

# Understanding Autism: How Family Therapists Can Support Parents of Children with Autism Spectrum Disorders

ALEXANDRA H. SOLOMON\*  
BETH CHUNG†

---

*The number of children diagnosed with an Autism Spectrum Disorder has increased dramatically in the last 20 years. Parents of children with autism experience a variety of chronic and acute stressors that can erode marital satisfaction and family functioning. Family therapists are well-suited to help parents stay connected to each other as they create a “new normal.” However, family therapists need updated information about autism, and they need to understand how family therapy can help parents of children with autism. Because having a child with autism affects multiple domains of family life, this paper explores how family therapists can utilize an integrative approach with parents, enabling them to flexibly work with the domains of action, meaning, and emotion.*

*Fam Proc 51:250–264, 2012*

The United States is facing an autism epidemic. The latest statistics suggest that one in every 91 children in the US has been diagnosed with an Autism Spectrum Disorder (ASD) (Kogan et al., 2009). The rate of ASDs has greatly increased from the 1980s when children were diagnosed at a rate of two to five in 10,000 (Kogan et al., 2009). Little debate remains about whether we are seeing an increase in actual cases or an increase in diagnosis, as recent research has indicated that, even when controlling for variables like casting a wider diagnostic net, the increase is real (Hertz-Picciotto & Delwiche, 2009).

As the term suggests, ASDs occur on a spectrum from “full blown” autism, to Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), to the mildest version, Asperger’s Syndrome. Although the names of the diagnostic labels are likely to change with the publication of DSM-5 (Swedo, 2009), the fact remains that a child with autism<sup>1</sup> presents with a variety of symptoms that impact the quality of his life and the functioning of his family.<sup>2</sup>

---

\*The Family Institute at Northwestern University, Evanston IL.

†North Shore Pediatric Therapy, Glenview IL.

Correspondence concerning this article should be addressed to Alexandra Solomon, The Family Institute at Northwestern University, Evanston, IL, 60201. E-mail: asolomon@northwestern.edu.

<sup>1</sup>Throughout the paper, the word autism refers to the entire spectrum of ASDs, from mild to severe.

<sup>2</sup>Because boys are four times as likely as girls to be diagnosed with autism, the masculine pronoun will be utilized here (Kogan et al., 2009; Yeargin-Allsopp et al., 2003).

Raising a child with autism takes a toll; parents of children with autism have higher stress levels than parents of typically developing children (e.g., Baker-Ericzen, Brookman-Fraze, & Stahmer, 2005; Brobst, Clopton, & Hendrick, 2009) and parents of children with other developmental disabilities (e.g., Abbeduto et al., 2004). These families also report lower family functioning (adaptability and cohesion) and lower marital happiness than norm groups (Higgins, Bailey, & Pearce, 2005). Parents of a child with autism are nearly twice as likely to divorce as parents without a child with autism (Hartley et al., 2010). Further, the risk of divorce for parents without a child with autism decreased as the child reached late childhood and early adulthood, while the risk of divorce for parents with a child with autism remained high through adolescence and early adulthood (Hartley et al., 2010). On the other hand, raising a child with autism can unify a family. Research has indicated that a considerable number of families with children with autism “display factors of resilience—reporting that they have become stronger as a result of disability in the family” (Bayat, 2007, p. 702).

In order to access that resilience, parents of children with autism may benefit from psychotherapy to address the multiple chronic and acute stresses of having a child with autism. Although there is no research on the efficacy of couple therapy specifically for parents of children with autism (Ramisch, 2010), it has been suggested that systemically oriented therapists are uniquely positioned to provide integrative support to these parents (Hillman, 2006). Parents face problems in multiple domains (accessing supportive/therapeutic/educational services, balancing work and family, and dealing with powerful feelings, to name a few), and an integrative approach allows family therapists to flexibly address interrelated problems or constraints.

Family therapists have a unique contribution to make to this population, but they may feel daunted by, or somehow not authorized to, work with these parents, perhaps because historically it seems that children with autism (and parents dealing with those children) have “belonged” to the developmental disabilities community. Or perhaps family therapists, who likely do not have expertise in autism, believe they do not know enough about the disorder to do this work. Parents seeking family therapy are likely to know more about autism than their family therapist ever can.<sup>3</sup> However, the family therapist carries important expertise about systemic dynamics and adaptive coping. As medical family therapy posits, family therapists are encouraged to remain humble and curious with parents, asking questions as needed and remembering they have been enlisted not as autism experts but as family systems experts, sitting beside parents and exploring the rippling impact of this diagnosis (Doherty, McDaniel, & Hepworth, 1994). It is our hope that by providing updated information about autism and by offering some clinical reflections, family therapists will feel more confident working with these parents.

