

Journal of the Motherhood Initiative

# **Social Work, Motherhood, and Mothering: Critical Feminist Perspectives**

Spring / Summer 2022

Volume 13, Number 1



**Hee-Jeong Yoo, Laura Lewis, Deepy Sur, Dawn Thurman,  
Erin Kuri, Janis Favel, Christine Walsh, and many more**

DENISE COLÓN, ESQ. MSW

## **Mothering a Child with Autism Under the Weight of Marianismo: Implications for Social Work Practice**

---

*This article explains and offers context for how marianismo undermines a mother's coping when her child has autism. It asserts that without an informed understanding of cultural value systems, such as marianismo, and how these values shape a mother's cultural and personal experiences, social work efforts to help Latino mothers and families cope with the implications of their child's autism are simply insufficient. Practice implications are addressed and suggestions for meaningful and impactful work provided.*

Erna Imperatore Blanche et al. correctly note that “relatively little is known about the experiences of Latino families who have a child with ASD [autism spectrum disorder], their perspectives on living with the diagnosis, and their interaction with service providers” (1). I assert that even less is known about Latina mothers’ experiences, thoughts, and service utilization when their child has autism. This is significant because Latina mothers are the anchors of the family. Their role is consequential. Although Latina mothers’ coping responses are not all the same, for many whose upbringing was infused with marianismo—the cultural value of moral conduct and self-sacrifice that shapes traditional Latina femininity (Da Silva et al. 2021)—the physical and emotional impact associated with learning that their child has autism is devastating. It follows that without an informed understanding of cultural value systems, such as marianismo, and how these values shape a mother’s experience with diagnosis, accessing services, and personal growth and wellbeing as a mother, social work efforts to help Latino mothers and families cope with the implications of their child’s autism are simply insufficient.

This subject is both timely and relevant to current social work practice. According to the United States Census Bureau, Latinos represent 18.3 per

cent of the total population, the nation's largest ethnic minority group (2019). Moreover, although autism has become increasingly prevalent in the United States (Centers for Disease Control and Prevention 2018), the prevalence of Latino children diagnosed with autism, compared to that of Caucasian children, has simultaneously increased (Nevison and Zahorodny 2019). As these demographics surge, the demand for social workers to provide culturally informed services to families who have a child with autism has never been more urgent.

This article unfolds into three main sections. In the first section, I discuss *marianismo*, its tenets, and how it manifests in popular Puerto Rican culture and within my family. In the second section, I discuss my personal journey trying to be an ideal mother as defined by *marianismo* and how my attempts to ascribe to this value system undermined my own coping with my son's autism. I offer my personal story as a point of entry to understanding the real impact of *marianismo* on mothering and to provide context for the last section on implications for social work practice. While looking at the specificity of mothering a child with autism, the goal of this article is ultimately to encourage the social work profession to consider the need for culturally relevant supports that facilitate Latina mother engagement and coping. My hope is that my experience as a mother, Latina, and former clinical social worker will lend credence to the recommendations offered and that these prove useful in advancing social work mothering theory.<sup>1</sup>

## **Marianismo**

Social workers agree that understanding a client's cultural value system is critical to providing quality and impactful supportive care. Yet the role of culture has scarcely been explored in supporting Latino families who have a child with autism (Imperatore Blanche et al. 2). This is an important point, especially since culture and cultural tenets, such as *marianismo*, significantly impact family coping and receptiveness to services. It is also important because although culture influences behaviour, people do not typically make the connection between the two (Gil and Vasquez 23).

Political scientist Evelyn P. Stevens developed the term *marianismo* as an extension of *machismo* to describe Latin American culture's perception of the ideal woman. In her 1973 essay, "Marianismo: The Other Face of Machismo," Stevens explains that in Latin American culture, the belief that women are semidivine, morally superior, and spiritually strong is almost universally accepted (94). She adds that a "real woman" is seen as having "an infinite capacity for humility and sacrifice," and for her, "no self-denial is too great" (94). Later, Rosa Maria Gil and Carmen Inoa Vasquez expanded on Steven's concept by discussing the impact of *marianismo* on Latina women's behaviour,

decisions, psychological wellbeing, and personal struggles. For context, they set forth the “ten commandments of marianismo,” which in “its purest, darkest form,” include the following: “Do not forget a woman’s place”; “do not put your own needs first”; “do not ask for help”; and “do not discuss personal problems outside of the home” (Gil and Vasquez 8). They argue that marianismo shapes women’s choices and actions as she continuously strives to be perceived as “a good woman” (3). Gisela Norat describes the exchange as an “implicit social contract,” whereby “*marianismo* promises to guarantee women upright standing and respect within their family and community if they model the behavior expected” (1). Adherence is held as “a badge of honor” (7), thereby enhancing a woman’s self-worth (Gil and Vasquez 78).

Until a few years ago, I had never heard of the term marianismo. This is not to say that I was unaware of how deeply influenced Latina women are by culturally defined gender roles. I was. In fact, I had strong feelings on the subject. Yet I surprisingly accepted many cultural expectations and norms as somehow natural and benign (Gil and Vasquez 23). To my knowledge, this set of attitudes and thought processes did not have a name. They simply existed and served as a moral standard for what I should seek to be as a woman, wife, and mother—a standard infused through culture, modelled from an early age by my mother and grandmother, and internalized and sometimes resisted over time, eventually becoming a moral compass for the woman and mother I struggled to be. Years later I learned that these culturally sanctioned and restrictive models of femininity were part of a bigger socialization process that many of us Latina women are influenced by, to one extent or another. In learning that this moral standard had a name—marianismo—I began to consider how its set of values were not as innocent or inconsequential as I had once believed. That is how the idea of writing this article began.

