

**Persistent Mourning:  
Parenting a Child with Autism Spectrum Disorder (ASD)**

by

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### **Abstract**

ASD is a complex lifelong developmental disorder characterized by deficits in communication skills, difficulty with social interaction and obsessive/repetitive behaviors that affect a child's ability to manage stimulus and function within age appropriate expectations. Conventional treatment methods focus solely on the child, relying on parents to be change agents through the administration and implementation of treatment recommendations, failing to consider parent's capacity to function in the role of a partner in the treatment process. This case study is a phenomenological investigation into the perceptions and experiences of parent's from three families raising children with ASD. The author considers how feelings of loss, grief, guilt, and shame affect parent's ability to acknowledge that their child has ASD and understand how their child is impacted, potentially exerting a harmful influence on the parent/child relationship. The implications for clinical practice are to establish a sensitive and honest rapport with parents that fosters their ability to explore the complicated emotions attached to raising a child with ASD and interpret the unique meaning on their lives. As illustrated in the following case vignettes, best outcomes for a child with ASD require that parents recognize and understand their child's impairments, modify their expectations, and amend family lifestyle to support and accommodate their child's specific needs. The benefits of direct intervention with parents demonstrated in this study support the need for further research on this topic.

*\*Privacy Disclaimer: Names and identifying details of the patients and their families have been significantly altered to protect the privacy of the individuals.*

*"A disability may be a better display board for the weaknesses of a cultural system than it is an account of real persons." (McDermott, R., Varenne, H., 1995, p. 327)*

### **Introduction**

Picture a child sobbing, tears running down his face; spasms rack his body as he gasps for air. There is no discernible warning, a switch is flipped, and he quickly escalates to a full-blown outburst. Flailing about, he screeches at the top of his lungs. He is disconnected from his surroundings and those around him. Terribly unhappy, he cries and tantrums habitually, relentlessly inconsolable. No words of reason, no terms of endearment, and no soothing gestures can reach into the chasm that has claimed this child. In her poem "Welcome to Beirut," Susan F. Rzucidlo equates the experience of raising a child with autism to being dropped in the middle of a war zone: "You sure as heck didn't sign up for this and want out NOW!" (Rzucidlo, 2013).

Just a few decades ago, autism was considered a rare disorder, but currently it is diagnosed in 1 out of 88 children (Autism Speaks, 2013). Reasons for such a significant rise in rates have eluded professionals who concur that improved diagnosis is a partial account, but not the full explanation. There is no satisfactory explanation, just as there is no known cause and no known cure. Adding to the mystery, there is no medical test specific to autism; diagnosis is based on the evaluation of a child's development and behavior. Historically, vague definitions combined with a wide range of symptoms and times of onset have resulted in inconsistent identification and diagnoses.

With the release of the Diagnostic and Statistical Manual of Mental Disorders (5<sup>th</sup> ed.; DSM-5; American Psychiatric Association [APA], 2013) in May 2013, the APA amended the diagnostic criteria for autism in an effort to eliminate confusion, improve reliability of diagnosis, and allow for earlier identification. The previous subcategories of Asperger syndrome, Pervasive Developmental Disorder-Not Otherwise Specific (PDD-NOS), and childhood disintegrative disorder have been absorbed under one classification, ASD. Best understood as a complex developmental disorder, ASD is characterized by deficits in communication skills, difficulty with social interaction, and obsessive/repetitive behaviors. The new definition includes symptoms

of hyper or hypo sensitivity to sensory input or unusual interest in sensory aspects of the environment (e.g., no reaction to pain, negative response to noise, fixation on lights). Intellectual ability varies widely, so that children with ASD may be academically or artistically gifted, just as they may have significant learning disabilities. About one quarter of the population with ASD do not acquire language skills, but some of these individuals may learn alternative forms of communication. In the most severe cases, ASD precludes independent living as an adult.

This paper focuses on phenomenological exploration of the experiences of parents from three families that have children who prior to the release of the DSM-5, met the diagnostic criteria for PDD-NOS and my work with them. Despite the defining features of impaired social skills and language development, their children's symptoms did not completely match the DSM-IV definition of autism. PDD-NOS was a diagnosis based on subtle, non-definitive symptoms that may have had a late age onset so that they were not easily flagged. Since developmental milestones such as sitting up, smiling, crawling, and speaking are measured within an age range as opposed to a specific age, indicators of atypical development in children can be complicated to recognize. This population comprises a significant portion of my private practice, referred by pediatricians and schools because I specialize in children with disruptive behaviors as young as three years old. Disruptive behaviors include: not listening and following directions, being uncooperative, acting with defiance, demeanor that does not match the situation (i.e., sudden and extreme mood changes), self-harm or harming others, or behavior that confuses the attending adults (e.g., rituals, hand flapping). There are many neurological and environmental reasons for disruptive behavior that include, but are not limited to: anxiety, attention deficit disorders, learning disabilities, trauma, loss, and a parent's mental health/substance abuse. Since ASD is a disorder of brain development, it impacts a child's ability to manage stimulus and function within age appropriate expectations. These children frequently present as physically awkward, impulsive, have odd speech patterns, demonstrate poor judgment and tend to be concrete thinkers with difficulty generalizing information. On a continuum from mild to severe, their disruptive behavior is symptomatic of an inability to cope with the environment and meet demands.

Writing of her own experience, Dawn Eddings Prince (2010), an anthropologist with autism, identifies unrealistic cultural expectations as a culprit in the failure to thrive of children with autism:

I knew from my earliest years that I lived in a culture that trains disconnectedness. Even kindergarten, can be the worst possible place for a naturally connected person to be. The loudness of bells, the smell of the other children, the endless, cramped facing one direction and trying to pay attention to only one person saying only one thing, and all this in a setting without the kind of warm freedom I understood, predicted that I would fail there. I would sit at my desk at school or on the steps of my house and feel the eating away on the inside of me and the growing pressure outside-on my skin, my eyes, my ears-and I would wonder if I would just disappear. I was sure it could happen and I would cry. I felt as though I was made of stone and pain, as if my frame was a crying fossil, my mouth an ancient desert without sound. (p. 56)

Self-identified as "naturally connected," Prince dispels the notion that having ASD means being disconnected or locked within oneself. In fact, we are presented with an opposing view. Prince describes feeling flooded with sensory input that she was unable to filter. Clearly overwhelmed, classifying kindergarten as the "worst possible place" we can infer that "warm freedom" means the ability to choose to take in only what is tolerable. Obviously, this is not possible in a one-size fits all education system that fails to account for individual differences or needs. Benchmarks of success are based on unified expectations for how children need to behave, how they learn and how they need to be taught. While our more current academic institutions have advanced, there are still many indicators of how we continue to fail children with ASD (Ochs et al 2001; Ochs 2002; Solomon and Bagatell 2010). The image of Prince "made of stone and pain" portrays the shut down that overtakes a child with ASD when he or she feels besieged. "My mouth an ancient desert without sound" can be understood as the accompanied sense of helplessness and inability a child has to communicate or explain what is happening to them. Prince's visceral description challenges the wisdom of traditional treatment plans aimed at conforming a child that has autism to fit within a predetermined system or to be an

outlier. Yet, conventionally that is what happens. The child's presenting behavior problem is treated with behavioral therapy, often in combination with medication. There is minimal to no consideration of how family, social or school systems might make accommodations that support the child's differences, meaning that the onus of successful adaptation is on the child and by extension, on the parents (Gray, 2002). Through following therapeutic recommendations and implementing behavior modification plans, parents become partners in treatment, but the focus of the intervention is the child. This leaves parents on their own to navigate the complex process of adjusting to their child's disability, a concept that does not adequately articulate the "confusion, doubt, and ambiguity" (Kearney and Griffin, 2001, p. 585) inherently attached to having a child with developmental disabilities.