This paper provides a general overview for family therapists, and it is divided into four sections. The first section provides basic information about autism. The second section identifies some challenges that parents may face on their way to getting a diagnosis for their child. The third section details the elements of a comprehensive treatment plan for the family and the child with autism. The fourth section examines how family therapists can work with action, meaning, and emotion in order to help parents

---

<sup>3</sup>In fact, if the parents have *not* become autism experts, the family therapist is advised to wonder what keeps them from learning more about autism. Learning about autism helps parents cope, select and coordinate appropriate treatments, and advocate effectively on their child’s behalf.

stay connected with each other and with their child. Although this paper will remain focused on the parental subsystem, there are significant ways that other subsystems (like the sibling subsystem) as well as the extended family system are affected by a child's autism diagnosis, and family therapy and/or individual therapy may be indicated. Comments about other family members are beyond the scope of this paper.

Examples are utilized throughout this paper. In each example, identifying information has been changed. Examples are drawn from the first author's various roles within the autism community: a licensed clinical psychologist who treats parents of children with autism, a presenter of workshops about children with autism for mental health professionals, a presenter of workshops for parents of children with autism, and a parent of a child with an Asperger's diagnosis. The second author completed a graduate assistantship with the first author and is now employed as a family therapist at an agency that serves children with special needs and their families.

### AUTISM 101

Revisions proposed for DSM-5 will alter both the diagnostic criteria for the ASDs and the names of the ASDs. According to the website ([www.dsm5.org](http://www.dsm5.org)), the category will now be called Autism Spectrum Disorder. Creators of DSM-5 are choosing a single spectrum disorder (rather than saying autism, PDD-NOS, Asperger's) because previously, the criteria "were equivalent to trying to 'cleave meatloaf at the joints'" ([www.dsm5.org](http://www.dsm5.org)). With these changes, clinicians will make a diagnosis of Autism Spectrum Disorder and assign a classification of the severity of the child's disability (Level 3, Level 2, or Level 1) (Swedo, 2009; [www.dsm5.org](http://www.dsm5.org)).

There are also going to be changes to the diagnostic criteria themselves. In DSM-IV, diagnosis rested upon three domains: qualitative impairment in social interaction, qualitative impairment in communication, and restricted and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association, 2000). In the proposed revisions for DSM-5, diagnosis will focus on two domains: persistent deficits in social communication and social interaction across contexts and restricted, repetitive patterns of behavior, interests, or activities.

Children with autism present with disparate symptom profiles. Some parents report that their children seemed "different" from birth, while other parents (perhaps as many as 50%) report many months of typical development followed by a regression, usually between the child's first and second birthday (Werner, Dawson, Munson, & Osterling, 2005).

Children with autism nearly always, if not always, present with sensory problems such as high pain tolerance, auditory hypersensitivity, and tactile defensiveness (e.g., tags on shirts, sand, and even snuggles), and they may exhibit "sensory seeking behaviors" such as crashing, squeezing, spinning, and flapping. Other possible symptoms/problems that do not appear in DSM-IV (and likely not in DSM-5) include: hyperlexia, seizures, sleep disturbances, food allergies, eczema, gastrointestinal distress, gut imbalances (bacteria, yeast), constipation, diarrhea, immune system dysregulation, and high levels of environmental toxins relative to neurotypical children.

Research suggests that the brains of people with autism show pervasive network underconnectivity that limits response flexibility (Minshew & Williams, 2007). At its core, autism is a problem with dynamic intelligence leading to a breakdown in the guided participation relationship, the "intensive but implicit learning process [which occurs] initially with parents and then with other adults" in every culture throughout

recorded history (Gutstein, 2009, p. 61). While children with autism can have average or above average static abilities (categorizing, organizing, imitating, and computing), they tend to have severe impairments in dynamic intelligence (anticipating, inferring, reflecting, and expanding).<sup>4</sup>

We have yet to adequately answer the question, “What causes autism?” Psychogenic etiology, Bettleheim’s “refrigerator mother theory,” has fallen out of favor, and there is growing consensus that autism is caused by complex gene/environment interactions (e.g., DeLong, 2011; Herbert, 2005). Genes “load the gun” and the environment “pulls the trigger,” making autism a complex, multi-systemic, environmentally affected condition—an ongoing biological process rather than a hardwired brain state (Herbert, 2005; Jepson, 2007; Sears, 2010). Given the exponential rise in cases, autism cannot be strictly genetic, as our gene pool cannot shift that quickly (Jepson, 2007), but examination of environmental triggers has become controversial and politicized as vaccines are frequently cited as potential culprits.