Importantly, not all Latina women conform to marianismo. In fact, I can imagine that some would find marianismo immaterial to their life experiences. Others simply may not recognize its influence in their daily lives. You see, marianista values, like all cultural ideologies, are not inherent or natural but learned.<sup>2</sup> They are also absorbed quietly, subconsciously and to different degrees, emerging as part of a woman’s persona over time. That is why, when applicable, its impact is so powerful. For instance, growing up as a bicultural American young woman, many of the tenets advanced by marianismo never became part of my value system. I was born in the United States and have lived here for most of my life. Moreover, my mother, grandmother, and maternal aunt, all of whom were my first female role models, spent a significant number of years living in the United States and thus absorbed many American values. My grandmother and mother taught me that I must strive to attain higher goals than they had achieved so that I could become independent while my aunt urged me to be less self-critical and fill my own bucket. As such, I felt

empowered to pursue my professional dreams. I was keenly aware of the sacrifices that my mother and grandmother had made, and I was fuelled by a desire to carve out my own path. I excelled in a little-known school in the Bronx and was accepted to Yale University. Later I pursued a masters in social work and thereafter a juris doctor degree in Law. I have always considered myself progressive, independent, and modern. Yet I did not realize the impact more subtle aspects of my Latino cultural value system had on the woman that I became. I may have seemingly been more progressive, but in fact I had quietly and unknowingly internalized many aspects of marianismo from my family and cultural environment.

Marianismo is an important aspect of Latino cultural texts and socializing institutions. When I was a young girl living in Puerto Rico, I specifically remember the priest and catechism teachers emphasizing that both girls and women should regard the Virgin Mary as the perfect example of strength, sacrifice, and perseverance. We were taught that she personified the ideal that we should all aspire to be as mothers and that our personal value and societal regard would be determined by how closely we emulated her. At the time, soap operas, or as we called them “novelas,” similarly reinforced Madonna-like constructions where a “good” woman’s suffering” was equated with “achieving purity through endurance” and “her vindication” with “achieving a heavenly prize” (Guerra et al. 213). Significantly, novelas were widely enjoyed by everyone, uniting family and friends while also providing stress relief and entertainment. As such, they were influential. My grandmother and I used to watch the afternoon novelas every day after school. Together, we both marvelled at the protagonist’s ability to sacrifice for the sake of others, keep her anger in check, and endure suffering with dignity and in silence. Everyone loved and admired her for her purity and selflessness and the handsome lead male could not help but fall in love with her virtue. I remember observing the look of admiration in my grandmother’s eyes as she watched the protagonist cope with adversity (e.g., temporary blindness or paraplegia, death of both parents at a young age, infidelity, being falsely accused and imprisoned) and ultimately triumph. I wanted my grandmother to admire me too. I wanted to be like the protagonist in the novela.

Marianismo ideals are also implicitly modelled and reinforced by family. My grandmother was a strong no-nonsense hardworking woman who was clearly in charge of running the house. She had been trained to be this way. The oldest of eight siblings, my grandmother stopped attending elementary school to take care of her siblings and household responsibilities while her parents worked. She accepted this role without reproach because she was taught that the collective needs of the family came before her own. Years later, after my grandmother married my grandfather and had young children of her own, it was she who took the initiative to move from Puerto Rico to the Bronx,

New York, in search of work in the early 1950s.<sup>3</sup> My grandfather, a well-liked man, served in the United States National Guard and worked continuously until he retired. However, in times of family need or crisis, it was the women in my family who rose to the occasion. My grandmother recognized the perilous circumstances her family was facing during that time and instinctively understood that she would have to take action to ensure their wellbeing, even if it meant taking a leap of faith by herself. As a Latina mother, she was the force, the centre, and the courageous one. A few months later, after she secured employment as a seamstress, my grandmother quickly sent for my grandfather followed by each of her three children, one by one, to begin a new life together in the United States. It took years before everyone was reunited, but she persevered and ensured that her family was provided for, even while apart. My grandmother would later boast that each day after work, she cooked a “good Puerto Rican dinner,” cleaned the house, and ironed my grandfather’s work clothes. She added that she never called in sick. Whether consciously or subconsciously, she aimed to fulfill what she perceived to be her womanly duty.

My mother was similarly undeterred by challenges; she was resilient and persevering. When she moved to the Bronx at the age of thirteen, she did not speak English. Yet she remained in a regular classroom and taught herself how to speak the language by reading the dictionary. When she reached college, she was completely fluent. My mother was part of the first generation of Puerto Ricans to attend college in New York City in the 1960s. While in college, she was an excellent math student who aspired to become an accountant. However, when she married my father, he made it clear that he expected her to remain home while he worked, so she relinquished her career aspirations for the sake of her marriage. Yet what she could not do for herself she did for her children. When I was nine years old, my mother moved with my brother and me from Connecticut to Puerto Rico—a temporary measure designed to ensure that we were surrounded by much needed love and support. She then worked and saved for five years in order to move back to the United States. This move aimed to provide us with more opportunities for wellbeing and advancement, which was her priority. My mother instilled in us a love for learning along with the expectation that we would succeed academically and pursue a career. Today, we are both professionals largely in part to her fearless efforts to carve a different path for us.

