancing. I did it because I knew that's what people expected to see. I would have preferred to just sit and eat and people watch." So I hope that this anecdote can remind you to remember to prioritize the preferences of the autistic person themselves over what you think that person should want to be doing.

VIDEO CLIP: Ethan Jalowiec (Carly's Husband)

[Video Transcript] A lot of our communication, we just really understand each other on a different level, I feel like. And that might be because we're both autistic. A lot of our communications are not verbal. And if someone sat in a room and watched us on an average evening, they might not think we liked each other that much even though we do. A lot of the time we just sit in silence and do our thing and that's not a bad thing. That's just how we are. The fact that we're just in the same room and sitting next to each other is enough for us.



[Video Transcript] When it comes to school and employment, these are the main places where my autism really feels like a disability. This post here encapsulates my feelings and experiences so well that I just had to include the whole thing. And it says, "applying for jobs is a hell designed specifically to torment autistic people. Here is a well-paying task, which you know in your heart and soul if they just gave you a desk and left you alone and allowed you to do it you would sit there and be more focused and enthusiastic and excellent at it than anyone else in the building. However, before they allow you to perform the task, you must pass through 3-4 opaque social crucibles where you must wear uncomfortable clothes and make eye contact while everyone expects you to lie, but not too much (no one is ever clear exactly how much lying is expected, "over" honesty however is penalized). You are being judged almost entirely on how well you understand these very specific and unclear rules that no one has ever explained. None of this has anything to do with your ability to perform the desired task."

THEN AND NOW...

- Excelled in school and LOVED IT (until high school)
- Attempted college 3x but unable to graduate
- **I was confused by the disconnect between my abilities and my intellect**
  - The "Grape Boycott" story
- Every job I had, I excelled at the work itself, but got burnt out and had to leave
  - Always cited "mental health issues"
- Employers loved me...until I struggled

- **A perfect example of "the easy things are hard"**
- School accommodations might have helped me graduate
  - Unsure what I would have asked for (especially without a diagnosis)
- Understanding my employment struggles allowed me to target better-fitting jobs
- **I have been able to thrive with basic accommodations!**
  - Late start/flexible hours
  - Working from home
  - Kindhearted organization ♥

[Video Transcript] So this directly ties back into the "easy versus hard" debate. I always excelled in school, up until the aforementioned high school explosion, and I was unable to graduate college after trying three separate times. One of my favorite encapsulations of the ways that my intellect and my abilities seem to conflict is what I like to call the "grape boycott story." In 10th grade, while in the throes of major depression, I was given an assignment to come up with a class simulation, and I chose the grape boycott of 1965. And I just threw something together. The next day the teacher pulled me aside and said my project was so good, I should submit it to a teaching magazine. Just that morning I had barely made it out of bed and refused to shower. So this was interesting and confusing news to say the least. Anyway, this obviously eventually translated to employment and I could spend an additional hour talking on this topic alone, but I will summarize by saying that autistic people are often excellent at the work a job entails, but they may not be as adept at handling the workplace culture. And until we are better able to redefine and offer accommodations, autistic people will continue to struggle in traditional settings.

VIDEO CLIP: Marc Millis (Carly's Dad)

[Video Transcript] Something that my parents did that I DID like, that I carried on, is my parents didn't try and force me to any particular occupation or way of life. They just kind of left it up to me. So when Carly exhibited the traits that I thought were normal, while the other ones were perplexing or whatever, and curious to see what she would evolve into, I wasn't trying to force her down any one path. Which I wonder in retrospect what that would have been like, if that would have been more revealing for whatever had happened. A lot of what might have been symptoms I might not have noticed, not only because I don't have them, but because we weren't really trying to force her into a certain career path or something like that that would be inconsistent. Another thing that makes sense in retrospect now is that when Carly started getting jobs, she would usually do well in the interview, get the job, she would work it, would do well, they would start to add more responsibilities on her, and then she would get overwhelmed with it and then have to quit. And that occurred a few times. And I'm thinking, "well, that's kind of a weird thing." But now, in retrospect, with the thing about being overwhelmed and wanting to keep like your narrow working pattern so that you can focus on that and do what you know you're good with. "Oh, OK, that makes total sense." So now that I'm glad she's at a much better fit for what those other jobs were. So that was definitely attributable to the autism sort of thing. And also one of those dual edged swords about it, where in many cases it's because of the focus and the intensity gives you a lot of capability, but that the other aspects of it, like the easily overwhelmed or not wanting to be interrupted comes in. And when she got the diagnosis and realized that where some of these things were coming from and that, "oh, OK, that all makes sense," that was like, "oh, OK, well, that's reassuring." That's now...now you know what it is that you're dealing with as opposed to, was there some other cause for that that needed some sort of other fixing thing or whatever. So that was another one that makes sense in retrospect.