Family therapists are advised to bear in mind the 1960s feminist slogan, “the personal is political,” empathizing with parents whose very personal struggle to understand their child’s autism occurs alongside sometimes-inflammatory media reports and difficult discussions (about vaccines, for example) with other parents on the playground or in the waiting room. In other words, the family therapist’s job is not to debate causation with parents but rather to understand the *parents’ beliefs* about what caused their child’s autism and how those beliefs impact their coping.

### THE JOURNEY TO “THE A WORD”

Some parents experience a straightforward journey to their child’s autism diagnosis—they raised concerns with the pediatrician, the pediatrician referred them to a neuropsychologist, and the neuropsychologist assigned the diagnosis and helped them build a comprehensive treatment plan. For others, the journey to diagnosis is long and winding, and by the time parents receive a diagnosis for their child, they may have developed suspicion and mistrust in “helping professionals,” feeling that clinicians minimized their concerns, thereby delaying diagnosis (Gray, 1995; Schall, 2000). The road tends to be longer and more frustrating for parents with lower levels of education and income (Goin-Kochel, Mackintosh, & Myers, 2006). Three common themes in the journey to diagnosis are examined here so family therapists can help parents whose children exhibit “red flag” behavior seek an answer more expediently *and* so family therapists can be empathic if disappointment with and distrust of helping professionals slow alliance-building.

#### Wait and See

Samantha took her 18-month-old son, Kyle, to the pediatrician, stating that she was concerned about his lack of babbling and his fascination with spinning wheels on his toy cars. Samantha’s doctor said he was “just being a boy” and encouraged her to give him time. At 30 months, Kyle still had not begun to speak, and his play seemed

<sup>4</sup>Those interested in a comprehensive examination of the core deficits underlying autism are directed to the work of Dr. Steven Gutstein, founder of Relationship Development Intervention (RDI), a treatment approach which works systemically (between parent and child) to remediate the core deficits of autism (Gutstein, 2009; [www.rdicconnect.com](http://www.rdicconnect.com)).

atypical to her. Finally, Samantha's doctor encouraged her to have him evaluated, but she was furious and saddened about the year of "wasted time" during which she knew something was wrong but her concerns were minimized by her doctor.

Tanya took her 18-month-old son, Eli, to the doctor for an ear infection. While there, she told her doctor that she was worried Eli had autism. The doctor asked, "Does he point?" During story time, when Tanya would say, "Eli, where's the cow?" Eli would point to the cow. So, she answered yes. The doctor told her that he does not have autism, and Tanya felt relieved. Eli would go on to receive an autism diagnosis at 26 months.

Eli's doctor had, in fact, asked the question incorrectly. By 18 months old, typically developing children demonstrate a behavior called *joint attention* which involves "use of gestures and eye contact to direct others' attention to objects, to events, and to themselves" with the intention of showing or spontaneously seeking to share "interests or pleasurable experiences with others" (Mundy & Newell, 2007, p. 269). Children with autism may be able to point, but they tend to struggle with joint attention, making the absence of joint attention behavior an important indicator (Lord & Risi, 2000).

The current zeitgeist strongly emphasizes the value of early, intense intervention to treat or potentially mitigate the impact of autism on the child. Therefore, a gap between the time when parents "knew" and the time when the doctor "knew" is painful. There is concern that physicians, teachers, daycare providers, and others are undereducated about autism (Shah, 2001). It is crucial to support pediatricians' abilities to recognize "red flags" (Rhoades, Scarpa, & Salley, 2007), as years later parents can be left wondering "what if we had started therapy sooner?"

### **Just a Speech Problem**

A second theme is that when parents raise their concerns, professionals may not encourage parents to seek a full neuropsychological evaluation. Ryan was using just a few words in an inconsistent way at 28 months of age. The pediatrician referred Ryan to a local speech therapist who began working with him on increasing his expressive language. Neither the pediatrician nor the speech therapist encouraged Ryan's parents to seek a full neuropsychological evaluation, and his autism went undiagnosed for many more months.