My grandmother and mother were family providers and pioneers; they were unafraid and tirelessly worked women. They were the backbones of the family. Without them, family circumstances would have deteriorated or remained stagnant to the detriment of us all. Yet the same marianista values that served to uplift the family also caused them personal harm. My mother sacrificed a promising career. She also never learned to cultivate a sense of individuality or

appreciate her worth. This is not something that was instilled in us as girls. In fact, self-love runs contrary to marianismo. Similarly, my grandmother emotionally disconnected to overcome times of uncertainty, lack, and physical pain. The very strength that allowed her to rise above adversity also became the wall that kept family members at an emotional distance (Télez 59) and later resulted in serious health problems. I remember how proud she felt when she signed to donate her organs upon her death. Yet her autopsy revealed that “she must have experienced great pain while alive” because her organs were so damaged; they were “unusable.”

I was fortunate that my aunt also played an influential role in my life. She was different than most of the women around me. She was vocal and opinionated, took pride in being single and independent minded, and prioritized her own personal needs and growth over seeking to be married or have children. A witness to the various cultural messages that I was receiving, my aunt encouraged me to recognize and honour my own feelings and not be afraid to challenge notions that were limiting to a women’s sense of value and self-respect. Her unwillingness to engage in the social contract described above may have diminished her regard within the family, but it saved me. She planted that ever-important seed of self-love that eventually gave me the strength to demand more for myself. However, that happened many years later. When I became a mother, not even her empowering influence could counter the marianista ideals that I had unconsciously incorporated in my persona.

## **My Journey**

My experience mothering a child with autism, advocating on his behalf, and learning of his diagnosis is deeply personal. Nevertheless, I share my experience during this specific four-year period, from birth to diagnosis, as a means of demonstrating how marianista values not only serve to undermine a mother’s wellbeing but may also prove crushing as she singlehandedly attempts to cope with the implications—both culturally and personally—of her child’s autism. As I go on to explain, it was not my son’s diagnosis that felt insurmountable. It was the combination of managing the cultural pressure to “make it better” while also quietly repressing the deep sadness and fear associated with raising a child with autism in a world that pathologizes his differences and fails to provide compassionate supportive options for his future. Through my story, I seek to offer insight and context for the recommendations suggested in the last section. Namely, that the social work profession must actively establish ongoing required cultural humility trainings on lesser known topics such as marianismo, seek to elevate the role of culturally informed social workers to that of essential partners in medical and psychiatric diagnostic settings, and

advance policies and procedures that enable practitioners to more actively and appropriately participate in helping mothers navigate their personal journey in such a way that they can emerge feeling validated, supported, and better informed about how their child experiences the world around them. Since “*Marianismo* is embodied in the mother’s role” (Gil and Vasquez 52), that is where I begin.

My transition from social work to law happened to coincide with the birth of my first son. From the onset, I understood that my career goals came second to my duties as a wife and mother. As such, I purposely accepted a legal position that did not require late work nights or travel. Being present and hands-on was important to me. After work, my daily routine included preparing a homemade dinner, as any good Puerto Rican mother would, feeding my son, bathing him, and putting him to bed, followed by cleaning the kitchen and preparing his school lunch for the following day. I also stayed home if he became sick, which as an infant was often. I wanted to be what I had been taught constituted an ideal woman, even if it meant carrying too much on my shoulders and relinquishing opportunities for career advancement. I was gladly up for the challenge. I had become my mother and my grandmother all wrapped up in one.

My efforts, however, resulted in unintended consequences. I experienced frequent migraines and other chronic health problems. I longed for rest and time for myself. My mother was incredibly helpful during this period. Yet fearing that it might appear as if I was not a good mother, I did not accept any more help “than was necessary.” Deep inside I knew, however, that I needed a break. My wants were simple, yet the thought of not being there for my son at all times and taking care of his every need made me feel inadequate. At times, I also felt resentful, then guilty for feeling resentful, then scared that I could experience anything but happiness for the gift of having a healthy, sweet, and well-behaved baby boy. I understood these percolating feelings to represent a weakness at a time when I strived to be perfect. Yet, somehow, I was able to successfully maintain the semblance of this ideal—that is, until I gave birth to my second son. That is when the weight of *marianismo* became impossible to bear.

When my first son was four years old, I gave birth to twins, a boy and a girl. My pregnancy was uneventful, and the twins were born seemingly healthy. However, my bladder tore during the delivery, requiring emergency surgery. Despite this unexpected challenge, we were all able to return home within days. Then suddenly my baby boy, Justin, became colicky. Aside from when he was nursing, he cried from the moment he woke up until he fell asleep again. His constant crying was maddening, nerve racking, and very scary. What was wrong? Was he in pain? What could I do to help him? Something must be wrong. I consulted with his paediatrician, changed his formula, and tried



every natural remedy I could find, to no avail. The only action that seemed to lessen his crying, slightly, was when I held him in my arms. Yet I also had another infant girl and a young boy to care for. Moreover, it was physically difficult to carry him for prolonged periods of time. My body felt painful as a result of the caesarean section, bladder surgery, and resulting temporary placement of a foley catheter. Emotionally, I felt helpless, incompetent, exhausted, and overwhelmed. I was also perpetually anxious, always anticipating or trying to get through Justin's screaming. I lost a lot of weight and worried about the wellbeing of my oldest son and infant daughter as they too were affected by their brother's constant crying. I prayed to God to please help my son. To make matters worse, during this time, Justin developed a potentially fatal virus and had to be hospitalized immediately. I was terrified. How long could I continue to be strong when my son cried incessantly and was now having trouble breathing without assistance? I was quickly reaching the end of my rope. Luckily, his condition gradually improved, and we were able to return home. Then, a month after being discharged, Justin's colic suddenly stopped. Just like that. After four long months. I was grateful and relieved that it was finally over. Little did I know that my journey had just begun.