Demoralized and frightened, parents may find it difficult to fully accept their child because the wish to be rid of the symptoms of the disability is in conflict with their love of the child. Since ASD is part of who the child is, inseparable as fingerprints, conceptualizing it as a condition to be eradicated from the child poses a substantial risk that the child may perceive the parent's rejection of the disability as a personal rejection, negatively influencing how the child feels about himself (Kelly, 2005). Further, a parent in denial may block access or thwart appropriate interventions necessary to the child's growth and development. Denial has been named the first stage parents experience in studies that compare the grief between having a child with ASD and the death of a child (as cited in Penzo & Harvey, 2008, Altieri & Von Kluge, 2009). Identifying the stages of grief as denial, anger, bargaining, depression, and acceptance (as cited in Kubler-Ross and Kessler, 2005), Dzubay (2011) explains that although not all people will go through each stage, grief is a non-linear ongoing process. Expounding on the grief surrounding a child's ASD diagnosis, she writes, "Grief for parents is cyclic since there is no real end, no closure, as when a child dies" (2001, p. 29). Describing the experience of unresolved recurrent grief, Simon Olshansky (1962) first coined the term *chronic sorrow* in writing about his work with the parents of children with mental retardation. Over time, this concept has been applied to parents of children with other types of disabilities that include ASD (Brown, 2013). Similarly, Pauline Boss (1973) developed the *theory of ambiguous loss*, grief that is without closure, initially correlated to care takers of

people with Alzheimer's or dementia. More recently, the *ambiguous loss theory* has also experienced a wider application including parents of children with ASD (Boss, 2010, O'Brien, 2007).

But focusing solely on loss and grief or acceptance versus denial is a reductionistic view of how parent's live and cope with raising a child with ASD. A broader and more realistic perspective acknowledges the child's positive contributions to the family, which creates a tension between "joy and sorrow" (Kearney and Griffin, 2001, p. 587). The concept of finding joy through parenting a child with ASD is easily missed because of the historical view that having a child with developmental disabilities is a personal tragedy. This bias attitude has great bearing on parent's perceptions of their child and their identity as parents of a child with ASD because not only are they faced with this prejudice from professionals, family and the public, but it is also ingrained within their own set of beliefs. Recognizing the tension that lies between trying to find positives and feel optimistic while remaining vulnerable to both the reality and preconceptions of a child's disability is a critical insight to clinical work with parents. It is imperative to best practice that therapists understand the complex emotional stages parents traverse in raising a child with ASD and grasp the implications of *chronic sorrow* and *ambiguous loss*. Identifying these cyclic patterns helps "individuals reorganize their thinking and thus begin to employ their usual coping mechanisms rather than remaining "stuck" in a pattern that is no longer appropriate to their changed family circumstances" (O'Brien, 2007, p. 145). The three case vignettes I include highlight parents at different emotional junctures, even within the same household, and my successes and failures in working with them.

### **Marek's Parents: Kristina and Joseph**

Kristina, mother of 12-year-old Marek. confided in me, her voice husky, thick with her Russian accent, "I know what I'm saying is wrong, but the words come out anyway; then I hate myself." Having challenged Marek's request to invite a few children to play at their home, she harshly spat at him that they were not really his friends. Confronting him further, she had demanded that he cite when he had been invited to their homes, knowing that he had not. Humiliated and angry, Marek had sobbed in my office, "I don't have any friends, nobody likes me. It's all her fault, she

hates me." I recognized those last few words as a mantra Marek often sang to his mom at home, "it's your fault, you hate me;" an accusation that had been the theme of many arguments Kristina felt Marek instigated. A master at baiting her when she attempted to limit his social media time, Marek commanded a full repertoire of provocations, from "No, I don't have to, leave me alone," to "Not now, I'm busy, don't talk to me." Relentlessly argumentative, attempting to negotiate and control daily interactions, Marek targeted Kristina with his ongoing tirades. Openly mocking her with contemptuous faces as he mimicked her words in a high pitched whiney voice, he ignored her requests to sit down for a meal, begin homework, turn off the electronics, shower, or go to bed. Dismissive of Kristina's authority, dad Joseph continually undermined her, giving in to Marek's demands to eat when it suited him, delay completing homework, have more time for electronics, put off showering, and extend his bedtime. Diagnosed ASD by a neurologist prior to our work, my services were engaged to address Marek's non-compliance, defiance, and poor social skills.

I treated Marek on and off over the course of more than four years, through a combination of group, individual and parent sessions with the result that his once incessant temper tantrums abated and the frequent phone calls from school stopped. However, his insolent behavior continued to be a dominant force at home, generating friction between himself and Kristina and between Kristina and Joseph, so after a seven month break in treatment, Kristina reinitiated services. While the family unit is intact, Kristina participated in regular parenting sessions with me on her own; Joseph refusing to attend beyond one meeting early in treatment because he did not believe there was a problem. His presence in my office was prompted by my invitation, extended through Kristina, communicating my sincere belief that he would want to know the person to whom he was entrusting the care of his child. Kristina sat quietly while Joseph did most of the speaking, sharing that he saw himself as a peacekeeper between Kristina and Marek, clarifying that he did not find Marek's behavior troubling, and demonstrating no insight to how his actions affected Kristina.

Jumping in, I said, "So, I'm just a little confused; maybe you can help me understand. If you don't think there is a problem, why allow Marek to see me?"

Raising his eyebrows in surprise, Joseph shared, "because it's what Kristina wants."

"Oh, so you want to honor how Kristina feels?" I asked.

"Yes, of course," Joseph responded.

Kristina's jaw dropped open as she stared at Joseph in wide-eyed disbelief, his words incongruous with his actions at home.

I felt my stomach churning with the challenge ahead. Leaning toward Joseph in my chair, I was mindful of keeping my tone neutral, "Well, I'm still a little confused. It sounds like there are times at home when Kristina feels strongly about how to structure Marek's time and you do not agree or support her. Is that true?"

Joseph's eyes met mine as he bobbed his head in agreement. "Yes," his voice resounded, "because she fights with him all the time, I can't take it, there's always fighting. He's a good boy, it's not necessary."

"I see," I affirmed, "you don't like the fighting; you don't think it's good for Marek, and you want the house to be peaceful. Is that correct?"

Nodding his head with a "Yes, definitely!" Joseph placed his open palms up in front of his body, a gesture of conciliation.

Thinking I had made some progress, I folded my arms over my crossed legs as I moved my body even more forward toward Joseph. "I think you are right," I validated, "the fighting is not good for anyone, and from what Kristina has shared, it seems you and she wind up fighting as well."

"Yes, yes, we do," Joseph agreed.

Here was my opportunity; we were on the same page. I had conveyed my esteem for his parenthood, appreciation for his love of Marek, and respect for his point of view. Perhaps, now he would consider participating in the parent sessions with Kristina. I sat up straighter in my chair, signaling my empathy with the slight up and down of my head, but stayed silent for a few moments so we could all absorb what was said. Finally, I ventured, "I'm sure that you would rather not fight with Kristina. I'm wondering if the three of us could meet again and try to figure out some ways for all of you to get along?"

Not surprisingly, Joseph was unwilling to commit, still refusing to acknowledge a problem. When one parent takes refuge in denial, it can have the inadvertent consequence of driving a wedge in the partnership. Hurt and exhausted, Kristina felt isolated in her mission to regain a sense of control, but she was determined to turn the situation around and continued to work with me. She diligently shared a synopsis of our

meetings with Joseph and gradually, over time, began to report that on certain occasions she felt Joseph supported her.

Reflecting back over the years we worked together, I am still struck by my first impression of Marek. He was a smaller version of his tall and thin frame as he entered the playroom with his telltale gawky gait, but it was the expression on his face that caught me off guard. Was he sneering at me? Was that disdain I detected? Reactions I anticipate, even understand from a teen, but not the usual response of an eight-year-old. Not even the sight of Rocky and Cleo, my two little shitkus, warmed his features, and they knew not to approach. As regular assistants in my office, they charm most and rarely stand back. Friendly, docile, and inviting, their presence is usually disarming, often irresistible, and has been demonstrated to have the potential to bridge social and emotional connections for children with ASD (Solomon, 2010). Marek's indifference was not a good first impression. Groaning inwardly, I thought that he looked unlikable; I felt sorry for him and even a little for myself in the belief that engaging him would be a real challenge. It turned out that I was wrong. Hungry for connection, his guard easily fell away and under the façade I discovered a fun loving youngster, anxious for respite from his loneliness. Marek frequently came to sessions with his body rigid and tense, but his shoulders would drop and his face would soften as we played games requiring movement, such as bubble bursting, charades, or volleying a beach ball. His laughter was infectious, creating the shared experience he craved. Although he could not recognize another person's jesting, he loved to tell me jokes and explain why they were funny. I took each credible opportunity to express awe at his cleverness, finding the occasions in our play that I could let him know that I admired his strengths.

He began to embrace our time together, sharing the details of his life, good or bad, at times barely able to contain his news until we reached the playroom.

"Miss Melody, do you know what happened today?"

"No, what happened?" I asked as I held out the requisite hand sanitizer.

Pumping the bottle twice and rubbing his hands together, Marek explained, "We were at the playground and this boy, this boy, he found change on the floor that he picked up."