Professionals, not wanting to be the "bearers of bad news" (Domingue, Cutler, & McTarnaghan, 2000, p. 371), may resist being the first to introduce "the A word." This collusion does not serve the parents, and it certainly does not serve the child. Once again, parents may end up feeling they lost time treating what they thought was a simple apraxia or sensory issue when it was actually autism. If there is any chance of autism, encouraging parents to seek a full evaluation is preferable ("better to be safe than sorry"), even if the helping professional risks a tear in the alliance. If parents engage a family therapist to address their child's concerning behaviors, it is important for that family therapist to be savvy about "red flags" and to make a strong and clear recommendation for a neuropsychological evaluation, ideally with a clinician who can utilize the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, Dilavore, & Risi, 2002) and the Autism Diagnostic Interview (ADI-R; Rutter, LeCouteur, & Lord, 2003).

### **Getting the News**

The third theme relates to how the news is given to parents, as all parents have a story about the day they were handed their child's diagnosis. Even if parents were

suspicious or had already begun to read about autism, receipt of the news constitutes a pivotal moment (McAdams, Reynolds, Lewis, Patten, & Bowman, 2001), birthing a narrative of “life before” versus “life after” that moment. Even in the best of situations, that moment is devastating and can become a traumatic, scripted chapter in the parents’ story.

Parents frequently report that when they received the diagnosis, they were sent off with very little hope and very little information. In a survey of 146 caregivers, only 40% reported that the diagnosing professional provided information about autism and resources (Rhoades et al., 2007). When asked where they turned for information about autism, only 15–20% of the caregivers reported turning to other healthcare, educational, or intervention specialists, and 71–73% of caregivers reported turning to media sources such as the internet (Rhoades et al., 2007).

Once parents get to “the A word”, they are launched into a complicated world of treatment choices. There are many available therapies, and parents are likely to spend countless hours googling the word autism and feeling overwhelmed about how to create a treatment plan. One father said poignantly:

when your child is diagnosed with cancer, nobody expects you to make your child better, but when your child is diagnosed with autism, it’s up to the parents to figure out how to help him get better.

Understanding the dizzying array of treatment choices is daunting enough without the added reality that children with autism benefit from intensive therapies which come at great cost. For example, when the parents of a newly diagnosed child asked their neuropsychologist how much therapy their son would need, her response was, “how much can you afford?” This response left them in an impossible position, as much more therapy could be afforded with a second mortgage or by moving in with their parents.<sup>5</sup> Ideally, the diagnosing clinician would remain connected with the parents while they build a treatment plan. Alternatively, the diagnosing clinician could/should refer the family to a family therapist who can help them navigate complex choices with precious resources like time and money.

### **THE THREE-LEGGED STOOL: CREATING A COMPREHENSIVE TREATMENT PLAN**

In order for family therapists to help parents advocate for services and to function as part of a team, they need to understand comprehensive treatment planning for children with autism. Treating a child with autism means working to minimize the impact of the autism on the child and working to maximize the child’s potential. Family therapists are most likely not in a position to directly treat the symptoms of autism; those treatments are typically provided by specialists like physicians, special education teachers, occupational therapists, speech-language therapists, developmental/play therapists, and behavior consultants.<sup>6</sup> However, family therapists should

---

<sup>5</sup>Perhaps the greatest injustice of autism is that access to services that can make a tremendous difference in a child’s life is substantially dictated by finances and geography. Presumably, all parents want to give their child with autism the greatest chance of improvement. However, not every parent can afford to do that, and not every parent lives near high-quality providers.

<sup>6</sup>One exception to this is that some psychotherapists become RDI-certified consultants, as RDI treats autism by targeting the parent-child relationship (Gutstein, 2009; [www.rdiconnect.com](http://www.rdiconnect.com)).

understand comprehensive treatment planning so they are prepared to help parents build and “quarterback” what is likely to become a team of providers.

The non-profit organization Talking About Curing Autism (TACA) utilizes the metaphor of a three-legged stool to represent the multiple domains that parents need to address. The first leg represents *traditional therapies* like Applied Behavior Analysis (ABA), Relationship Development Intervention (RDI), The Developmental, Individual Difference, Relationship-Based Model (DIR/Floortime), speech therapy, occupation therapy, and educational supports. The second leg represents *biomedical interventions* like the Autism Research Institute (ARI) approach. The third leg represents *emotional support* for the family. Without attention to any one of these three “legs,” the family system and/or the child with autism becomes, or remains, out of balance. Clearly, the leg which is most relevant to family therapists is emotional support for the family, but family therapists should have some understanding of the other two legs.

