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My Autistic Childhood and Adult Life: Four Stories of Abuse and Survival

Dafne Zuleima Morgado Ramirez

he following collection of four stories are the result of a process of self-reflection (Franks, 2016). In what follows, I describe moments of my own self-discovery, while narrating my story of family abuse of a vulnerable autistic child and an adult woman navigating marriage. I focus on recounting moments of insight as I write these moments. I hope that readers will reflect on my childhood and adult experiences, recreated from what I can remember of my life, as I grew from a child whose autism was ignored to an adult woman owning her autism.

I am Latinx, and to my knowledge, only one study has made specific reference to the cultural effect of being Latinx on autism diagnosis (Ratto, Reznick, & Turner-Brown, 2016). The study found that there is a tendency for autism underdiagnosis or delay in diagnosis among Latinx, with cofounding factors such as diminished access to healthcare and socioeconomic status (Ratto et al., 2016). Although the paper focuses on the Latinx population living in the USA, it accurately characterizes Latinx culture as collectivist as well as family and society oriented. Latinx culture seems to pay less attention to areas of human functioning, leading to autism symptoms being missed or treated as behavioral problems in need of discipline (Ratto et al., 2016).

The study also showed that Latinx mothers were significantly less knowledgeable about autism compared to non-Latinx mothers, even when results were controlled for education (Ratto et al., 2016). The study did not include fathers or members of the extended family in its examination of autism knowledge. Another study in the USA found that mothers of autistic children found diagnosis and treatment information confusing and complex, that medical and educational systems do not match each other, and thus mothers do not achieve the standard professional care recommended by leading autism organizations (Brewer, 2018). Mothers who had to reduce their participation in the workforce faced precarity, especially when they were single mothers or from a low socioeconomic class (Brewer, 2018). Note that it is not the autistic child affecting the family, but a system that is not designed

to support families with autistic children, where family is yet another unsupported and unmonitored system (Hastings, 2016). There is a need to improve autism research to include contextual factors of family and culture (Long, Gordillo, & Orsmond, 2020) and to acknowledge the advantages that multilingualism brings to the autistic experience (Nolte, Fletcher-Watson, Sorace, Stanfield, & Digard, 2021).

In my own Latinx family, I grew up not knowing how to take care of myself. I was not taught about the significance of routines and was not supported nor motivated by my parents in doing so. I remember being given a share of the house chores and even burning myself with the iron at times. But no one taught me how to take care of my hair and my skin, how to manage my food intake, or how to make and preserve friends. I never learned how to identify unhealthy individuals or recognize abusive parenting, how to establish boundaries with family members or manage feelings, how to figure out if I liked boys or girls or both. I was not taught how to build relationships with individuals beyond my friends or family members or how to survive in a normative patriarchal context. I had no other trusted person to talk about my dysmenorrhea and menorrhagia or my anemia. How I wish social media existed at that time and that I had access to it. Nowadays social media based autism communities provide support through Twitter and blogs (Saha & Agarwal, 2016) and online social interaction affords young autistic individuals easier social interactions compared to offline experiences (Gillespie-Smith, Hendry, Anduuru, Laird, & Ballantyne, 2021). I grew up not knowing about well-being, and I was not well.

Story One: Parental Physical Abuse

The parenting style I experienced was hostile: overly critical, controlling, suppressing, aggressively punitive, negative, stressful, neglectful and limiting (Russell & Lincoln, 2017). It was only when I cut ties with my mother and stepfather and started a parentless life that I realized that extent of this hostility. The inner family circles of my first cousins experienced the same hostility. In fact, I only learned a parenting style based on teaching and redirecting in a kind and respectful manner when I met my husband.

I remember being told to flex and lay down on my bed with my face down, then being hit on my ass with a folded leather belt—several times and hard. Pain lasting over a day. Sometimes I was hit by my mother; other times by my stepfather. Sometimes just with the leather, others with the buckle. But I do not remember why. I also remember being hit with the hose of the washing machine, just outside the kitchen, in the patio, when the washing machine hoses were stiff black rubber. But I do not remember why I was hit. I just lived with it. My experience as an autistic child was not uncommon. A 2019 study found that autistic children are significantly referred more to a child abuse hotline (17.3%) in comparison to non-autistic children (7.4%), in addition, autistic girls were found to have substantiated maltreatment at a greater percentage (13.6%) compared to boys (1.9%) (Fisher et al., 2019). Unfortunately, this only tells us about the cases in Tennessee (USA) and cases that did get referred, not the likely thousands of cases that are never referred.