Even after Justin was no longer colicky, he showed great distress when surrounded by people or upon hearing the slightest noise. Attending social gatherings became a challenge. I also noticed that he did not make eye contact, would only fall asleep when I rocked him or while swinging on a mobile swing, and appeared disengaged, even with me. I feared something was just not right. Sensing, in my heart, that time was of the essence, I compartmentalized my feelings and began seeking answers.

When Justin was fourteen months old, he was evaluated by a neurodevelopmental psychiatrist who concluded that although "autism was a possibility," it was too early to diagnose him. That was the first time I considered the possibility of autism. Her words shattered my heart. Autism is a life-changing diagnosis. The emotional pain associated with knowing that my child could possibly face life-long challenges and require care beyond my lifetime cut deeply into my heart. Ironically, she did not appear to understand the magnitude of her statement and the resulting needs. Instead, the neurodevelopmental psychiatrist simply offered an early intervention pamphlet and suggested that I call soon. As I stood in the hospital hallway waiting for the elevator, I remember thinking how different my experience may have been if the psychiatrist had been working in partnership with a social worker. Based on my professional experience, I know that a social worker would have understood how lost I felt in that moment and would have ensured that I left feeling more informed, supported, and aware of my options.

I enrolled Justin in early intervention services immediately after. During this time, several other concerns emerged. For example, he developed repeated

ear infections necessitating surgery for the placement of ear tubes. He was also diagnosed with sleep apnea, which led to additional surgery to remove his adenoids and tonsils. He was subsequently diagnosed with a heart murmur, and then an endocrinologist followed him due to concern that he was not growing at the expected rate. I was embarrassed at the frequency I had to call in sick to attend to Justin's medical concerns. I was overwhelmed. I remember thinking that I deserved an equal opportunity to flourish in my career, and how never calling in sick was such a source of pride for my grandmother. Yet despite my sense of professional shame and frustration, there is no place else I would rather be than holding my son as I prayed for God to have mercy and grant him relief.

At age three, Justin transitioned from early intervention to prekindergarten. Although he continued to receive special services, nothing really changed. He did not speak, avoided circle time, showed little retention of classroom learning, was hyper and impulsive, and required constant supervision. I was obviously missing something. A good mother is able to tune into her child's needs. Instead, I was failing my child when he needed me most. Once again, I knew I had to do something. My mother would have advocated for me. I remembered the time when I moved from Puerto Rico to the United States, and my mother refused to allow the school principal to place me in an English as a second language (ESL) class, insisting that placement be based on my excellent grades. The principal voiced concern that as a bilingual student, I would not be able to keep up. We both proved him wrong.

I needed to figure out what to do next. I simply did not have the luxury of waiting to see if he would outgrow these concerns only to later discover that something could have been done if only I had acted sooner. I decided to pursue additional special services and applied behaviour analysis (ABA) therapy through my private insurance and appealed each denial until they finally approved.<sup>4</sup> I needed to explore every possible avenue available for help. I kept a close eye on his teachers' communication logs and advocated for modifications to address sensory concerns and promote learning. This was a particularly exhausting and emotionally difficult time. I remember the sense of desperation I experienced trying to learn how I could best address Justin's needs while simultaneously advocating for additional services. I also remember repeatedly attempting to reach Justin verbally and through eye contact, in vain. Words cannot adequately express the despair I felt inside when I could not find a way for him to connect with me. Then there were the sudden unpredictable and unexplainable aggressive behaviours. One minute he was fine, the next he would begin to cry, scream, and hit his head or others for no apparent reason. His obvious distress was once again heartbreaking because I wanted to provide him with relief and did not understand how. I was also physically exhausted from working full-time and managing most responsibilities, as expected. Yet

seeking help for myself never crossed my mind. I inherently understood that my concerns and struggles, as a mother, should be handled internally and without creating a “fuss.” Moreover, seeking help would have required me to acknowledge to friends and family that my son was struggling and I could not figure out how to help him, something I was not prepared to do. Instead, I pushed through my despair and placed Justin’s name on a waiting list to be evaluated by yet another neurodevelopmental psychiatrist with the hope of obtaining answers. If I learned about what Justin was experiencing, then I could address the source of his distress. By providing him with relief, I would be proving (to him) that I loved him and that he could rely on me. Six months later, the psychiatrist told us that despite “obvious concerns,” Justin was too young for her to feel comfortable diagnosing him.

Justin was four at the time, so he qualified for another year of prekindergarten. Given his perceived limited “progress” (at a school designed for neurotypical children), I challenged the adequacy of Justin’s individualized education plan (IEP). After a year of meetings with the child study team (CST), the school district finally agreed to transfer him to a specialized school. Yet soon after the transfer, the school nurse began calling repeatedly for me to pick him up. Justin was reportedly either “hyper” or “upset,” and they did not know what to do to “calm him down.” This is when I realized that this school was not supportive of Justin either. Although I felt as if I did not have more energy to give, the thought of Justin attending a school where he was seen as a “problem” motivated me to persevere. I pushed for a one-to-one aide who could render compassionate tailored help but was met with resistance and further delays. Ironically, the CST case manager, who was also a social worker, seemed most disconnected and insensitive to my efforts. She must have seen the profound sadness in my eyes, yet she never acknowledged how difficult it must have been to attend meetings where each member discussed what was reportedly “wrong” with my child. She looked to me for solutions, rejected my ideas, and then failed to provide any suggestions for how the school could meaningfully help. As a former social worker, I instinctively recognized that she could have played a crucial role in making the process seem less adversarial and more focused on addressing Justin’s unmet needs. In contrast, my actions would have been more in line with Justin’s subsequent CST case manager/social worker, who empowered me to navigate an unknown world with sensitivity, useful information, resources, and advocacy in the best interest of my son. During this time, we took Justin to be evaluated again—this time by an interdisciplinary neurodevelopmental team. After four separate visits, we were given the news. They were the very words that I did not want to hear and yet knew were coming. Justin had autism. He also had attention deficit hyperactivity disorder (ADHD).