A computer analogy is sometimes used to describe the recursive relationship between traditional therapies and biomedical interventions. Biomedical interventions repair the hard drive (heal the child’s body), and the traditional therapies reinstall the software (allow the child to re-do missed developmental milestones).

*Traditional therapies* like ABA, RDI, and DIR/Floortime give children with autism the opportunity to gain social, relational, play, and academic skills, usually in a one-on-one or small group setting, sometimes many hours a week. TACA’s website has useful descriptions of many of these therapies. Private providers offer these therapies, and autism health insurance legislation, recently enacted in some states, often helps make these therapies affordable to socioeconomically diverse families. Further, state-funded early intervention programs (for children from birth to age 3) provide these therapies at a clinic or in the child’s home (usually on a sliding fee scale). These therapies can also be written into a school-aged child’s Individualized Education Plan (IEP), as special education legislation mandates a free and appropriate education for all children. Although family therapy with an outside provider is not a mandated special education service under applicable law, parents may be eligible for parent counseling, training, and support through their child’s school, which could complement work with a family therapist. Parents may need to be directed to a special education attorney or a legal aid clinic for support obtaining and negotiating a comprehensive IEP.

*Biomedical interventions* address the physiological imbalances underlying autism. Autism is increasingly considered a treatable and preventable biochemical disorder, and supporters of this paradigm shift argue that autism, which has traditionally been defined behaviorally, is in fact “merely one symptom of an underlying disease process that affects the immunological system, the gastrointestinal system, and the toxicological system, as well as the neurological system” (Jepson, 2007, p. 44). The Autism Research Institute (ARI; [www.autism.com](http://www.autism.com)), created by Dr. Bernard Rimland in 1967, provides training for health care providers so they can attend to the medical concerns underlying autism (e.g., Buie et al., 2010; Cubula-Kucharska, 2010).<sup>7</sup> This paradigm shift remains somewhat controversial, yet researchers continue efforts to elucidate

---

<sup>7</sup>Bibliographies of the latest research supporting these interventions can be found in Sears (2010) and on the websites of these organizations: Autism Research Institute (ARI; [www.autism.com](http://www.autism.com)), Talking about Curing Autism (TACA; [www.tacanow.org](http://www.tacanow.org)), and Autism Speaks (AS; [www.autismspeaks.org](http://www.autismspeaks.org)).

the extraordinarily complex relationships between genes, environmental triggers, the body, and the brain in autism (Buie et al., 2010).

Creating a comprehensive treatment plan for their child is part of what helps parents move from crisis to coping, and models like the three-legged stool can help overwhelmed parents with that daunting task. Parents may be at risk of over-focusing on legs one and two (therapies for their child with autism), and family therapy with parents may provide much needed space to address the equally important third leg, emotional support.

## **WORKING WITH ACTION, MEANING, AND EMOTION IN FAMILY THERAPY**

This section identifies concerns that parents of children with autism may bring into therapy and provides thoughts about working with those concerns in the service of keeping the parental subsystem strong and intact. Autism, as a pervasive developmental disability, leaves few, if any, “conflict-free spheres of functioning” for the child and, therefore, for the family. Every aspect of family life may be affected including sleep, meals, toileting, play, travel, education, and work. There are likely to be multiple interrelated presenting problems (overwhelming schedules, parental conflict secondary to exhaustion and grief, confusion about creating and maintaining a treatment plan, etc.). Utilizing an integrative approach allows family therapists to flexibly work with multiple problems or constraints through the exploration of action, meaning, and emotion. Action, meaning, and emotion have been identified as nonspecific treatment dimensions that: account for outcome, mutually interact and influence client functioning, and operate as powerful change entry points for integrative therapists (Breunlin, Pinsof, Russell, & Lebow, 2011; Lebow, 2006; Pinsof, Breunlin, Russell, & Lebow, 2011). These dimensions interact with and inform each other, yet each provides a specific entry point for change and healing. Therefore, discussion will be organized in this way.

### **Action**

Helping parents stay connected in the face of autism is likely to involve helping them find ways to “do” their day-to-day lives as well as they can, given the realities of raising a child with autism. Working in the domain of action can reduce parental stress, making way for greater resilience.