[Video Transcript] And this brings us full circle to what was discussed in the typewriter computer metaphor at the beginning. This post says, "the autism late diagnosis grief cycle: Euphoria - now everything makes sense! The "wait a minute moment" - realizing how you've been mistreated your whole life. Rage - see number two. Identity crisis - if I'm not my mask, who am I? And repeat until acceptance."

[Video Transcript] I hope I have made it clear the degree to which well-meaning messages got internalized and converted into pain. I had no idea just how cruel I was being to myself and just how potent the pain of being misunderstood truly was until having the diagnosis. My autism diagnosis is the best thing to ever happen to me. I don't even know a succinct way to summarize the benefits of having this context. This slide just begins to cover the big ones, namely that I no longer see myself as broken, defective, or problematic. That I have given myself the space to exist that I had previously denied myself. That I am learning how to advocate for myself and my needs. That I am finally finding ways to communicate with my body. And that I can finally embrace all the things I used to hate about myself. In other words, I love being autistic.

VIDEO CLIP: April Millis (Carly's Sister)

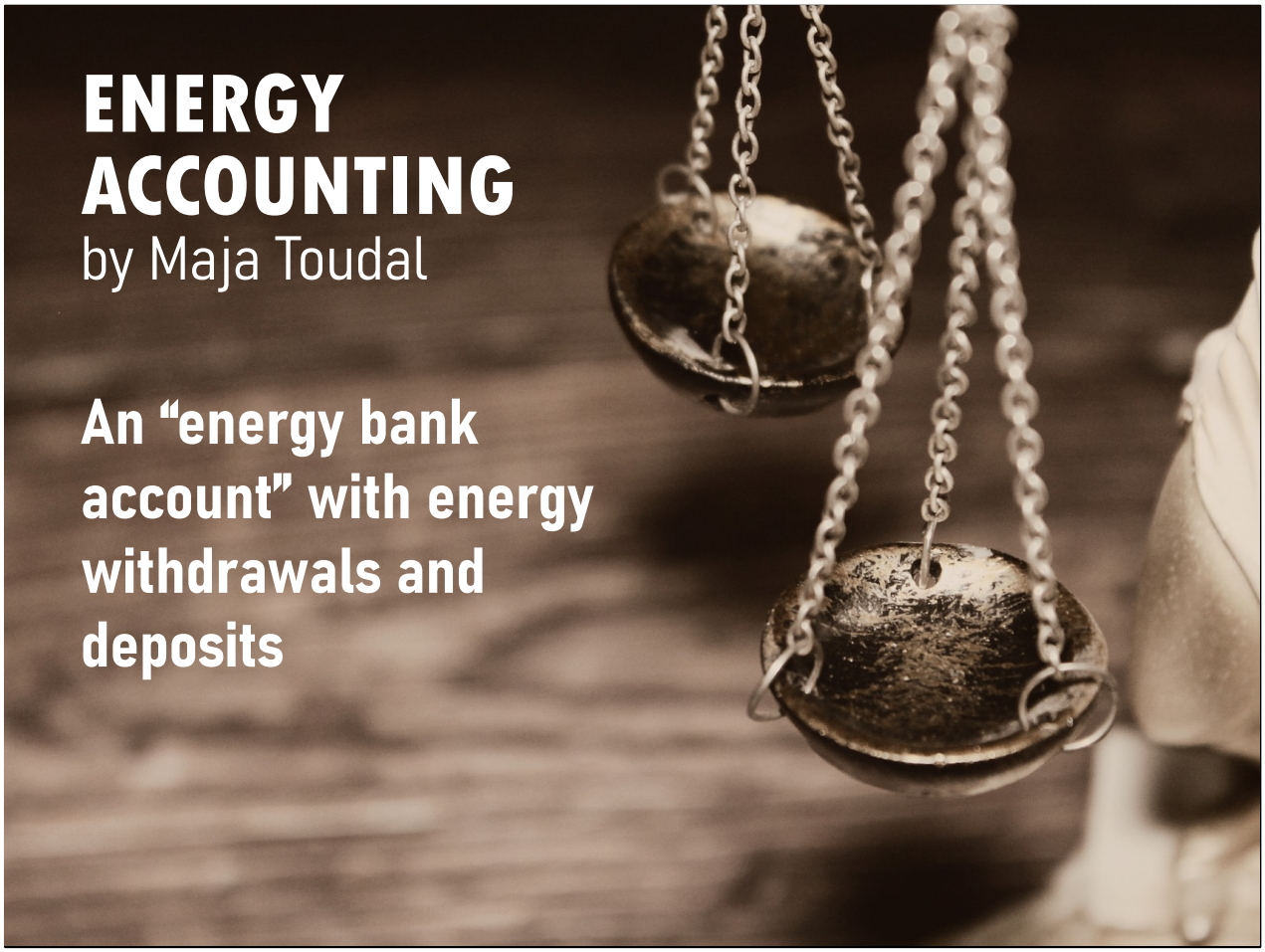
[Video Transcript] Here are some thoughts that I have about her journey and to her autism diagnosis versus who I knew growing up. On the whole I really see the authentic version of herself now from this diagnosis. I think this answered a lot of questions for her. I think this really gave her a place to stand and be proud of who she is instead of feeling like she doesn't belong or really to be ashamed that she doesn't belong. I really understand now just a lot of different brain functions and that there are not things that she lacks or is detached from or cannot provide. It's not this like lesser than experience being autistic. If anything, it's an overwhelming more-ness, right? She experiences sounds and lights and textures and feelings so much more intensely than I think a lot of people do, than neurotypical people do. And even as someone with ADHD, and who even had that diagnosis at a very young age, doesn't mean I necessarily understood what autism was when Carly came to us with the diagnosis, or really the search for the diagnosis, I think the search in and of itself was this liberating experience for her, and it led to her being and doing what she is now, which is fantastic. You know, what a what a great way to use that experience to help others.