No doubt inspired by the tireless advocacy of women who brought me here,

I had been steadfast in my efforts to obtain appropriate help for Justin and determine the source of his unexplained behaviour. However, when the doctor stated her diagnosis, my heart stopped. I could not breathe. At the time, I understood a diagnosis of autism to mean that my child would be vulnerable, misunderstood, and overwhelmed by the world around him for the rest of his life. I remember being unable to respond when my mom asked what the doctor said. I could barely utter the words. The news was just too devastating. Up until then I had been running on empty, but now I felt broken.

Many parents share experiencing the moment they learned of their child's autism diagnosis "with the same intensity as a death" (Fernandez-Alcántara et al. 316). For me, there was a finality associated with learning of Justin's diagnosis. It was the end of a vision and hope that all three of my children would someday grow up and be able to successfully navigate their life course without me. By extension, my profound sadness stemmed from the realization that my son may never be able to live independently and could possibly require supportive care, beyond my lifetime. When I died, who would step in and try to understand and respect his preferences, empower him to reach his highest potential, treat him in a loving manner, and make his wellbeing a valued priority?

As I struggled to understand how this could have happened, I remember feeling a deep sense of guilt inside. Oya Onat and Kocabiyik and Yesim Fazlioglu note that upon receiving an autism diagnosis, guilt is one of the most intense and difficult emotions families struggle to overcome (33). Despite loving my son unconditionally, I also wondered if somehow my actions had caused him harm. It did not help that someone in my inner circle, whom I loved and respected very much, casually mentioned that Justin's autism must have resulted from my "genetic family make-up." I was immediately sickened by the comment, recognizing it as mean spirited, cutting, and mother-blaming—a pervasive societal practice that holds mothers responsible for their children's abilities and psychological health (Caplan). Despite this awareness, due to our close relationship, the comment served to cement my guilt. I carefully examined my past. I remembered eating well during my pregnancy, faithfully taking my prenatal pills, and living a healthy lifestyle. I knew that these decisions could have a profound effect on my children's health and wellbeing. I did not smoke, drink, or use drugs ever. I also fulfilled my end of the bargain and complied, to the best of my ability, with the culturally sanctioned "rules" that governed my behaviour as a mother. I did not forget my place as a woman vis-à-vis my family. I did not put my own needs first. I had not asked for help. I did not discuss my personal problems outside of the home. Instead, I was patient, self-sacrificing, and accepting of all challenges. How could God forsake me when I had done everything seemingly right?

Research shows that Latino family caregivers of disabled children or adults

examine spirituality in an attempt to cope (Salkas et al. 38). Religion or spirituality is generally looked to as a source of strength and higher meaning. Kristen Salkas et al. conducted a study to gain a specific understanding of the role of spirituality on Latino parent coping when their child has autism (38). According to their findings, most Latina mothers believed that their child's autism was a "positive sign from God" (e.g., "a blessing," "a part of God's plan," or a sign of their worthiness as parents) (47-48). Moreover, even those who reported feeling uncertain, remained open to the possibility of a link between the disability and God (49).

I can personally confirm that trying to understand God's role and purpose is part of an internal dialogue that many of us Latinos have when trying to make sense of something unexplainable. My cultural and religious upbringing taught me that I was supposed to have faith that God would help me, that everything occurred for a reason, and to be grateful that Justin was otherwise healthy... was he? I was angry at God. I felt betrayed. I stopped praying. How could I pray for God to grant me hope, strength, and acceptance when I was simultaneously so furious at Him. It felt hypocritical. Yet my internalized cultural values made it impossible for me to openly express my anger, let alone my anger at God. Presented with this internal conflict, I reverted to my default position in times of crisis and chose to repress my feelings (Gil and Vasquez 262). My son needed me to remain focused so that I could continue to advocate on his behalf and connect him with services that would enable him to thrive. I also needed to hold it together for my other children who looked to me for reassurance that everything was going to be okay. There was just no time for me. With these thoughts in mind, I immediately presented the school district with Justin's evaluation results. Justin was then transferred to an out-of-district school for children with autism.

Norat uses contemporary Latina writings to argue that "Adherence to *marianismo* as a basic gender directive can jeopardize women's health and the stability of the nuclear family, paradoxically, the very social unit essential in perpetuating Hispanic culture" (2). She notes that *marianismo* prompts Latinas to ignore their wellbeing (1) and often health issues go unnoticed because a "good woman' rarely voices distress" (10). Over the course of the years described above, I repeatedly suffered with bronchitis and pneumonia. When Justin was five years old, I also developed an ulcer in my stomach, severe irritation of my esophagus, and gastritis. The doctor warned that I should seriously address the source of these conditions if I wanted to avoid developing graver problems in the future. That was my wakeup call. I realized that the expectation that one should continue to stoically give more of oneself at a time when the demands of having a child with special needs were growing was not only physically and emotionally depleting but also dangerously unhealthy. I suddenly considered what might happen if I failed to seek help for

myself. I remembered what happened to my grandmother. Motivated by fear, I sought guidance from a therapist who observed that perhaps my gastrointestinal problems were due to my inability to express anger, choosing to swallow it instead. I then realized that by perpetuating such a limited and punitive value system, I was also harming my children. If I wanted them to develop a healthy expectation of self, I needed to model behaviour that supported this goal. Moreover, if I did not change, I risked losing my own sense of self and with it the ability to be the best mother I could possibly be.