Children with autism tend to function best with schedules, structure, and routines (Lokshin, Gillis, & Romanczyk, 2005; Steward, 2007). One father said, “Imagine looking through a kaleidoscope. That’s how I imagine my son’s world looks. Nothing makes sense and nothing fits together.” Dealing with the demands of doctor appointments, special education meetings, and therapies, in addition to the needs of other family members, means that *parents* of children with autism need structure and routines as well. However, it is also the case that when parents become slaves to structure in order to preclude a child’s meltdown, the family is actually inadvertently “feeding the autism” (Gutstein, 2009).

Much has been written about American families moving at warp speed in order to accommodate demanding careers and children’s activities (e.g., Doherty, 1999). Parents of children with autism are in a bind because these children need many hours of therapy, *and* these children tend to be incredibly sensitive to stress and chaos. Family

therapists can look with parents at their days and weeks in order to prioritize and set reasonable expectations (for themselves and for their child).

Parents sometimes receive support from their child's treatment team to create and maintain a maximally therapeutic home environment. This may include putting toys, especially preferred ones, away in order to increase a child's need to communicate with parents. Screens of any kind can be compelling, bordering on addictive, to children with autism, likely because their static predictability appeals to children who feel overwhelmed and incompetent in the messy and dynamic world of relationships. Parents can be supported in utilizing screen time selectively and carefully, perhaps as a reward.

Setting a therapeutic home environment can be further complicated when parents also have typically developing children. Siblings of children with autism are at greater risk of emotional and behavioral problems (Petalas, Hastings, Nash, Lloyd, & Dowey, 2009), and they may report feeling either invisible or too visible at home (Safer, 2002). There may be excessive attention on the child with autism and too much responsibility on the typically developing sibling. Or, the typically developing sibling may feel too visible, compensating for the sibling with special needs with attempts to be all-good and all-successful (Safer, 2002). Depending on the family's needs, a home visit may allow the family therapist to support parents' efforts to create a home environment that meets the needs of all members.<sup>8</sup>

Research has suggested that parental stress is strongly correlated, not with the child's level of impairment, but with the child's level of negative behavior (Estes et al., 2009). Parents may work with a behavior consultant to create a behavior plan derived from a functional behavior analysis. If it is not feasible for parents to utilize a behavior consultant, family therapists can work behaviorally with parents to address negative behaviors like tantrums and rituals, which compromise a family's quality of life.

Family therapists are well aware of the perils of gendered divisions of labor and of the reality that even the most feminist couples are challenged to keep their ideals alive once a baby arrives. The additional financial and caretaking demands of a child with autism seem to press parents (opposite-sex and same-sex) to fall back on "traditional" arrangements. In one study, half of the mothers interviewed reported that their child's autism "prevented them from either working at all or restricted their hours and/or type of employment" (Gray, 2002, p. 218).

When parents adopt an unanticipated and undesirable division of labor, they can benefit from "couple meetings" in order to report in from their respective spheres and reduce the risk of slipping into disconnection and blame. Breadwinning parents may report that when they get home from work, they are eager to reconnect and hear about the day, especially how the child with autism felt, behaved, and reacted to therapies. They can feel frustrated when the stay-at-home parent, who has been talking about, thinking about, and dealing with their child's autism all day, withdraws. Knowing that they will talk about their respective experiences at their couple meeting can soften this polarizing cycle.

---

<sup>8</sup>Family therapists also may need to encourage parents to talk about autism with typically developing siblings, as siblings sometimes carry misinformation. One research study indicated that 20% of a sample of siblings, ages 5–17, were unfamiliar with the word "autism," 25% thought autism was contagious, and across all ages, children had a narrow view of the definition of autism, focusing only on one concrete symptom to describe it (Harris & Glasberg, 2003).

Date nights can help parents of children with autism remember that they are a couple in addition to caretakers. Parents who balk at this recommendation with a litany of very compelling reasons (“we don’t have the money,” “no sitter can handle our son,” “we don’t have the time”) may need support to persist and to think outside of the box, for the wellbeing of the *entire* family.<sup>9</sup>

Finally, it is easy for parents to feel like they are never doing enough. There are always new treatments to research, and without minute-by-minute engagement from a parent, a child with autism is likely to go toward scripted, repetitive play, triggering guilt and shame in a parent who is therefore missing that opportunity to “fight” their child’s autism. Parents may need support identifying and making use of self-care activities which can provide much needed sanctuary and a break from worry. Action-oriented interventions can impact parents’ day-to-day functioning and influence the domains of meaning and emotion.