I had no one to talk about this physical abuse, I had no friends, and my school offered no family abuse education. I was in a Catholic school, so they were more concerned with teaching about virginity, the lowly status of women, and God almighty. I did not know that what I was experiencing was abuse. Even today, I wonder if there is a way of preventing parents from physically abusing children with developmental disabilities. A recent review of 31 parenting interventions in China found that only one intervention measured the actual incidence of abuse, while the rest of the interventions were more interested in "reducing child emotional and behavioral problems" and only 11 of the included interventions were focused on parents of autistic children (Fang, Barlow, & Zhang, 2022).

This pervasive interest in normalizing autistic ways of being is notably affecting the priorities set in parenting interventions, as this example in China indicates. Instead, the priority should have been teaching parents to understand and accept their children, to learn ways to communicate with them, to realize that physical abuse is not okay, and to practice techniques that respect the autistic child without seeking to normalize them. Parents should also be taught that autistic individuals are more vulnerable to co-occurring mental health conditions such as attention-deficit hyperactivity, anxiety, disruptive-impulse control-conduct disorders, depression, obsessive compulsion, bipolarity and schizophrenia (Lai et al., 2019), sleep problems (Schreck & Richdale, 2020) loneliness as adults (Ee et al., 2019), reduced life expectancy (Hirvikoski et al., 2016) and suicide (Culpin et al., 2018).

When I reflect on my own childhood, I remember feeling awkward. It was not until my late autism diagnosis as an adult that my past experiences started to make sense. I experienced guilt, anger, and sadness. Guilt for what I could have handled better, had I known I was being mistreated, neglected, and abused. Rage for having been abused and not knowing what I did not know. Sadness for the thought of the high probability of this not being a unique experience to me, given the millions of autistic individuals living in similar normative and patriarchal family conditions. How sad human society can be at times. I remember being hit, shouted at, misunderstood, unloved, unsupported, repressed, infantilized, lied to, and punished. I do not remember anyone from my inner circle with love, I do not miss them, I do not desire their company nor worry about their death.

Story Two: An Abusive Older Sister

I do not recall having ever a good relationship with my sister: she was vindictive, dishonest, intrusive, and antisocial with me. She rejoiced in insulting me, betraying my trust, violating my privacy, and destroying my few social relationships. It was hard and traumatic. I remember that when I was a child, I was sitting with her at the trunk of my mother's yellow minivan, my sister took the antenna of a radio and inserted into my ear. Now as an adult, I sometimes have a pulsating pain and a ringing in my ear. And my hearing is a bit damaged, although not bad enough for a hearing aid. I do not remember the pain, but I remember being taken to the public hospital afterwards. Research suggests that siblings abuse their siblings for complex reasons, but the underlying cause is family dysfunction (Greydanus, Hawver, & Merrick, 2017). My older sister may have been trying to replicate the abuse we experienced from our mother and stepfather. Thus, she was not only a victim of abuse but also a perpetrator of it. As Greydanus et al. (2017) found, sibling abuse has been present in society for thousands of years, and it is predominant in children's fables, religious texts, and fiction. Cinderella, for example, was expected to preserve a sweet and submissive temperament while enduring the abuses of her stepmother and stepsisters (Friedman, 2010).

My frustration at my sister as a child was accompanied by the helplessness at the lack of intervention from my mother and stepfather. This dismissal of sibling abuse by parents may be an intergenerational pattern (Perkins &

Meyers, 2020). Research on the incidence of siblings abuse of their autistic siblings, specifically when none are aware of the autism, is hard to find. One study does demonstrate that when siblings *know* their siblings are autistic, they show kindness and tolerance towards them (Gorjy, Fielding, & Falkmer, 2017). The authors do not report on specifically recruiting siblings in dysfunctional families, thus it is likely that their context was not abusive. To this day, I avoid any contact with my older sister, it is a physical and emotional boundary that according to Perkins and Meyers (2020) is also observed as the impact of sibling abuse in childhood.