"Okay," I responded, grabbing the ball from the top of the cabinet, "why do you want me to know that?"

Having moved to the far side of the room, Marek was looking down and pacing the floor in small circles, as he half shrieked, "Well, he was stealing, it's not his!"

"Oh, I see," I acknowledged, sitting down at the children's table with the ball in my hands. Marek's eyes, set in his pinched face, met mine expectantly as he stood still for a moment. He was agitated and I wanted to be careful not to escalate him further. Shifting my chair to face him directly, I shook my head no to indicate I understood what he was telling me, "It didn't belong to the boy who picked it up."

"Noooo!" Marek cried out, looking down and away while he went back to pacing, "and I told him, I told him, he was stealing, but he took it anyway!"

The dicey territory of Marek's black and white thinking presented a challenge; I did not want to heighten his ire. I gently prodded, "Was this at school or the park?"

"The park," he answered looking up, but still walking in circles.

Sinking lower in my chair and looking away so that Marek would not feel confronted, I inquired, "Was anyone around that the change might have belonged to?"

"No, I don't know," he conceded, his brow furrowed with the annoyed shake of his head that foretold of an impending black mood, "there was no one else there, but I told him that it wasn't his, he was stealing it."

Still looking away, I explored "What did the boy say?"

Standing still, hands clenched at his sides, Marek's stiff body leaned toward me as he shouted, "He said he wasn't, that he could keep it because he found it. But that's not true, he did steal it!" His anger crested like a wave in the ocean and I felt the ground around us crumbling.

I could visualize Marek's frustration leading to a full-blown temper tantrum that would derail the remainder of the session, and possibly ruin the rest of his day. On the other hand, he needed to have some experiences that would allow him to build some tolerance and learn to be more resilient. Attempting to defuse his anger, but provide an alternative view, I acknowledged, "Well it is true that it wasn't his, but, I'm not sure I can agree that he was stealing if he found the money on the floor and there was no way to figure out who it belonged to." Hoping that Marek would take the opportunity to reconsider, I asked, "What do you think he should have done with it?"

"I don't know, give it back" he shrugged.

"Okay," I said cautiously, "can you tell me how he could he give it back if no one else was there?"

"I don't know, but he was stealing it!" Marek snapped, his defenses filling the space between us, shielding him against what he perceived as a threat to his integrity.

Wanting to avoid the inevitable distance that an overt challenge would put between us, I validated his feelings, "I can see you are upset by what happened at the park today. I don't think I would have felt the same way, but I do understand how you feel."

Marek continued his circular pace briefly, then abruptly asked if we could play a game.

Gaining trust in the authenticity of my interest in his joys and sorrows, he revealed more of his private self, brimming with deep sensitivities, overwhelmed by intense emotions, seeking support for his hurts and an audience for his successes. Our connection and the confidence Marek had in my ability to share his world brought me great pleasure; at the same time, I felt profoundly sad about all the ways that Marek found the world alien and the world mirrored these sentiments about him. Prince (2010) offers her insider view of ASD as a "disability of context, that what have been labeled symptoms of autism in the context of my culture are inherited gifts of insight and action" (p. 59). I see these gifts in Marek who has great capability and a genuine interest to contribute and share, but remains outside the mainstream because his raw experience of the world cuts through common etiquette. His gentle soul is easily offended by things he does not understand so that he is mistrustful and guarded, using his intellect as a defense, presenting a haughty air of superiority that has been a factor in being exiled by his peers. Context eludes his very literal interpretations causing him to misunderstand social information, leaving him feeling at odds, frequently confrontational with others. Indiscriminate and offhanded, he offends peers and adults alike.

I knew it was important to help Kristina understand that when Marek appeared tactless or insensitive, it was a result of his strong sense of right and wrong, a fact of his black and white thinking. His inability to tolerate being challenged required a delicate balance of supporting him while gently chipping away at his one-sided perspective that I hoped she could learn. In order to feel safe, Marek, like the rest of us, needed to believe that the people in his world were on his side. But, because Kristina's grief was packaged as disappointment in Marek, this was the message

she communicated and to which he responded. Despite our many conversations about disengaging with Marek's goading, Kristina had been unable to contain her wrath. Driven to defend herself, she would retaliate, matching his childlike behavior by responding to his taunts, giving him the power to pull her into one argument after another. An educated professional, a woman who has grown her own business, Kristina was mortified that she could be reduced to respond in kind to her son's temper tantrums. Perceptive to the plight of parents in their book *Emotional Muscle*, Novick & Novick (2010) write:

Parental self-esteem derives from several sources. First is a person's own base level of good feeling about himself or herself. A feeling of competence as a parent, a sense of strength and mastery from developing emotional muscles, builds upon that base. Then comes the assessment of how your child is doing. Is his functioning good enough? Will he be ready for the next step when the time comes? All parents are deeply invested in their work as parents. They also have to face the limits of what parents can do. Other factors are part of the equation, for instance, your child's endowment of capacities and temperament, the occurrence of medical or physical issues, the fact that you are not the only influence; there is the other parent, grandparents, family, care providers and teachers, peers and so forth. (p. 234)

Defying the expertise of parents, ASD hinders a child's functioning and inhibits their readiness for the next step, engendering feelings of shame, guilt, and embarrassment that color parent's interactions with the child. Not only do they assume blame, it is assigned to them by watchdogs of cultural standards that a child "fails" to meet, reinforcing the concept of "their" faulty parenting. Attacked within by their emotions and without by public view (Neely-Barnes, Hall, Roberts, & Graff, 2011), parent's coping skills are weakened, their self-esteem is compromised, and the relational foundation with their child is jeopardized.

Although I had spent much time educating Kristina on the impact of ASD to Marek, she struggled with reconciling the reality of him to the image she held of who he would be. Demonstrating some acceptance through engaging in the parent work to learn how to encourage Marek's success, she continued to vacillate between the stages of grief evidenced by

unrealistic expectations and anger when he did not meet them. I wanted to explore the bitterness in Kristina's attitude toward Marek, hoping that discovering the source of her anger would help her begin to cope with her feelings so that she could rebuild the bond with her child.

"I know you are very frustrated with Marek's behavior at home, I prodded, "it sounds like the two of you go toe to toe on quite a bit of stuff."

Kristina's brow lifted, "Oh yeah, he doesn't listen to me. Everything is an argument."

Holding her gaze, I corroborated, "Yes, we have talked about this many times. Marek has a mind of his own. He's extremely bright and he likes to goad you." Pausing for emphasis, I continued, "In the long run, you lose because all the fighting hurts your relationship."

Shaking her head in agreement, "He is very bright. He is so smart." Kristina pursed her lips as she leaned toward me, her right eyebrow arched high, "He thinks he's smarter than I am, so should I just let him get away with what he wants?" Kristina rocked back in her chair.

We had talked about this before and she knew what I would say, but she needed to hear it again. "No, of course not," I chuckled at the absurdity. Rearranging my face to match the seriousness of my words, "But right now, he's the one in charge. He's more powerful than you are. He is not listening to you and he pulls you into the same arguments over and over again." Looking down with a sigh, Kristina agreed, "I know, but I can't help myself."

Attuned to her mood, I also sighed, "I can see it's very hard for you, something is getting in the way of picking and choosing your battles. Dealing with Marek can be very difficult because he is so smart; it's easy to forget he has some impairment. But, the first thing to remember is that he's a kid and kids rarely see things the way adults do. Then second, because Marek is on the spectrum, he has some blind spots, he doesn't think about things the same way you do. Kristina, we've talked about all of this before, so why do you think that you still get so angry that you lose control of the situation?"

Kristina immediately made a connection to her triggers. Squinting her eyes, Kristina recalled, "Life was very hard in Russia, not like here, we didn't have very much. There were children like Marek at school, I remember, but nobody paid attention."

Curious, I asked, "What do you mean, nobody paid attention?"

Kristina shrugged in response, "They were ignored, the teachers didn't put up with their behavior."

"What does that mean, were they disciplined?"

Quick to dispel my inference, she said, "No, no, not like that. They just were ignored."

"You mean they fell through the cracks?" I revised.

"Yes, exactly; nobody paid any attention to them," Kristina said. Her mood intensified as she reminisced, "It was very tough there, my parents, oooh," there was a pause as she shook her head in emphasis, her eyes far away. "It was different, children were expected to be quiet. We had to pitch in and be cooperative, we had to be respectful. That's the way it was."

"Marek does not fit this profile," I verified.

Kristina's face registered the connection, "Yeah, exactly, that's it."