## Meaning

Creating a narrative about a child’s autism is no easy feat (Gray, 2001), but family therapists can help parents co-construct a sustainable story about how their child’s autism shapes who their child is and who they are. Working with meaning can help parents, perhaps for the first time, witness each other’s journeys and cultivate deep acceptance for differences between them.

Connection and empathy are likely compromised when parents disagree on, or become mired in, questions about “why?” Parents who believe their child’s autism is the result of “faulty genes” may curse their bad luck. Parents who believe their child’s autism was ignited by vaccines and environmental toxins come face-to-face with choices *they* made on behalf of their child. These parents’ narratives may include anger at themselves for not doing enough research and at those in the medical establishment for treating their child like “collateral damage in the war against disease,” as some parents put it. Therapeutic space may need to address the coexistence of multiple stories (Gray, 2001), and family therapists may need to help parents transcend this question in the service of resilience and connection with each other.

Working with meaning may also involve supporting parents’ efforts to integrate their spirituality into their story about why this child and these parents are facing this challenge. Supporting parents’ efforts to create a narrative that is “thick enough” (Freedman & Combs, 2008) and nuanced enough to hold all of the complexities of their journey may foster transformation, both personally and relationally (Scorgie & Sobsey, 2000), opening the door for increased connection and empathy between parents.

## Emotion

Parents of children with autism face complex and powerful emotions, and how they handle these emotions can constrain or facilitate their connection with each other. Having a child diagnosed with autism is an ambiguous loss for parents (Boss, 1999, 2006; O’Brien, 2007). With early and intensive treatment, some children with autism improve, and some improve dramatically (Itzchak & Zachor, 2009). This complicates what might otherwise be a more straightforward grieving process, leaving parents to

---

<sup>9</sup>Maintaining a two-parent family structure is crucial for emotional *and* pragmatic reasons. One mother said tearfully, “We have to stay together because I literally cannot do this without him!”

ask the impossible question, “Do we grieve and accept this disabled child, or do we fight for recovery?” If a parent’s story is, “I will pull my child through the autism window” (McCarthy, 2007), grief may center on sadness, fear, and frustration about needing to wage a war on autism. If a parent’s story is, “This is autism, and I want to maximize his potential given this lifelong diagnosis,” grief may center on the loss of the dream.

Parents may report waging an exhausting internal battle between fighting and accepting, reinforced by the fact that children with autism are notorious for inconsistent functioning (O’Brien, 2007), looking more “autistic” some days and less “autistic” other days. What often gets posited by parents as a black or white choice is better conceptualized as a need to engage a complex dialectic of acceptance *and* change. A father may find himself working to accept that he will never sit on the sidelines at his son’s soccer game... until his son masters a previously elusive skill. Then the father may berate himself for having given up so easily, returning to a commitment to “beat this thing.”

The tension between grieving the loss and fighting for recovery is palpable in the spaces *between* parents as well—in waiting rooms, at support groups, over a beer. Parents of children with autism, hurt by other parents’ tales of typical development, may crave the safety of other parents of children with autism, who “get it.” Along with the safety of feeling understood by fellow parents on the journey, there exist a number of land mines, one of which is this dialectic of accept/fight.

Parenting a child with autism can feel very isolating (Woodgate, Ateah, & Secco, 2008).<sup>10</sup> Isolation is heightened by the unpredictable behavior of a child with autism, which can make even the most extroverted parents feel anxious about attending social events, which can involve sensory overload and unpredictability, increasing the chances of a child’s meltdown. Parents may be split with one feeling too anxious to chance it and the other feeling that the only way the child can learn to cope is to keep trying. Family therapists may need to help parents transform “go” or “don’t go” dichotomies. Perhaps the family goes, but only for 45 minutes. Perhaps they take two cars so that one parent and the neurotypical sister can stay if the other parent has to take the child with autism home early. Perhaps the parents request accommodations like quiet snapping rather than raucous clapping to celebrate the extinguishing of the candles at a birthday party.