It was around this time that I found the courage to share my spiritual struggle with a wise friend. I shared that I felt angry at God because He had allowed my baby boy to experience so much distress. I was also angry because I had followed “the rules” and yet He was absent when I needed him most. Voicing these feelings out loud made me feel ashamed. My friend quietly listened and eventually noted that part of having a healthy relationship with God is being able to be angry with Him and working these feelings through. Her gentle, supportive, and nonjudgmental words normalized and validated feelings that I was taught were taboo. It was the most liberating and supportive response I had heard until then. With newfound permission to express my true feelings, I was able to take empowered steps toward healing from the psychological burden marianismo had imposed in my life. With healing came perspective, courage, then acceptance.

### **Upon Reflection**

In the previous section, I have aimed to convey my true experience from the time I gave birth until Justin was diagnosed. In referring to Justin’s experience, particularly within the school system, I am referring to behaviour that seemed to indicate that Justin was experiencing pain and terror in relation to the world around him. My concern centred around my lack of knowledge surrounding autism, resulting inability to respond to his distress, and efforts to try to connect with him so that I could understand how I could better address the source of his apparent anguish. His distress became my distress. I am sure many mothers can relate.

Nearly ten years have gone by since Justin was diagnosed. My understanding and thoughts regarding autism have evolved. However many of us mothers are not mentally prepared or knowledgeable on day one. Day one is messy, scary, and overwhelming. There should be space for mothers to describe these messy experiences without having to worry about how they may be received. Again, day one looks very different than ten years down the road. But our emotional healing and acceptance would never occur without being able to share our day one.

To be clear, I have never tried to fix Justin. However, as previously stated, I

am painfully aware that one day I will no longer be able to care for Justin. This concern highlights our failure, as a society, to support families and people with autism in a manner that conveys value, respect, and compassion for neurodiverse people. Over the years I have worked hard at teaching Justin functional and self-care skills with the hope that one day it will enable him to be more easily cared for by a family member or kind person who will show him the love, compassion, and acceptance he deserves. I do not equate this goal with showing any inclination towards ableism. I accept Justin for who he is. He is such a source of pride and joy! He is resilient, clever, charming, funny and has an amazing mischievous sense of humour. I know that Justin must be aware of the enormous amount of love he is surrounded by. I believe he feels safe, understood, and happy, and it shows. I have learned so much from Justin, and now that I have a better understanding of how he communicates and interprets the world, I feel more at ease because now I get it. That being said, I do have a duty to help him reach his fullest potential, as I do with my other two children. That, in my opinion, is part of loving.

### **Implications for Social Work Practice**

Social work practitioners understand that culture plays a significant role in family and individual coping with life-changing events. However, most practitioners are not knowledgeable about cultural values such as marianismo. They are also unaware that Latina mothers who ascribe to this ideal often experience an added layer of pressure, responsibility, and isolation that undermines coping with their child's autism. Without a clear understanding of this culturally sanctioned belief system, a social worker's ability to effectively provide a subset of Latina mothers with needed support and promote healing is substantially diminished. As such, it behooves the social work profession to play an active role in promoting efforts to strive for cultural humility (Sanchez 67) and empowering culturally informed social workers to provide meaningful services. Practitioners must also be proactive, cautious, and creative in their attempts to render culturally informed services.

For any meaningful change to occur, it must be sanctioned from above. I therefore propose that each official governmental office charged with licensing social workers provide practitioners with access to ongoing cultural humility trainings, on lesser-known topics, such as marianismo. I also propose that these offices mandate cultural humility trainings as part of the continuing education credit requirement. We are living in an increasingly diverse society. Culturally informed practice must be actively cultivated. It requires continuous professional development, recognition of within group differences, and introspection. Mothers are a critical entry point to successful engagement with community. As such, increased knowledge of mothering experiences

across cultures is crucial to offering culturally receptive services in a manner that facilitates forward movement, as defined by the client mother. Social work must consider ways to bring mothers knowledge and experiences into social work training by creating opportunities for their voices to be heard. This may be accomplished by inviting existing Latina client mothers, of all ages and levels of acculturation, to participate in focus groups and research, which could shed light on their experiences, receptiveness to services, and identify possible service gaps. By creating and fostering a best practice standard, whereby social workers are expected to consistently build on their understanding and awareness of the cultural impact on coping specific to the population they work with, licensing offices can take a leadership role in addressing the needs of populations served by their licensed professionals, including Latina mothers of children with autism.

Promoting cultural knowledge and its impact on coping among social work practitioners is not enough. In the process of learning, social workers must be mindful not to develop stereotypes or erroneous assumptions that could undermine, instead of foster, a therapeutic relationship. We are all different. To address this concern, it is important that social workers adopt a cultural humility approach and enlist the help of clients, as experts, in efforts to learn about their culture and its possible impact on their life (Sanchez 67).

Humberto Reynoso-Vallejo's study of a radio support group intervention for Latino caregivers highlights the benefit of using cultural humility in servicing the Latino community (67). With the understanding that Latinos are not easily responsive to traditional intervention models of support, Reynoso-Vallejo's study demonstrates how practitioners can effectively use cultural humility as a means to engage Latino clients in the process of identifying barriers to service delivery and develop creative intervention strategies accordingly (67). Significantly, by taking on the role of an interested learner, honing into the complex needs of Latino caregivers, and tailoring services offered to conform with culturally sanctioned values and priorities, the researchers in the study were able to develop useful coping materials, which were well received by all families involved (67). Reynoso-Vallejo concludes that innovation coupled with cultural humility approaches are promising (67), yet more research is necessary (76). As previously noted, the need for such research remains today. Only through learning can practitioners create interventions that are culturally responsive, helpful, and realistically utilized by Latina mothers of children with autism.