Demanding, manipulative, and contrary, Marek enjoys many luxuries that represent the reasons that his parents immigrated to the United States. Having previously shared what it was like to wait on line for bread, watch her parents scrape by for bare necessities and be discouraged from laughing out loud in public, Kristina had wanted more for her child. Very different from her childhood, Marek has had the advantages of food in the refrigerator, a plethora of home entertainment, and freedom from political constraints. While logically Kristina understands his lack of appreciation for what he takes for granted, emotionally she is reactive. Overcome with fury when Marek is disrespectful and unappreciative, she knows these behaviors were unthinkable and would never have been tolerated when she was a child.

Parenthood raises many feelings regarding a parent's childhood and the ways they were parented; it is a time when parents consider the strengths and flaws in their upbringing, honing what they liked and rejecting what they did not. Just as they imagine who their child will be, they also imagine themselves as parents, forming an identity with parenthood based on their idealized beliefs. Identity however, is a fluid, interactive construction, framed within social context that continuously evolves (Bagatell, 2007, Holland, D. & Lave, J., 2009, Rocque, 2010). For parents that have a child with ASD, their identity is altered through their experiences with seeking diagnosis, dealing with professions, researching autism and making decisions on treatment (de Wolf, 2013). While these interactions gradually shape "identity as autism parents and with an autism lifestyle," de



Wolf specifies “several crucial moments that signaled dramatic change... 1) the diagnosis moment, 2) early intervention services, and 3) telling family and friends about autism” (2013, p. 76). As a clinician, it’s important to understand that these “moments” are not necessarily sequential, but function as markers that signify to parents that their life and role as a parent has forever changed. It is during this transition that parents begin to live with the contradictions of *ambiguous loss*, the unresolved, recurrent grief associated with the incurability of ASD. Therapists need to be aware that this grief is non-linear and on going to recognize the complex emotions parent experience in various situations and contexts. Astutely, O’Brien observes, “Although parents may accept and cope with the presence of an ASD in their lives, they will never entirely let go of their image of their child *before* they learned the diagnosis” (2007, p. 145). Acknowledging and respecting the image parents hold of their child before the diagnosis is an integral component of treatment.

While exploring Kristina’s impulse to strike out at Marek when he wanted to invite children to play, she revealed how hurt she felt that he was not included with the other children. Very occasionally they would come when invited, but would never reciprocate by inviting him to their homes. Despite her repeated observations of Marek being bossy, arrogant, and generally annoying in social situations, she directed her anger at the other children. Flippantly, she declared that she did not want to entertain them. “Why should I?” was her defense to me. As I reflected softly on Kristina’s pain, putting words to her sorrow, she allowed the sadness hidden beneath her anger to surface. Voice choked up, tears free flowing, Kristina managed, “I don’t know what’s wrong with me; I just can’t accept it.” The “it” are Marek’s limitations, his diagnosis never spoken in the hope that it will cease to exist. As many parents of a child diagnosed with ASD, Kristina suffers along with her child.

Without a cure and treatment that merely targets symptoms, ASD is a lifelong force that the child and family need to learn to live with. Treatment and prognosis are intimately entwined with the parent’s attitude toward their child. Faced with a long bumpy road, filled with the reality that a child does not measure up to her peers, parents are confronted with reconciling their hopes and dreams to the truth of who their child is. Illuminating the intricacies of this process, Larson (1998) writes:

Under careful scrutiny, it becomes apparent that blanket terms used by health professionals such as acceptance, and denial do not clearly capture the mother’s emotional processes in parenting a child with disability. The mother’s acceptance of the child’s disability is often viewed as a first step in a healing process, as described by professionals. Yet acceptance, as borrowed from the conceptualization of Kubler-Ross (1969) of the stages of grieving, may not be accurate in this instance where instead of a certain future, mothers face an indeterminate future for their child with disability. (p. 868)

Larson focuses her study on mothers, but in my experience, both parents mourn the loss of all they believed their child to be and despair about what the future holds. Whether they come to terms or not, there may be denial of the seriousness of the impairment, anger that a child is affected, grief for lost expectations, sadness at missed opportunities, and fears about the long term implications. At the center of it all is heartbreak; being powerless to fix the problem. Each reminder of a child’s impairment aches, evoking strong feelings of shame and embarrassment; emotions that not only influence the relationship between parent and child, but determine if and when parents seek help. The delicate work of engaging these parents is contingent on recognizing the power of these emotions. Baffled and often battle weary, these parents struggle with who their child is.

#### **Genna’s Parents: Lana and Alex**

Imagine how it might feel to be asked to join a game that everyone else appears to be enjoying, but you simply are not able to grasp the rules. You try to get it, but it is elusive. This pattern repeats itself over and over resulting in feelings of fatigue, frustration and irritability that generally lead to meltdowns in children. The meltdowns were only one of the many reasons that nine-year-old Genna wound up in my office. Her difficulty in social interactions, rigidity and recent physical aggression at home were wearing out her parents, Lana and Alex, their attempts to reason with her or set limits triggering severe temper tantrums and hitting. To avoid these conflicts, the family was working very hard to accommodate Genna, held hostage to her moody and unreasonable behaviors. While they had long known that something was not right, they feared learning what it was.

Tears of humiliation welled in Lana's eyes, amassed through the years, her feelings of incompetence surfaced as she described the desperate attempts to deal with Genna's problematic behavior beginning as a toddler. Speaking soft words of comfort, her husband Alex patted her hand, encouraging her to continue as she detailed various accounts of Genna's increasing defiance, non-compliance and public meltdowns. He smiled and nodded while she spoke, occasionally commenting, "It's not so bad," to which she responded, "I know, I know, but we have to do something." Lana's request that I just "work a little bit" with Genna and "teach her some things" made it clear that they were hoping for a quick fix, but I knew this was unlikely as behavior becomes entrenched over time. Cautious in my response, I simply shared that I needed a chance to get to know Genna and that I would do the best I could to assist them with their situation. Their relief was apparent; even if it was for a brief time, they had just handed off the problem to me.

Siskind (1997) writes, on the symbolic transfer of power:

Some parents are able, or willing, or even eager to place their child into the hands of a psychotherapist or psychoanalyst. There are many reasons for this, ranging from despair at their own failed efforts, recognition that their ability to help their child is no longer equal to the situation, childhood pathology so severe that parents cannot cope, extraordinary external events, and all manner of variable ranging from enormous faith in the therapeutic process to parental depression, indifference, and abdication of caring. (p. 133)

Engaging the help of a professional is often a last resort after parents have tried on their own to rectify what they believe is the problem. Some parents accord the expertise of a professional with the authority to remedy the problem and demonstrate their trust through unfettered access to their child. Other parents want to escape the pain the problem has caused to both the child and themselves so they place the child in the hands of a professional to assuage their feelings of helplessness. It was clear that Lana and Alex were disconsolate about their lack of control; however, in their resolve to seek treatment they had identified the problem as belonging to Genna. They perceived "the problem" as fixable, a job they believed they were hiring me to do. Through assigning the trouble to Genna and the solution to

me, they absolved themselves from blame for her behavior. Designating me to be in charge, they created a much-needed break through the temporary illusion that I could and would restore the child they thought their daughter ought to be.

Arriving in my office dressed in mismatched attire, flaunting a style of her own, Genna radiated brightness from within, her smile quick and easy so that I immediately liked her. Peering directly into my face as she spoke, she stood almost nose-to-nose revealing an overly familiar manner that might have been off putting, but I was charmed by the amusement dancing in her eyes. She instantly engaged with me, Rocky and Cleo, asking a multitude of questions about the dogs, the pictures on my walls, where various doors in the hallway led and the hourglass that decorates the desk in my office. Nothing escaped her attention. Her parent's description of how Genna's overreactions to small events controlled the household was difficult to reconcile with the sweet little girl in my office. They painted a picture of a sad, moody, and argumentative child, who did not listen and follow directions, often acted without thinking, was frequently unkind to her younger sister, and had temper tantrums that went on for excessive periods of time.