[Video Transcript] I'm sure by now many of you are wondering where my mom's videos are. Hers is a little different and it deserves its own special treatment.

VOICEOVER: Robin Millis (Carly's Mom)

Hi, I'm Robin, I'm Carly's mom, and I can apologize for not being on a video but I don't really like it. So we're just doing audio here. [Laughs] This is really kind of hard for me. Of course, you know, I wanted to be the best mom that I could be. And I kind of feel responsible for Carly's misdiagnosis. You know, what made it worse was my ignorance of so many things that a person is kind of naturally born with. That whole nature versus nurture thing. You know, for example, I thought fear was kind of taught and if you taught your kid not to be afraid of anything, they wouldn't be afraid of anything. And that's so not the case. I didn't realize how much anxiety a person can actually be born with. So I guess I was trying to make Carly someone I thought she should be and not accepting who she was. I use the analogy of a sculptor with clay. When you're a parent, you think that you're going to mold your kid like you mold clay. But in the reality, I think it's more like chipping away the excess clay and discovering and revealing who your child really is. Had I known about her autism, I would have hoped I would have been much more understanding of her differences instead of trying to make her something that she's not. It created so much pain in her thinking that something was wrong with her and she was not OK just the way she was. Since her diagnosis, Carly is so much more self-confident, relieved that there is nothing wrong with her as she always was taught and felt. I know I did the best I could with what I knew as a mom, but that does not mean that there are not lasting scars for the both of us. Carly is an awesome, wonderful woman, and I am so proud of her. I know as Carly was growing up, she did not hear enough affirmations to make her feel good about herself. I was more a service love language person. It is so wonderful to see her learn and grow and become the woman that she is. If I die tomorrow, I know I would not have to worry about Carly. She would be able to take care of herself. She would find a sense of purpose for herself. She would live a full and happy life. And she would be the best Carly that she could be. But until then, Carly and I are having a wonderful, loving, close relationship as mother, daughter, and friend.

[Video Transcript] With everything being said, now it's time to discuss next steps. What's hard about this is how little control we have over the state of the resources. We are facing a massive provider shortage, not just the kinds of providers that understand adult, female, or minority autism presentations, but regular autism providers. In fact, back when I went for my diagnosis, there was only one qualified provider in my region, who is now no longer taking new clients due to overwhelming demand. I don't know the best solutions for this other than calling attention to it, and I hope presentations like mine can help close this gap. But one thing I always consider is the fact that the people who need to hear these messages the most are the ones that don't know they should be paying attention. So the more we can spread the word using the avenues and tools at our disposal, the greater chance we have that the information will reach our intended audiences.