Interventions must also address other possible cultural barriers to effective service delivery. For example, practitioners must be mindful that Latinos are generally less inclined to seek mental health services (Andres-Hyman et al. 695). This is especially true for Latina women who adhere to marianista values. It is therefore important that the practitioner start where the client is. Mothers



must feel that the social worker attributes value to what they deem important and the reasons why. To this end, practitioners must remain respectful of a Latina mother's cultural beliefs and begin work within the reality of this framework without judgment or pressure. Moreover, it is critical that practitioners seek to understand the mother's relationship with her family, especially her children, as well as her level of compliance with conventional gender norms that support marianista ideals (Andres-Hyman et al. 699). Adopting a cultural humility approach, as described above, may be helpful in this regard.

Practitioners should also consider restructuring services.<sup>5</sup> For example, Latina mothers of children with autism may initially respond to services offered within a setting that provides practical information about autism and resources for their children. Therefore, social workers should aim to create a space that addresses the needs of the child first, followed by the specific needs of the mother. To this end, practitioners can cofacilitate workshops with other professionals on such topics as understanding autism, school advocacy, estate planning, and therapeutic options, to name a few. They can also provide information on community organizations that offer recreational programs for children with autism as well as state-sponsored supportive and financial resources that can help defray the cost of these programs. Starting with the concrete needs of the child is key.

Next, practitioners must create realistic opportunities for Latina mothers to participate in individual or group therapy and ensure that these services are rendered in a culturally responsive manner. Scheduling is critical to success. When possible, educational and supportive programs for Latina mothers should be scheduled at the same time when their children are otherwise engaged in supportive programs of their own. Providing recreational or therapeutic programs for the children simultaneous to programs for Latina mothers would address possible resistance and enhance participation. Alternatively, practitioners can assist mothers to access respite care so that they can participate in these activities more freely and without the guilt that often accompanies self-care.

Latina mothers who have a child with autism would greatly benefit from being able to discuss their struggles with other similarly situated Latina mothers. A culturally informed practitioner would be able to lead a group that promotes mutual support while remaining sensitive to the internal conflicts presented by marianismo. When indicated, goals can be framed to support personal narratives, for example "helping a mother to assist her family" (Andres-Hyman et al. 699). Finally, culturally responsive support groups can serve to normalize these mothers' experiences and perhaps encourage them to begin to re-evaluate their understanding of mothering and find healthier, less judgmental ways of coping.<sup>6</sup>

Lastly, I assert that social work administrators and executives must advocate for medical and psychiatric physicians to routinely include the expertise of culturally informed social workers as part of their service delivery model. They must also provide practitioners with the support and resources necessary to render culturally informed services. Hospital, school-based, and community-based social workers regularly conduct bio-psycho-social assessments as part of their practice. As such, they are privy to a person or family's psychological functioning, strengths, supports, challenges, and needs. Equipped with this knowledge, culturally informed practitioners are ideally positioned to provide comprehensive and meaningful help at every point of entry, regardless of their work setting. By elevating the role of social workers to that of an essential partner and advancing policies and procedures that enable practitioners to play an active role in supporting the mother client, administrators and executives can create meaningful change. Failure to promote a cultural understanding of motherhood will result in missed opportunities for the profession to reach, engage, and empower a segment of Latina mothers struggling to cope with the implications of having a child with autism, under the weight of marianismo.

## **Conclusion**

Trying to extrapolate myself from marianismo values remains work in progress. I now realize that I cannot follow an ideal that invalidates me. Instead I must simply be the best person, woman, and mother that I can humanly be. This does not take away the pain of my journey, but it does lift an enormous burden. As I move forward in my quest to provide my son with every opportunity I can for him to thrive and reach his full potential, I continue to remind myself that it is okay to cry in front of my children and to feel sad, angry, and vulnerable, and to seek help. My hope is that by attempting to model this more realistic and forgiving posture, my children will internalize a healthier example of the role of a woman and mother and thereby avoid the damaging effects of living a life constrained by "the invisible yolk of Marianismo" (Gil and Vasquez 7). I am certain that many Latina women who have a child with autism can relate to my struggle.

In this chapter, I demonstrate how marianismo ideals are absorbed by Latina women, to different degrees, without their knowledge and regardless of class or education. I share my own experience growing up quietly influenced by marianista ideals and discuss how my efforts to adhere to these beliefs proved damaging. I argue that marianismo tenets not only deprive Latina mothers of critical support but are unrealistic, cruel, and crushing to both their spirit and wellbeing. As a Latina mother and a social worker, I maintain that social workers are uniquely qualified to play a meaningful role in easing

the added strain marianismo imposes on Latina mothers as they attempt to cope with the implications of their child's diagnosis. However, to be effective, the social work profession as well as individual social workers must consider the need to cultivate culturally receptive practices and create change to address this need and support meaningful service delivery. By tuning into the burden that marianismo imposes on Latina mothers, culturally informed practitioners can play a vital role in empowering these mothers to break free from a set of values that has imprisoned them for most of their lives.