Given Genna's history of delayed speech, difficulty in social interactions, rigidity and low frustration tolerance, I suspected ASD. In sharing my concerns with Lana and Alex, I recommended a comprehensive assessment through a child evaluation center, an opportunity for several disciplines that may include any combination of a developmental pediatrician, a psychologist, a neurologist and a learning consultant to collaborate on their evaluations of a child. Aside from the complexity of diagnosing children that are continuing to grow and develop, it's important to obtain a thorough assessment for a child that has ASD because it may be comorbid with language disorders, cognitive delays, anxiety and mood disorders, attention disorders, learning disabilities, neurological disorders and medical issues. These children often function very well in some areas, despite significant difficulty in others, making diagnosis difficult and contributing to confusion about why a child does well some of the time and not all the time. Pinpointing areas of strengths and weaknesses is critical to ensuring that a child receives all appropriate interventions with a specific understanding of developmental windows of opportunity, that once closed cannot be recaptured. Genna's assessment revealed a pattern of strengths and weaknesses consistent

with her above average intellect, but reflected the difficulty she had been experiencing both in the academic environment as well as the social arena, confirming my diagnosis of ASD. Four to five times more common in boys than girls (Autism Speaks, 2013), ASD generally takes longer, although the reasons are not clear, to be diagnosed in girls, as was the circumstance for Genna. In situations such as hers, when a child is of above average intellect, it is expected that the child can and should manage herself appropriately. It may appear that a child is intentionally misbehaving so that the adults in their world can become confused, frustrated and angry. This was certainly the case in Genna's family.

There are always two clients in working with children, the child and the parents. The challenges of engaging a child are separate from those of engaging parents which can be complicated by many factors such as: how the therapist and parent view each other's roles; parents willingness to participate; issues of confidentiality; who participates when parents are divorced; who is included in blended families; and parents own mental health are some of the considerations in developing a rapport. While this list is not exhaustive, it is exhausting and may intimidate child therapists from fully extending themselves to parents of their child clients. The intricacies of the working alliance between parent and therapist are the basis of Diana Siskind's book, *Working with Parents* (1997). Her appraisal of the dearth of specialized material on this topic exposes a professional gap indicative of an aversion to this work. Siskind (1997) writes:

More often one has to look to books and articles on child treatment to find mention of this aspect of our work. And then we typically find these references to the child's parents to be brief, cursory, and confined to what are viewed as practical considerations: how often to see the parents, how much to tell them, how to gain their cooperation. Not infrequently these references carry a cautionary tone: parents can be dangerous if one does not find a way to get along with them, parents can undermine the therapist's work, and in some situations parents can even take their child out of treatment. There is frequently an attitude of resignation, one that suggests that parents are the special burden that the child therapist must bear. (p. 4)

To be effective in the delivery of an ASD diagnosis and treatment plan, the therapist must be sensitive to how life altering it will feel for parents to learn that their child has a chronic disability without cure. Responses may range from disbelief, intense anger to deep despair. Branding the internal strife that seizes parents "The embrace of paradox," Larson (1998) identifies the rivalry between "...loving the child yet wanting to erase the disability, hoping contrary to the received opinion of others and recognizing there was no cure all the while seeking solutions to ongoing problems" (p. 870). As is appropriate with any client, the therapist needs to start where the parents are, even when they are not ready, willing or able to hear. Larson (1998) calls attention to how professional agendas that focus on parental "acceptance, denial, overprotectiveness, under-expectation and wishes for miraculous cures" (p. 867) communicate judgments that interfere with developing a productive relationship. While it is the therapist's job to offer a professional opinion about what is best for a child, it is also our job to support parents by respecting and validating their feelings, although they may not be what we would like. As role models, we are in a unique position of demonstrating exactly what we want parents to emulate at home, acceptance and unconditional regard, which means we need to communicate the high value we place on the parent's role in the child's life and an appreciation for what that entails. While some parents make this difficult by directing their angst toward us, it is a good reminder of how parents feel when children do the same.

I had a premonition that this would be the case with Lana, so I prepared myself for the inevitable as I invited Lana and Alex into my office. Sitting halfway forward in her chair, tense and upright, Lana inquired, "So what do you think," attempting to take charge, while Alex said nothing, his eyes downcast as he squirmed in his chair. They were nervous and so was I. It is never easy to tell parents what they don't want to hear and Lana had already requested a quick fix, it was my job to tell her that there are no quick fixes for ASD. As a parent myself, I had an inkling of how staggering this news would be and validated their sentiment at many points in the conversation when Lana repeated, "But she's so smart," while Alex nodded in agreement as he added "Yes, she is." They wore these words as a suit of armor, protection against my pronouncements and a barrier from my judgment while they kept their guard in place.

Lana bristled, "So if she's so smart, what are you saying?"

Cautious and slow, I answered, "Yes, you are right, she is smart, and that's part of what makes the problem so confusing. You expect her to behave according to how smart she is, but what we're talking about is independent of her intelligence. Genna has some delays in her development and a different way of thinking about things that get in the way of her ability to function the way you would expect for a child of her age."

Lana resisted, "I don't understand, if she's so smart, why she is behaving that way?"

My stomach tightened. I weighed her question against the contradiction of her body language and tone of voice, and chose my words carefully: "Well, I'm trying to help you understand that not all of Genna's behavior is in her control. If we look at some of the things that happen, it demonstrates what we're talking about. Think about how easily she gets overwhelmed, then she has temper tantrums like a much younger child because she cannot cope. You've shared that when she doesn't want to do something, she becomes inflexible and you can't budge her, she is not able to see how you feel about things. As you've described, there's a lot of fighting about homework or eating with the family and it still doesn't get her to do what you want. You've also been concerned about all the time Genna prefers to play alone—she's not interested in playing with her sister or spending time with the family. I know this upsets you, but it's just the way Genna is, it doesn't mean she doesn't love or care for all of you, she just operates a little differently. The things that are important to you do not have the same meaning to her."

There was a long stretch of quiet while Lana and Alex tried to absorb what was said.

To fully understand the root of disruptive behavior, the child's capability to meet demands and expectations needs to be considered. Through exploring parents' visions for their child, the gap between the imagined child and the real child with ASD is exposed. Helping parents face this gap is a pivotal step toward addressing their grief and loss, both for the imagined child and the impairments of the real child. The goal is to assist parents in confronting their fears, disappointments and helplessness, strengthening their ability to cope. Working with parents through this process, therapists have the opportunity to foster understanding, tolerance and acceptance, building blocks of a healthy parent-child bond.

Alex broke the silence, "I see what you mean."

Lana's body deflated with his words. Her prickly tenor restrained, she asked, "So you can work with her?"

Noting the tension in my shoulders, I tried to relax as I breathed out, "Yes, I can work with her. Genna needs to build some coping strategies, but I also want to work with you and Alex. You need some help understanding Genna and managing her behavior at home." Amenable, Alex nodded, "Yes, I can see that. It's like we're always fighting."

Unwinding further with Alex's admission, I stated the facts, "Well, it's definitely important to eliminate the fighting. It's not good for anybody and it hasn't really worked. Genna is still not doing the things you want her to do and your relationship has become adversarial."

Lana's posture straightened and her expression became serene. Her voice composed, she dropped her guard momentarily, "It's true, what you're saying is true. I just want to be able to take her shopping or spend the day doing girl things, but she doesn't want to, she's not interested. It's not the way I want it."

The room stilled with the vulnerability behind her words, "It's not the way I want it," the hush resonating with her despair. Like many parents, Lana's dreams of Genna were shaped through the assumption that she would be an extension of her; she had not yet visualized her as separate and distinct. Accepting a child's individuality sounds deceptively simple, common sense perhaps, but it is not. Novick & Novick (2010) lay bare the forces that conspire to complicate it: "From the very beginning, parents are challenged to acknowledge the separateness of their baby rather than taking an easy way out by putting on to the baby their own preconceived ideas or expectations. Only after digesting that idea can we turn our full selves to the task of getting to know *this* baby" (19). Their message is that determined effort is required to recognize and respect a child's uniqueness. Initially, as parents form a relationship with their newborn, it is natural to rely on personal experiences and preferences to identify and interpret the child's needs and feelings. To develop a full appreciation for a child's individuality however, is the result of a conscious endeavor not to take the "easy way," which means that parents need to be aware of and resist the inclination to project themselves and their aspirations onto their child. Nothing had gone the "easy way" for Lana and Alex in parenting Genna, yet, because they had not understood her, they had held onto their image of who they hoped she

would be. Based on Lana's demeanor, I suspected it was going to be more difficult for her to let go of the imagined Genna.

"So you think you can help?" Lana's voice quivered.

"Yes, I do think I can help," I reassured, "But it will be important to work with you and Alex as well as with Genna. I can't promise you that Genna is going to be interested in going shopping, but I know we can improve the relationship."

"Okay, Lana conceded, "So let's start with Genna, and we'll see from there."

I realized I was holding my breath as I exhaled, correctly having anticipated that it was going to be a job to chip away at Lana's defenses; she did not want to participate in parenting sessions.