[Video Transcript] Don't worry, it's not completely hopeless. I do have one very helpful strategy to share called "Energy Accounting," which I first learned about from, you guessed it, Dr. Attwood's presentation.

Energy Bank Account: Withdrawals and Deposits

WITHDRAWAL

- Socializing
- Change
- Making a mistake
- Sensory sensitivity
- Daily living skills
- Coping with anxiety
- Over analyzing social performance
- Sensitivity to other people's moods
- Being teased or excluded
- Crowds
- Government agencies
- Body shape
- Perceived injustice
- Certain people

DEPOSIT

- Solitude
- Special interest
- Physical activity
- Animals and nature
- Computer games
- Meditation
- Caring for others
- Nutrition
- Sleep
- Reading
- Mental health vacation day
- Information on the internet
- Being with pets
- Certain people

SOURCE/CREDIT: Dr. Tony Attwood

VIDEO CLIP: Dr. Tony Attwood

[Video Transcript] The idea in energy accounting is that you have in your day the concept of that energy bank account. That sometimes events will occur or people that you meet will drain you of energy. And in that draining of energy, you are going to become energy depleted. So there are energy withdrawals and energy deposits. There are things that will energize you. So what we do is go through what may be potential energy withdrawals and deposits. This is the cheat sheet. So in energy accounting, we have a currency, a numerical value. How much an activity is draining or refreshing from day to day with an energy range from one to a hundred. So on some days you may get socializing "ah, socializing was like a, today was a 20" "ugh, today, 90...no, a hundred! Today was a hundred." So what you're trying to do is balance the books between energy depletion and energy restoration. So we add a numerical value of debits or credits and if needed, must schedule more energy infusing activities into the next day or week. So we fight autism with autism. We're pedantic and we have lists. So this is the list of withdrawals and deposits. So you may have on the left column, what is it that drains you of energy? OK, add it up 20, 40, 60, 80, 20, total, 360. What were today's deposits? 20, 20, 30, 40. Total 240. Oh dear. You can cope with that for a while, but as you are sinking, you'll reach a tipping point and you'll just go straight down into a depression. So please, emotion regulation and management is important because if you don't they may discover ways of achieving it that we do not recommend

Female autistic children are often overlooked because they tend to be more social, more compliant, and less outwardly problematic than their male counterparts.

♦ ♦ ♦

Providers have an outdated idea of autism that influences not just diagnoses, but the treatments and therapies provided (in ways that can be HARMFUL).

♦ ♦ ♦

Autistic people experience and communicate their emotions and internal experiences VERY differently! They also socialize and show love in unique ways.

♦ ♦ ♦

Unless you experience them yourself, sensory sensitivities, meltdowns, and lack of self-regulation can be hard to grasp or empathize with. It's difficult to understand just how drastically the world isn't built for autistic people.

♦ ♦ ♦

It's important to reframe the way we look at strengths, weaknesses, and abilities, not just in the context of each individual person, but in the traits we value as a society overall.

♦ ♦ ♦

Autistic people, diagnosed or not, know they are different. The diagnosis isn't bad news: it's helpful (and often liberating!) context.

[Video Transcript] To recap, here are some key takeaways. Female autistic children are often overlooked because they tend to be more social, more compliant, and less outwardly problematic than their male counterparts. Providers have an outdated idea of autism that influences not just diagnoses but the treatments and therapies provided, in ways that can sometimes be harmful. Autistic people experience and communicate their emotions and internal experiences very differently. They also socialize and show love in unique ways. Unless you experience them yourself, sensory sensitivities, meltdowns, and lack of self-regulation can be hard to grasp or empathize with. It's difficult to understand just how drastically the world isn't built for autistic people. It's important to reframe the way that we look at strengths, weaknesses, and abilities, not just in the context of each individual person, but in the traits we value as a society overall. And lastly, autistic people, diagnosed or not, know that they are different. The diagnosis is not bad news. It's helpful (and often liberating) context.

[Video Transcript] That's all I have for today. But you are more than welcome to contact me with questions or comments or if you want follow up on anything that I talked about. And I do hope that you download a copy of this presentation to save for your future reference. Thank you!

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