Perkins and Meyers (2020) found that it is not only parental abuse but also sibling abuse that can have implications in adulthood such as interpersonal difficulties, which affect relationships through adulthood. There is a potentially detrimental effect in my lifespan due to the sibling abuse that I experienced and that my mother and stepfather neglected. Yet, Perkins and Meyers (2020) have not specifically studied if the detrimental effects of sibling abuse are ameliorated or exacerbated when the abused child is autistic—they only studied typically developing children.

Story Three: Psychotic Episode Or Post-Traumatic Stress?

Children with neurodevelopmental disorders are also more vulnerable to maltreatment and neglect (Hoover, 2020). Research suggests that autistic individuals are more susceptible to Post-Traumatic Stress Disorder (PTSD) but less likely to be diagnosed with it (Hume & Burgess, 2021). Women with autistic traits, specifically, are more likely to be physically and/or emotionally abused, mugged, and pressured into sex. They have more PTSD symptoms when compared to men (Roberts, Koenen, Lyall, Robinson, & Weisskopf, 2015). In addition, Perkins and Meyers (2020) noted the adverse effect that sibling abuse has on mental health of typically developed children. So, which one is which? There is no diagnostic guideline that can unravel PTSD from autistic traits. What does autism look like without PTSD?

The abuse that I experienced as a child had well-being repercussions. It affected my dreams and it led me to confuse reality with dreams. In one dream I had while in secondary school, I was being driven to school in the morning by my stepfather when he suddenly hit another car, fell on the side of the road, and was dramatically beheaded with the door of the car. During

the dream, I sit there unmoved, watching and unhurt, more worried about getting to school than anything else. This dream was likely a response to trauma-trauma that autistic children and adults grow up with. I have no desire to kill anyone today, and I have no interest or any feeling towards my stepfather. I have detached from him and my mother, for my own well-being.

Another terrifying dream that was mixed with reality, like daydreaming, was due to the abuse I experienced from my older sister. I was dreaming then that she was trying to kill me and had recruited her friends to help her do so. In my extreme fear, I managed to get out of my room in the middle of the night and seek help from my neighbors. I had to free myself through the window of my room that had iron bars for security. The iron bars did not have a gap big enough for my skull to go through, so in my desperation, and still only half-awake, I forced my head through the bars, injuring myself. I gave myself abrasions on each side of my head, the type of abrasions you get on the skin of your knees when you fall while running or while riding a bike and you are wearing shorts. So, I bled and ran through the garden to my neighbor's house, while my dogs followed, I did not knock at the front door-I went into the back of their house and started knocking desperately at a window I must have frightened them so much.

Then I tried to explain. I have no idea if I muttered understandable words, but I climbed through their window. Only when I was inside their house did I wake up completely. I was ashamed. I was scared. I was afraid of the repercussions, which in my mind at that time were being punished by my mom and stepdad, being hit for running out in the middle of the night to the neighbors. That was what I feared. So, the neighbors walked back with me. The next morning, the doorbell rang quite early, it was still cold outside, I did not come out of my room. I am sure it was the neighbors talking to my parents. I was in fear in bed, ashamed. I pretended nothing happened and so my parents. I do not remember if they hit me afterwards, they hit me so many times that I no longer link the why with the hitting. I only remember how the hitting felt and how frequent it was.

Story Four: The Wife Who Could Not Meet Expectations

With no positive example of marriage from my parents, I was convinced I should never marry. I should have stuck with that. It was wise. Perhaps sad but wise from an autistic perspective but challenging in a couple-normative world. I met someone that bedazzled me while I was studying my master's degree. I was not looking for any romantic relationship, but I changed my mind and proposed to him. He doubted at first but then accepted. I was thrilled. It was unbelievable at first, the sweetness that I had never experienced, the honest caring and attention, the company without fear, the help without a social debt and the walking without the eggshells. He became my special interest.

I was happy with what I had: him, my dream research job, and a place to live that I could call home. But my husband wanted more. He reproached me for not becoming best friends with his sister and two sisters in-law. How could I make such a leap with my new in-laws? With the family abuse I endured, I became a cautious adult who takes time to open the door to others. Some autistic adults who have experienced trauma and may have PTSD find it more difficult to empathize with others (Hume & Burgess, 2021). It also takes energy to lower my guard to get to know other people and to let them get to know me. A neurotypical would likely see this as selfish, even narcissist, but to me this is a boundary, a management of resources that autistic adults do for self-care and survival. I explained to my husband that I was willing to develop the relationship, but it was not my priority, and it would take me years to reach the point of what he expected. Needless to say, this disappointed him.