Efforts to reshape disruptive behaviors are a two-fold process that involves both the child and the parents with interventions tailored specifically for each child to build coping strategies, resiliency, social skills and self esteem while the parent component centers on education and support. I wanted my work with Lana and Alex to focus on educating them about Genna's impairments and directing them in the establishment, implementation and maintenance of appropriate structure and goals. Guiding parents of a child with ASD includes assisting them to: recognize strengths as well as weaknesses; determine appropriateness of fit between the child and goals for the child; organize the child's time and environment to support their success in meeting the goals; provide explicit directions; disengage from undesirable behavior; and pick and choose their priorities. Like many parents that have a child with ASD, Lana and Alex needed to change their interactions with Genna, but that requires parents to be united and vigilant, which is best achieved when both parents are involved in treatment. Alex brought Genna to all her appointments, shared concerns he and Lana wanted to address, and communicated the results of our conversations with Lana. I knew the arrangement was not ideal; something gets lost in the translation of third party information, but it was what I had to work with. Many of my contacts with Lana were on the phone, when she would call to solicit my advice about a particular situation, the conversation always ending with my suggestion that we meet in person. Lana consistently remained polite, even when I stated that the topic was too complex for a brief phone conversation, offering her work schedule as a reason for not being able to come in. Over time, I found myself returning her calls when I knew I

had a little extra time to spend on the phone, understanding that she would not schedule an appointment unless she felt desperate. I began to help Genna jot little notes about her progress to take home and share with her family. On several occasions, I reached out to Lana by phone to share the details of an exciting break through. Despite these efforts, Lana's lack of involvement in the parent sessions resulted in the family's continued difficulty sustaining the committed daily effort required to uphold the structure that appeared to work best for Genna. There was some success with getting homework completed on a timely basis, having meals with her family, and bathing regularly, but it was intermittent. One of the most far-reaching benefits of treatment was the improvement in the relationships with her parents and siblings as her extreme temper tantrums diminished and she stopped hitting.

There are many reasons that parents may resist having sessions that they perceive as focusing on them or stirring up unwanted emotions. In a rare meeting with Lana, she shared that it was simply too painful for her to face the reality of Genna's diagnosis because she believed that Genna's behaviors were a reflection of her inadequacies as a parent.

"It's amazing," Lana gushed, "Everybody is getting along better now and we have you to thank."

Surprised by her display of gratitude, it took a moment before I said, "Actually, the credit goes to all of you. You, Alex and Genna have done all the hard work." I paused as I measured my words, "The structured routines and small natural consequences we put in place have really helped, but because they're not implemented consistently, we don't get the full benefit."

Tension creasing her brow, Lana asked, "So what do you suggest?"

Seeing an opportunity to persuade Lana to participate in parenting sessions, I wanted to be diplomatic. "It's a lot of hard work to be so structured and monitor Genna so carefully," I emphasized, "Basically it's a full time job."

Her brow smoothed as Lana conceded with a smile, "Yes, it really is."

Trying to gauge the risk of rupturing the connection, I laid out my line of reasoning, "But we have seen how well it can work, Genna's behavior has improved, but it could still be better. You would get much greater results if you and Alex attended parenting sessions together. It's extremely difficult to maintain the high level of support Genna requires to be successful and I

think the sessions would help the two of you be more consistent.”

Lana’s reply was meek, “Probably you are right, but it’s too much for me.”

“What is too much?” I matched her tone.

Emotion trembling in her voice, Lana said, “I guess it’s just talking about Genna and the way she is. I always blame myself. I feel responsible, like I’ve done something wrong.”

We sat in silence as the weight of her words settled, her pain so tangible that my body responded with a sudden heat that began in the middle and worked its way up. Reflecting on her grief, I understood her avoidance as denial. While I believe she tried to accept the truth, her sadness was so overwhelming that she retreated back to the shelter of her denial.

Wanting to offer comfort, I shared, “Lana, I certainly don’t want to minimize how you feel, but I do want to present you with another perspective. Genna’s ASD is something she was born with; it has nothing to do with something you did or did not do. She has many wonderful qualities that make her who she is. She’s intelligent, usually has a smile on her face, she can be very sweet, and she has a great sense of humor. Just like the rest of us, she’s not all one way or another, but a combination of strengths and weaknesses. I’m wondering if sometimes you forget about her strengths.”

Straightening in her chair, the mood lightened, Lana acknowledged, “Maybe sometimes, thank-you for that.”

I have encountered sentiments similar to Lana’s in several other families; children that exhibit disruptive behavior can challenge the core of who a parent is. In the first chapter of *Far From the Tree*, Andrew Solomon (2012) enumerates the implications of raising a child with a disability:

Parents’ early responses to and interactions with a child determine how that child comes to view himself. These parents are also profoundly changed by their experiences. If you have a child with a disability, you are forever the parent of a disabled child; it is one of the primary facts about you, fundamental to the way other people perceive and decipher you. Such parents tend to view aberrance as illness until habituation and love enable them to cope with their odd new reality—often by introducing the language of identity. Intimacy with difference fosters its accommodation. (p. 6)

Solomon’s insight into how children come to see themselves is often eclipsed in parenting a child with ASD, as attempts to remediate disruptive behaviors may unintentionally wound an already fragile self-image. These are children that feel out of sync with their environment and others, fail to develop age appropriate skills to self soothe, and begin on a negative trajectory, which is often reinforced through disapproval at home and school. The disparagement parents experience may cloud their judgment and worse, potentially be directed at a child. Solomon traces the road of habituation, love, and coping with the potential of leading to the language of identity. It is how the journey on this road is travelled that defines who the child will be, who the parents will become, and what their relationship will look like. The relationship between Genna and her parents had suffered through Lana and Alex’s efforts to win a perceived battle of wills; their nagging, yelling, and punishing were alternated with giving in, and at times, giving up. In seeking help with Genna’s disruptive behavior, Lana and Alex had been unaware of their role in the problem and therefore, their role in the solution as well.

#### **Noah’s Parents: Kimberly and Jorge**

The stricken look on a parent’s face when they first register the news that their child has ASD is best described as an implosion. When parents learn that a second child also has ASD, it is a demolition by a fast moving wrecking ball. Kimberly and Jorge initially requested treatment for their older daughter Betsy who had not yet been diagnosed with ASD; her symptoms were subtle with a predominate lack of interest in the social arena. Like many girls, Betsy’s diagnosis came late at age nine, but this time my referral to a child evaluation center was more than collaborative, it was to uncover the diagnosis that I just couldn’t put my finger on. Extremely social herself, Kimberly was particularly perturbed by Betsy’s preference to play alone, so we agreed to try group therapy to address her social isolation, but it quickly became clear that she dreaded coming to the groups, endured them, and could not wait for them to end. I did not see the benefit in continuing to subject her to this format of treatment, but the decision to terminate was difficult for Kimberly to accept. She repeatedly stated, “I don’t understand, it shouldn’t be this way,” and asked, “Isn’t there anything else to do?” Kimberly’s anguish captures how “assuming that there is one way to be in a culture encourages the

misunderstanding that those who are different from perceived norms are missing something, that it is their doing, that they are locked out for a reason, that they are in fact, in reality, disabled" (McDermott and Varenne, 1995, p. 326). An intelligent, easy-going, compliant child with the typical autistic characteristics of limited interests and repetitive play, Betsy was basically content. The greatest result was helping her parents to understand that while she was not interested in being social, she was neither lonely nor unhappy.

It was during one of these parent sessions that Kimberly and Jorge raised some concerns about their five-year-old son, Noah. They described him as non-compliant and defiant, reporting that he had recently been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) by a neurologist. A chubby little boy with a swarthy complexion and stocky body build, Noah resembled his Dad; presenting with his head down and shoulders slumped, he impressed me as a child who felt dejected. He instantly developed a mutually affectionate bond with Rocky and Cleo, spending much of his time holding, petting, and talking to them, which suited his discomfort with eye contact. Noah could be coaxed to look up and even make eye contact, but his face would distort into a grimace, emphasizing the expense of his effort. Maintaining a consistent effort to coach him to look at people when they or he spoke, coaxing "Come on buddy," Kimberly and Jorge would not concede to his discomfort. I was in awe of Kimberly's tireless energy, vivacious, always smiling, she habitually bestowed Noah with a soft chuckle, campaigning against his grouchy moods.

