

## **Autism and Eating Disorders: A Journey of Acceptance and Awareness**

Rev. Ryan Althaus; MDiv MBC

Today is what I've come to call a *disorder day*—an unpleasant, often unpredictable, pill-popping, anxiety-ridden, hold fast to whatever sane or stable thing that you can, *just want to get through it* kinda day. For anyone fortunate enough to be oblivious to these *dis-orderly* durations of agitation and agony...keep it up—you're living a great life. However, to those for whom these perilous 24-hour periods of pain and panic are a part of existence, allow the fact that I am writing you from within the throngs of one offer assurance in that you are not alone.

Needless-to-say, regardless of who you are or what incited the day's insanity, one truth is universal: *disorder days* suck. However, at the ripe old age of 38—following 20+ hours of intense psychiatric interrogations, a near-deadly eating disorder relapse complete with a few rounds of residential treatment, and several decades of self-deprecating internal dialogue—something strange happened. My demoralizing *disorder days* underwent a name-change: a grammatically subtle, yet psychiatrically significant, two-syllable shift from *disordered* to *disabled*. Let me take you there...

"I must say, Ryan, you present one of the more interesting cases of Autism I've ever studied."

"Autism?!" I parroted the passive diagnosis back to my evaluator in the form of a question. *Did he just call me Autistic?* I looked towards, though, not into, his wrinkle-lined eyes. Rarely did I look into anyone's eyes; the emotions that fill them are too intense for that. Instead, I've learned to look at the bridge of my conversational partner's nose—their metaphysical *third eye*. A fitting response for someone who feels as though they are trapped in a different dimension than the other earth-bound beings whom they are interacting with. Luckily, in a society where most conversations involve or are interrupted by a screen, merely looking towards one's face is often enough; however, just to be safe, I also tend to tack on my trademark turquoise-tinted sunglasses. Whereas a fashion accessory to most, these magical lenses act as an essential defense mechanism to dim the bright sights, loud sounds, and overbearing creatures of a world that I seem especially sensitive to.

"Yes, autistic..." He smiled. "And *interesting*."

We sat in silence for a few seconds; then, void of a reply, he proceeded to explain. "The professional and personal life that you've created to allow for your ritualistic behaviors—coupled with the ways in which you've learned to mask your anxieties, forgo your feelings, and play the part of a charismatic public figure through compulsive exercise and eating practices—is pretty extraordinary." He paused. "But, unfortunately, your *extraordinary* is also isolating, exhaustive and, as is the too often the case with eating disorders, potentially deadly."

Rewind:

From as early as I can remember, I have always had a rather *peculiar* relationship with food and movement. As a child, I'd separate foods via their textures and tastes; then, consume them in abnormal quantities and ritualistic ways at specific times during the day. As for exercise? Somehow, early in life, I figured out that physical exhaustion provided a quick fix for emotional uncertainty and anxiety—far before I ever understood the terms *emotion* or *anxiety*. Thus, while most kids were playing video games and watching cartoons, I could be found running laps around the yard until my legs went numb—content with the company of my own shadow—because the forced-fatigue freed me from my feelings. This *quirkiness* was considered cute and harmless as a kid, but as my eating and exercise idiosyncrasies evolved, that *quirky-cuteness* transitioned into a dangerous eating disorder. *And, as for the road of recovery and relapse to follow...?* Whereas it has been intense and exhaustive at times, my hope is that it will prove equally insightful and instructive in reflection. So here goes:

After a high school senior year of self-starvation landed me in an in-patient eating disorder center upon graduation, I managed to regain my footing in college. Quite literally, in

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fact, in that my inclination towards the repetitious movement of running paved the way for a successful NCAA Cross Country career, a stint on the professional marathon circuit, a few years as an elite Ironman triathlete, and the launching of a nonprofit organization that utilized endurance athletics as an addiction recovery resource.

*As for the food side of things?* To this day I still struggle to dine publicly in socially accepted ways; however, with the help of a nutritionist, I was able to figure out how to properly fuel my body via my *unique* consumption habits.