After my autism diagnosis at the age of 35, my clinical psychologist gave me a brochure that in summary said that the local authority where I lived had no resources whatsoever for autistic adults, only for children. If I wanted to connect to other autistic adults, I would have to do that through charities or on my own accord. Unfortunately, the diagnostic criteria does not give recommendations for follow-up assessment of PTSD (American Psychiatric Association, 2013). Mental health services for autistic adults do not adequately support us and can even cause additional harm (Brede et al., 2022). My husband was present in the diagnosis process and contributed greatly with his experience of living with me. After the diagnosis I had an identity crisis, that baffles my husband still to the present. I have left him. We are separated.

I communicated to my husband repeatedly that I did not want children. Yet, he did not take this literally and kept hope that I would change my mind. He wanted children and I did not. Before proposing to him, I suggested the idea of maybe exploring having children, and the "maybe" turned into a "no" for me over the years, and a resentment for him. How could I? At this point our relationship was not good. I was having reduced to no sex drive, and the best friend I had in my husband was no longer there. We tried counseling. My husband found a counselor with whom I had a detrimental experience because they had no awareness nor training on adult autism. A recent systematic review and thematic meta-synthesis confirmed that mental health services for autistic adults do not adequately support us and can even cause additional harm (Brede et al., 2022). In our case, this experience left me untrusting of any counseling in the future and left additional tension in my relationship with my husband.

I was also coerced into sex, and I think that this could be an interpersonal trauma for me (Reuben, Stanzione, & Singleton, 2021). A study found that autistic women linked social and sexual vulnerability to their difficulty with social inference skills (Sedgewick, Crane, Hill, & Pellicano, 2019). They highlighted the need of tailored, personal safety training and support for autistic women to have positive and safe transitions to adulthood and adult relationships (Sedgewick et al., 2019). Another study found that the autistic sensory processing is relevant in sexual and relationship experiences; and that clinical practice and education would benefit from further research on how to support autistic individuals in achieving safe and satisfying sex and relationship experiences (Gray, Kirby, & Graham Holmes, 2021). Unfortunately, current sex and sexuality education in schools do not include autistic experiences nor identities of sexuality (MacKenzie, 2018). What is more, autistic sex and sexuality is often seen as problematic, in need of being "treated" or managed (MacKenzie, 2018).

Working on myself is hard enough that it is not right to have to do so for a life partner that chooses not to take care of themselves. My husband presented depression symptoms and had a dysfunctional family relationship that drained him emotionally and physically. I asked him for years to seek help, but he did not. Trying to take care of someone who does not want to take care of himself is a red flag that took me a long time to see. I invested an unfair amount of energy in another while taking from my self-care and thus

it became an act of self-harm. This is autistic burnout or in Raymaker et al. (2020) words: "having all your internal resources exhausted beyond measure and being left with no clean-up crew."

Concluding Reflection

My family now consists of my official assistance dog and some colleagues who have started to become friends. I am studying how to have relationships and how to care for myself. I know that the abuse and neglect were not my fault. It was what it was. Whether I have PTSD or not, I am aware that I struggle with relationships and taking care of myself, but others also struggle too with building relationships with me. We need to meet each other in the middle (Milton, 2012). The autism diagnosis criteria (American Psychiatric Association, 2013) has helped me to identify where I may struggle in social interactions and relationships, and whether it is a result of trauma and PTSD is not as relevant as to what I can do to take care of myself and preserve relationships in my life that are bidirectionally valuable, positive and motivating.

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Alison Lam identifies as a neurodivergent, interdisciplinary, socially engaged artist using differing materials such as porcelain, metals, glass and paper. Alison explores the idea of grief, discardment and ostracization, through exploring and investigating process led investigations. She often refers to this process as "drawing with her hands."

The needs of her sons required her to take time out of professional work; having entered a challenging time of home schooling and tackling the local authority to ensure the right education provision for her two boys with autism and complex needs. Consequently, Alison is conversant in the legislation around SEN support, despite being challenging, this period has been instrumental in informing and inspiring her work and is the reason she then went on to study a MA in Fine Art and Social Practice.

The film The Notion of the Beautifully Discarded was the beginning of her family's journey and research of what makes us look again and take time to process, much like that of many autistic families.

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