So much of diagnosis with young children is dependent on collateral reporting from parents, teachers, other professionals, and even children when they are old enough to provide insight into their experiences. Soon into my work with Noah, I began to observe behaviors beyond the scope of ADHD, realizing that Kimberly and Jorge had not provided all the information. Irritated by unseen forces, Noah frustrated easily, resorting to growling and baring his teeth, stunning me by banging his head into my office furniture and punching himself with his fists. That invisible switch would flip and much of his verbalizations would become garbled, often incomprehensible and occasioned with self-depreciative declarations. Astonished that Kimberly and Jorge had failed to mention these behaviors, I was even more amazed that for each revelation I shared, they responded with the cool calm of parents

humoring a toddler with the belief that the behavior will be outgrown.

"I've been concerned about some of Noah's behaviors and I wanted to talk with you about them," I began.

Watching me expectantly, Jorge cleared his throat, a nervous habit, while Kimberly's smile froze in place.

Unsure how they would respond, I gingerly eased into Noah's symptoms, "He has actually growled and bared his teeth in my office."

Grinning as though amused, Kimberly laughed weakly, "Yeah, he does that sometimes, I think it's when he gets frustrated."

My eyes swept Jorge's face, expressionless as he nodded his agreement.

"Yes, he seemed unhappy with how his drawing was turning out," I acknowledged, "But growling and baring his teeth demonstrate extremely poor coping skills."

Attempting to normalize the behavior, Kimberly murmured, "That's my quirky little boy."

Shifting in his chair, Jorge cleared his throat again, revealing his unease.

"I have to say, even more concerning," I stressed, looking in each of their faces, "Was that he was banging his head into my cabinet?"

Kimberly's nonchalance surprised me, "Oh, sometimes he bangs his head into his headboard at home when he's upset."

Noticing the twinge in my stomach, I worked to keep my voice impartial, "He was banging his head pretty hard; obviously, I don't want him to get hurt. Does he bang his head that hard at home?"

"Yes, I have to stop him," Jorge came alive, "Sometimes I need to restrain him for a while or he hits himself."

With a nervous giggle, Kimberly blurted, "Yeah, that's our little Noah," minimizing his behavior.

My responsibility to Noah foremost in my mind, I detailed how he had also punched his head with his fists in my office simultaneously calling himself stupid and an idiot.

Kimberly became solemn as I explored triggers for his frustration, relaying, "We're not always sure, it could be something very small, like he thinks he didn't do something right." Automatically, a smile returned to her lips, incongruent with the heavy sigh she released, as she said, "He's such a munchkin."

Joseph intervened, "We don't really know, anything might upset him and then he does those things. We just thought he would outgrow it."

"How long has this been going on?" I questioned.

The dawning awareness that I might say something they didn't want to hear drained the color from Kimberly's checks.

Circumspect, Jorge's face grayed with his answer, "A few years. Why? Do you think something is wrong?"

I knew I had to tell them what I thought, but I empathized with how difficult it would be to hear. Green (2003) combines her own with other parent's experiences of having children with disabilities, documenting how professionals objectify the disabled and their families leaving them "...feeling marginalized and even pathologized rather than understood, respected, and valued" (p. 3). Endeavoring to be candid without alienating Kimberly and Jorge, I presented my case, "I think that we can see that Noah's reactions are pretty extreme and from what I've seen and heard, they don't match the situation. I've worked with a lot of kids in his age group and these are not behaviors most kids have. I don't think he will just outgrow them."

Kimberly's forehead creased with alarm, "Really? You don't think it'll just get better as he gets older?"

"No, I don't," I answered sincerely, "I can't say for sure what will happen, but there is a chance these behaviors could get worse. Right now, he's small enough to physically restrain if you have to, but think about what will happen as he gets bigger. Will you be able to prevent him from hurting himself?"

I waited for their response, but they were stoic, their glassy eyes staring right through me. Certain that I would be devastated in their position; I knew that there was no good way to deliver this news. Straightforward, I said, "I think that Noah shows signs of being on the autistic spectrum. He should be evaluated by the developmental pediatrician that saw Betsey to confirm. If there are things we can do to help Noah that we are not already doing, we want to do them as soon as possible."

A brief flicker of emotion passed over Jorge's face as it rearranged into a blank while Kimberly, with her glass half full personality, faltered momentarily before masking the hurt behind her smile. They had attempted to explain away Noah's aberrant conduct; desperate to see him as typical, they had held onto the hope that one out of their two children would fulfill the role of an average kid in the family. I could sense the wall Kimberly erected to keep the information out, a force field of denial swirling around her. While almost all parents ask me questions about my opinion on a

child's diagnosis, Kimberly and Jorge did not. Nor did they challenge or dispute the relevance of symptoms I referenced as indicators of ASD, as most parents do. They were unusually silent, followed through on the evaluation, gained confirmation; but never spoke Noah's diagnosis aloud. This second serious blow spun Kimberly and Jorge apart, unable to support one another with their grief. The distance between them was palpable during parenting sessions when they sat separately and did not look at one another, speaking directly to me, but barely to each other. Jorge was mostly observant during these meetings while Kimberly took over, intuitively focused on Noah's strengths, dubbing him "such a sweetie," punctuating her choice to see him that way. With the understanding that Noah's self image was tied to her perception of him (Solomon, 2012), Kimberly was determined to remain positive, directing her anguish toward Jorge by lashing out and criticizing his predisposition toward quietness as though it were the root of the problem. Impassive as he absorbed her frustration and anger, the tension in his body language gave away the strain. I felt like a spectator to a marriage disintegrating, the enormity of having two children with disabilities more than it could survive. We agreed that Kimberly and Jorge needed to have their own sessions, which were helpful, but uncovered some problems beyond the scope of adjustment to their new identities as parents of children with ASD. Since they associated my involvement with their family specific to the children, I referred them to another professional for marriage counseling and decreased the frequency of our sessions to an as needed basis. While they persevered as a couple, their relationship remained shaky.

What began as blinders to Noah's deficits was repackaged into an elegant model for parenting with consistent attempts to understand Noah's perspective regardless of his limitations. Kimberly and Jorge showered him with love, adjusted their expectations, helped him navigate road blocks, and smoothed his path as much as possible completely eliminating the conflict between parent and child that occurs in so many families that have a child affected with ASD. Easy in theory, implementation is not because we live in a culture eager to substantiate our "potential failings as a single entity" (Prince, 2010, p. 62), subjecting child and parent to ongoing scrutiny and censure, burgeoning their strain. Unable to keep up academically, socially or emotionally, Noah's behavior became a frequent source of shame and



embarrassment, replicating the behaviors exhibited in my office at home, school, family gatherings and a multitude of public venues when he became overwhelmed. Kimberly and Jorge never allowed it to cloud their judgment, constantly advocating with school, camp, and extended family, educating the adults in Noah's life on how to help him be successful while simultaneously trying to create opportunities for him to feel good about himself. As long as Noah remained in treatment, many of his early self-injurious behaviors subsided, but during the nine years we worked together, attempts to extend time between treatment sessions would result in a resurgence of these outbursts and under duress, he would regress to garbled mumbling and growling. For many children, early intervention can truly minimize the impact of ASD, but this was not the outcome for Noah; as he grew older and the demands grew greater, despite many combinations of medication, therapeutic intervention, and one-on-one academic assistance in mainstream education, he presented increasingly impaired. His lack of improvement points to Solomon's assertion regarding autism, "To add to the frustration, many children are unresponsive to any form of treatment, but the only way to figure that out is to treat them for a long time and then give up" (p. 223). While I agree that in some extreme cases of autism a child may not respond to treatment, in Noah's case despite an apparent lack of desired response, I still believe he benefitted. Arriving in my office downtrodden, filled with doom and gloom, he would gradually brighten, leaving visibly lighter with his head up, even attempting to look in my direction as he mumbled, "Good-bye Miss Melody."

How can we know or fully appreciate what a child might gain from being therapeutically supported when his ability to share that information is so compromised? Treatment does not necessarily erase or even significantly reduce the symptoms of ASD, but it does provide acknowledgement and unconditional regard that may be the only respite from a constant onslaught of corrections and criticisms for a child with disruptive behaviors. Demonstrating his appreciation for our time together, Noah gifted me an assortment of school and camp hand-made treasures, cards for occasions, clay figures, holiday decorations and pottery pieces that still decorate the shelves in my office. He touched my heart. I did not want to let him down, but as he aged up there were more and more times that he appeared disconnected in our time together and I could not

seem to reach him. Having worked with Noah from such a young age, this was terribly painful for me to witness, these sessions leaving me depleted, feeling helplessly ineffective, and unsure how to proceed. His downward spirals were consistently triggered by his inability to manage an age appropriate expectation, most often within his academic setting, despite his high level of support. Still, Kimberly and Jorge never spoke of his diagnosis, one or the other stating, "I don't know why he's like this," and heaving a sighed, "Yeah, I know," to my reminders about Noah's limitations.