## Endnotes

1. Prior to becoming an attorney, I obtained an MSW and worked as a hospital, community-based, and oncology social worker. Although I had always been interested in the law, working with clients diagnosed with cancer who required reasonable accommodations at work reignited my interest in legal advocacy.
2. In this chapter, I use the terms “marianismo” and “marianista” interchangeably. However, more specifically, marianismo refers to a cultural value system, whereas marianista refers to a person.
3. Arturo Morales Carrión provides a comprehensive description of Puerto Rico's changing socio-economic and political status during this time and how it led to mass migration from the island to the United States.
4. Although applied behaviour analysis (ABA) therapy has been identified as an effective therapeutic intervention for children with autism, many disability scholars and parents strongly oppose its use.
5. Reynoso-Vallejo's study highlights researchers' attempts to develop various creative and culturally responsive interventions aimed to respond to Latino caregivers' needs (67).
6. For example, Argentinian group Mothers of the Plaza de Mayo set aside traditional expectations of women and mothers to demand accountability for the disappearance of their children (Fabj 1). Salvadorian mothers who migrated to Canada during El Salvador's civil war adjusted their mothering preferences to help their children thrive (Carranza 86-96), and author Angie Cruz began accepting much needed help after her resistance to do so almost cost her infant son his life (54).

## Works Cited

Andres-Hyman, Raquel C. et al., “Culture and Clinical Practice: Recommendations for Working with Puerto Ricans and Other Latina(os) in the United States.” *Professional Psychology Research and Practice*, vol. 37, no. 6, 2006, pp. 694-701.

- Caplan, Paula. "Don't Blame Mother: Then and Now." *Gender and Women's Studies in Canada: Critical Terrain*, edited by Margaret Hobbs and Carla Rice, Canadian Scholars' Press Inc./Women's Press, 2013, pp. 99-103.
- Carranza, Mirna. "Mothering Through Acculturation: Reflections of Salvadorian Mothers in Canada." *Journal of the Association for Research on Mothering*, vol. 9, no. 2, 2007, pp. 86-96.
- Cruz, Angie. "Learning the Hard Way." *Latina/Chicana Mothering*, edited by Dorsía Smith Silva, Demeter Press, 2011, pp. 51-56.
- Da Silva, Nicole et al., "Marianismo Beliefs, Intimate Partner Violence, and Psychological Distress Among Recently Immigrated, Young Adult Latinas." *Journal of Interpersonal Violence*, vol. 36, 2021, pp. 3755-77.
- "Data & Statistics on Autism Spectrum Disorder." *Centers for Disease Control and Prevention*, [www.cdc.gov/ncbddd/autism/data.html](http://www.cdc.gov/ncbddd/autism/data.html). Accessed 4 Mar. 2022.
- Fabj, Valeria. "Motherhood as Political Voice: The Rhetoric of the Mothers of Plaza de Mayo." *Communication Studies*, vol. 44, no. 1, 1993, pp. 1-18.
- Fernandez-Alcántara, Manuel et al., "Feelings of Loss and Grief in Parents of Children Diagnosed with Autism Spectrum Disorder (ASD)." *Research in Developmental Disabilities*, vol. 55, 2016, pp. 312-21.
- Gil, Rosa Maria, and Carmen Inoa Vasquez. *The Maria Paradox: How Latinas Can Merge Old World Traditions with New World Self Esteem*. G. P. Putnam's Sons, 1996.
- Guerra, Petra et al., "The Telenovela Alborada." *Latina/Chicana Mothering*, edited by Dorsía Smith Silva, Demeter Press, 2011, pp. 209-23.
- "Hispanic Heritage Month." *U.S. Census Bureau*, [www.census.gov/newsroom/facts-for-features/2019/hispanic-heritage-month.html#:~:text=59.9%20million,of%20the%20nation's%20total%20population](http://www.census.gov/newsroom/facts-for-features/2019/hispanic-heritage-month.html#:~:text=59.9%20million,of%20the%20nation's%20total%20population). Accessed 4 Mar. 2022.
- Imperatore Blanche, Erna et al. "Caregiving Experiences of Latino Families with Children with Autism Spectrum Disorder." *The American Journal of Occupational Therapy*, vol. 69, no. 5, 2015, pp. 1-11.
- Kocabiyik, Oya Onat, and Yesim Fazlioglu. "Life Stories of Parents with Autistic Children." *Journal of Education and Training Studies*, vol. 6. no. 3, 2018, pp. 26-37.
- Morales Carrión, Arturo. *Puerto Rico: A Political and Cultural History*. W. W. Norton & Company, Inc, 1983.
- Nevison, Cynthia, and Walter Zahorodny. "Race/Ethnicity-Resolved Time Trends in United States ASD Prevalence Estimates from IDEA and ADDM." *Journal of Autism and Developmental Disorders*, vol. 4, 2019, pp. 4721-30.
- Norat, Gisela. "Health Risks to Latinas: An Indictment of Marianismo." *Label me Latina/a*, vol. 8, 2018, pp. 1-11.

- Reynoso-Vallejo, Humberto. "Support Group for Latino Caregivers of Dementia Elders: Cultural Humility and Cultural Competence." *Ageing International*, vol. 34, no. 1-2, 2009, pp. 67-78.
- Salkas, Kristen et al. "Spirituality in Latino Families of Children with Autism Spectrum Disorder." *Journal of Family and Social Work*, vol. 19, no. 1, 2016, pp. 38-55.
- Sanchez, Belkys. "Cultural Humilty: A Tool for Social Workers When Working with Diverse Populations." *Reflections: Narratives of Professional Helping*, vol. 26, no. 2, 2020, pp. 67-74.
- Stevens, Evelyn P. "Marianismo: The Other Face of Machismo." *Female and Male in Latin America*, edited by Ann Pescatello, University of Pittsburgh Press, 1973, pp. 89-101.
- Téllez, Michelle. "Mi Madre, Mi Hija, y Yo." *Latina/Chicana Mothering*, edited by Dorsía Smith Silva. Demeter Press, 2011, pp. 57-67.