Finally, in regard to the social side of life...my undergraduate studies in English and education, coupled with dual graduate degrees in Divinity and Communications, taught me how to script my speech and express *empathy*—an ability that the *neuro-typical* world all-too-often deems their *neuro-diverse* neighbors devoid of. In other words, I became a master in the art of masking, and I was able to maintain this moderately healthy life balance for over a decade. Needless-to-say, the exhaustion associated with maintaining an alternative identity eventually took its toll, and my body and psyche couldn't withstand the beating. Thus, upon eventually retiring from marathon running, I managed to muster up the energy to crawl my way from my home in Kentucky, to surf-city, Santa Cruz, California, in an attempt to flee from a lifestyle that I could no longer live up to. Unfortunately, what I came to find was that no matter how fast or far one might run, crawl or creep—it is impossible to evade an eating disorder by fleeing from it. Instead, you must face it head on, and I was forced to do so shortly thereafter when the added anxiety of the COVID pandemic triggered a full-blown anorexic relapse that landed me in an ICU bed. You can dive into the details of my disordered downfall and the climb back to life thereafter in my book, *Emaciated to Emancipated*, but the more pertinent question in regard to this writing is this:

*Why am I straining to scribe this article amidst this disorder day, while struggling to reclaim my physical and mental health following that relapse?*

Answer: Because the road that I have traveled in regard to my eating disorder and recent ASD/ADHD diagnosis didn't have to be nearly so rocky, and the prospect of paving a smoother path for others puts purpose to the pain!

Over the past decade, eating disorder and Autism diagnosis' have each experienced an exponential rise; though, the overlap between the two is often overlooked. My eating disorder was never about numbers or looks—like many on the spectrum, I've never been overly concerned with my appearance or other's perception of me. Instead, my food and exercise patterns have always been based on the sensation of starvation and satiation, the comfort found in ritualistic eating, and the difficulty I have in identifying hunger cues and signals of physical fatigue. What's more, with a proper understanding and support structure, being *different*, in terms of one's eating habits, does not have to mean *disordered*. It just might require a little creativity and intentionality to match one's energy output with foods and meal rituals that adhere to their unique taste and texture needs.

For most my life, my behavioral patterns around food and exercise were seen as evidence of an Eating and Obsessive Compulsive Disorder, and were treated with exposure therapy and forced re-feeding. However, whereas an anorexic compulsion exasperates anxiety, an autistic ritual alleviates it—and you cannot *expose* away Autism! In fact, exposure therapy and forced feeding in terms of autistic-anorexia can cause long term trauma and further inhibit one's ability to fuel a healthy and *happy* life.

In closing I'd like to reiterate that simple adjective, *happy*. Like far too many mis-diagnosed Autists, I spent most of my life made to think that I was *disordered*; thus, in response to this recent shift in self-identity, I did what any 38-year-old child would do...I called my mom!

“He diagnosed me autistic!” I exclaimed, while still in shock.

“That seems about right...you've always been pretty unique.”

“What?!” Her calm agreement was far from the reaction that I expected. “Well then, why didn't you ever get me diagnosed as a kid?”

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“You were a bit *weird* since the day you were born, Ryan.” She laughed lightly under her breath. “But you were the *happiest weird* kid ever! Why would I want to have you diagnosed as *disabled* or *disordered*, when you were so contently and creatively you?”

She was right: It wasn’t until the world told me that I was wrong, broken or *disordered*, that I truly started to struggle. And the internal battle that ensued thereafter took the form of restriction, isolation and anxiety. *Happiness* is rooted in self-acceptance—and, whereas my ditching the self-deprecating label of *disordered* did not change my identity, it has set me on a journey to accept it, once more, as I did in childhood.

*Is it going to be an easy journey?* Not in the slightest. I saw my anorexia as a phase—something I’d outgrow with age and therapy; however, I have had to accept that I will never *outgrow* my autism. Instead, my work now lies in exploring and embracing the gifts of autism in a balanced way.

*Was the diagnostic process simple?* Absolutely not! Adult Autism evaluations are absurdly hard to attain—and finding support thereafter has proven to be equally challenging. That said, things are slowly changing and I hope to be an advocate for others moving forward.

*Finally, am I glad I pursued this diagnosis?* Incredibly! The treatment protocol, from medication to mediation to meal formation, is very different for Autism, as opposed to traditional Anorexia—and, although it is going to require a lot of work and support to fully reclaim my health, I finally feel as though I am on the right track.