I worried about his quality of life, certain that he would be happier in an alternative school environment. Sadly, Kimberly and Jorge were slow to follow my recommendation, which surprised me because I knew that they truly understood that his success was dependent on an appropriately supportive environment.

"The school called again today, Noah was growling and hitting himself with his fists. They weren't sure what set him off," Kimberly reported matter of fact, adding, "He went to the counselor's office and she calmed him down."

Disappointed at the casual acceptance of Noah's ongoing distress, I broached the subject of his school placement as I had numerous times before, "You know that this is happening increasingly often. Truthfully, I'm surprised the school has tried so hard to maintain him; his behavior is so disruptive."

Sitting at the edge of her seat, looking perplexed, Kimberly was quiet.

I forged ahead, "My concern for Noah is that these frequent outbursts demonstrate that he is not comfortable in this setting, and he's directing his frustration and anger at himself which is debilitating. The school has tried very hard to accommodate his needs, but it's clear that it's not working. I really believe he would do much better in a more appropriate setting."

"I know you think that," Kimberly countered, "But we just can't do that. He needs to learn how to cope and hopefully, he will."

Sympathetic to her sorrow, I touch on her denial, "We would all like that for Noah, but so far, it hasn't happened," continuing, "I think Noah needs to be in a place where he feels safe and then he can begin to progress."

Squaring her shoulders, Kimberly whispered, "I can't do it."

While denial was at the root of their decision not to follow my recommendation, I also wondered about bargaining. It seemed as though

Kimberly and Jorge believed that if they played down the signs of Noah's low threshold of tolerance, somehow through their willpower, he would magically develop the necessary skills to function in the mainstream. Fully cognizant of how besieged Noah felt, Kimberly and George held onto the idea that he might still get better, possibly desensitized to his persona they did not recognize how much he was suffering. They finally acquiesced about a year later, when Noah recurrently verbalized suicidal and homicidal ideation. Drained and weary, Kimberly and Jorge dreaded facing what they thought would be a fight with the school district. Unequipped, however, to manage Noah's frequent threats of harm to himself or others, the district was quick to comply and many of Noah's disruptive behaviors were diminished in his new setting. Designed with the flexibility to accommodate a child's specific needs, the alternative environment supported Noah—a very different experience from mainstream education where he was subjected to daily reminders of his school failure. Recounting their sorrow about Noah's inability to function in public education and the fear of what it meant to have him attend an alternative school, Kimberly described it as the culmination of a series of failures. I sympathized with Kimberly's perspective that placing her son in an alternative school felt like failure, recognizing the influence of public perception. Confronting the institutional construction of disability, McDermott and Varenne (1995) state, "It takes a whole culture of people producing idealizations of what everyone should be and a system of measures for identifying those who fall short for us to forget that we collectively produce our disabilities and the discomforts that conventionally accompany them" (p. 337). Defining success as the ability to function within particular parameters of mainstream relegating those who cannot to an "alternative school," we clearly marginalize the children that fall outside these arbitrary limits. This ubiquitous attitude pervades our culture so that children with ASD are consigned to fit or fail. They are the square peg being forced into the round hole and it takes parents with strong emotional muscle (Novick & Novick, 2010) to recognize that it is their responsibility to alter the shape of the round hole to accommodate their square peg child. It was almost immediately after Noah began his new school placement that Kimberly and Jorge realized how much better it was for Noah and, in turn, their family; his mood stabilized as he felt less threatened, his acting out behaviors decreased

substantially, and he made a couple of friends. Following Noah's quick adjustment to his new placement, we were able to terminate treatment, but to my great pleasure, I still receive an occasional call from Kimberly, filling me on Noah's latest gains and how well he is progressing.

### Conclusion

ASD is a lifelong developmental disorder with no known cause or cure that presents with confusing symptoms, complicating diagnosis and treatment. The grief of having a child with ASD has been compared to the grief parents experience when a child dies, except that there is no closure. The lack of resolution for parents of children with ASD creates a cycle of recurring grief that has been termed *chronic sorrow* by Simon Olshansky (1962) or *ambiguous loss* by Pauline Boss (1973). The child looks physically healthy, but fails to attain anticipated milestones, does not meet expectations, and exhibits lifetime impairments, perpetuating the parent's mourning. Although they may not all be experienced, and can occur in any order, the stages of grief include: denial, anger, bargaining, depression, and acceptance (as cited in Kubler-Ross and Kessler, 2005). The cyclic nature of grief for parents of children with ASD is unique in that movement can occur between stages at various times during the child's life (Dzubay, 2011). Adjustment to having a child with a chronic, incurable disability is so overwhelming that denial is the usual first response (Altiere and Von Kluge, 2009), but traditionally, therapeutic services are limited to the child. Parents receive minimal support, primarily in the form of recommendations or referrals for augmentative services. Kearney & Griffin (2001) suggest that a missed aspect to therapeutic work with parents is the ongoing tension they face in their efforts to balance hope and optimism with the reality of their child's developmental disability (p.587) while contending with social and personal biases. In her ethnographic study, de Wolf (2013) explains, "With all these efforts focused on what autism is, who has it and in what form, what causes it, and what can treat it, there has been little scholarly attention paid to the way it can be experienced in the everyday lives of those affected, especially parents" (p. 24).

It is my hope that this case study will contribute to the small but growing body of research on the phenomenological experiences of parents that have children with ASD. Fundamental to a child's personhood, as a way of being, ASD has

a profound effect on parents as well. It has been my experience that a holistic family approach that provides support for parents as well as the child, results in the best prognosis for living with ASD. Because parents have the responsibility to coordinate services and orchestrate the recommended therapy strategies at home, they become facilitators of their child's development, suggesting that the parent-child relationship is a compelling predictor of the child's success. Engaging parents of children with ASD in treatment requires sensitivity toward how their lives have been changed. There is a transition from being the parent of a "normal" child to being the parent of a "disabled" child, which is informed by interactions with professionals, schools, family, friends, and the general public (de Wolf, 2013). Aside from confusion and despair about their child's diagnosis, parents are subjected to the negative perceptions of others (Gray, 2002) adding to their distress. They have a story of all these experiences, a narrative of the contradictions of emotions they live with and their interpretation of what it means to them. I suggest that therapists need to encourage parents to tell their story, building trust through communicating interest and respect for their journey into the world of autism. A meaningful rapport can only be established by demonstrating curiosity and high regard for the opinions and ideas they hold about their child and treatment. "Parents may or may not be experts on autism, but they are experts on their child" (Altiere & von Kluge, 2009, p. 150).

As in any therapeutic encounter, it is the relationship with the therapist that allows parents to bare their vulnerability and be open to support. Although each parent experience is different, I have found that one of the most significant impacts I can have is to validate their sense of loss, putting words to the ambiguity of their situation. O'Brien (2007) claims, "Labeling the experience of ambiguous loss for parents of children with ASDs is important, because, in most cases, parents are not aware that their distress, confusion, and immobility are located in the inherently ambiguous situation and not in themselves" (p. 145). Through acknowledging and exploring parent's fears, anger, shame, guilt, and disappointment, therapists can validate the grief felt for the loss of an imagined child, helping to process emotions that block acceptance of the real child with ASD. Then, parents can be assisted to identify and focus on their child's strengths, finding new, more appropriate meanings of success for their child, and in turn for themselves.

Another facet to working with parents entails educating them on how to best advocate on behalf of their child. Since the needs and environment of each child vary, so too do the ways parents need to advocate. However, it is pivotal to treatment that therapists comprehend the magnitude of this responsibility, regularly encountered with schools, family, friends, and the general public. Sharing her thoughts on parenting her autistic son, anthropologist Dawn Eddings Prince (2010) eloquently expresses how the task of advocacy translates for many parents that have a child with ASD: "...because being seen as broken is, to a large degree, dependent on context, I would protect him from the elements of this culture that would wound him wrongly" (p.61). She draws attention to social philosophies that define disability, discrediting those so defined, extending stigma to their parents (Gray, 2002). Overcoming the barrage of judgments and reinforcing the necessary sustained efforts required to advocate for a child is much of the work with parents. This can only be accomplished through creating a sensitive and honest relationship with parents that establishes a precedent for them to explore and interpret the meaning of their experiences (Kearney & Griffin, 2001). I join with Prince and an increasing circle of others in an effort to examine the fear and ignorance that stands in the way of re-conceptualizing an ethos of acceptance that ultimately supports and integrates all of our members.

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