Taking their child with autism to social events may trigger in parents those parts of themselves that feel shame about their child’s autism. Feeling ashamed of the shame, parents may shut those feelings off by avoiding the whole experience. Similarly, events that involve neurotypical children may trigger feelings of intense jealousy, sadness, and anger (Woodgate et al., 2008). Perhaps the couple can sit on the sidelines together at these events, quietly sharing inappropriate humor (about how boring and braggy those neurotypical children are anyway). Isolated *together* in that moment, co-construction of meaning occurs, offering strength and healing.

This final example illustrates how the domains of action, emotion, and meaning can intertwine to constrain or enhance parents’ functioning. Family therapists can facilitate dialog in order to explore the *emotions* that each parent has about taking

---

<sup>10</sup>Single parents and parents without connections to extended families and/or social supports may feel particularly alone, and therapy may provide a particularly crucial space for witnessing and reflection.

their child to a social event. Exploration of emotions helps parents construct a narrative about what the social event *means* to each parent. From this collaborative place, parents can hopefully create an *action* plan that feels “good enough.”

## CONCLUSION

Armed with a basic understanding of autism, a commitment to keeping current on new developments in the area, and a deep sense of curiosity, family therapists are well-suited to help parents of children with autism stay connected as they face the chronic and acute stresses of autism. Parents are likely to be worried about their risk of divorce, and this worry is reasonable given the nature of what they face. There are the emotional, practical, and financial challenges of creating and executing a comprehensive treatment plan for their child's autism. If they are also raising typically developing children, they need to support their journeys, which are complicated by the experience of having a sibling with autism. They need a sustainable work-family balance. And all of this needs to be done while not losing sight of their connection with each other.

A family therapist who works with the parents of a child with autism is likely to be one member of a team of educational, therapeutic, and medical providers. In order to enhance and support the work of the other providers, the family therapist may be called upon to provide not only couple therapy but also some amount of advocacy work. Advocacy work may include attending IEP meetings, consulting and coordinating with other providers, and helping parents access resources such as local support groups.

Given the added strain of parenting a child with autism, parents need to bring their “A-game” to their relationship. In addition to working on *their* unique constraints, family therapists may need to provide basic psychoeducation about healthy intimate relationships.

Parents of children with autism are challenged to hold multiple dialectics: hope and despair, perfection and disability, acceptance and fight, shame and pride, selfishness and selflessness. It is our hope that with an understanding of autism and an appreciation for the interplay between action, meaning, and emotion, family therapists will feel better equipped to provide much-needed systemic support to these parents.

## REFERENCES

- Abbeduto, L., Seltzer, M.M., Shattuck, P., Krauss, M.W., Orsmond, G., Murphy, M.M. et al. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation*, 109(3), 237–254.
- American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders* (4<sup>th</sup> ed., text rev.). Washington, DC: American Psychiatric Association.
- Baker-Ericzen, M.J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research & Practice for Persons with Severe Disabilities*, 30(4), 194–204. doi: 10.2511/rpsd.30.4.194
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9), 702–714. doi: 10.1111/j.1365-2788.2007.00960.x
- Boss, P. (1999). *Ambiguous loss*. Cambridge, MA: Harvard University Press.

- Boss, P. (2006). *Loss, trauma, and resilience: Therapeutic work with ambiguous loss*. New York: Norton.
- Breunlin, D.C., Pinsof, W., Russell, W.P., & Lebow, J. (2011). Integrative Problem-Centered Metaframeworks therapy I: Core concepts and hypothesizing. *Family Process, 50*(3), 293–336.
- Brobst, J.B., Clopton, J.R., & Hendrick, S.S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities, 24*(1), 38–49. doi: 10.1177/1088357608323699
- Buie, T., Campbell, D.B., Fuchs, G.J., Furuta, J.L., VandeWater, J., Whitaker, A.H. et al. (2010). Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: A consensus report. *Pediatrics, 125*(1), S1–S18. doi: 10.1542/peds.2009-1878C
- Cubula-Kucharska, M. (2010). The review of most frequently occurring medical disorders related to aetiology of autism and the methods of treatment. *Acta Neurobiologiae Experimentalis, 70*, 141–146.
- DeLong, G. (2011). A positive association found between Autism prevalence and childhood vaccination uptake across the U.S. population. *Journal of Toxicology and Environmental Health, Part A, 74*(14), 903–916. doi: 10.1080/15287394.2011.573736
- Doherty, W.J. (1999). *The intentional family: Simple rituals to strengthen family ties*. New York, NY: Harper Paperbacks.
- Doherty, W.J., McDaniel, S.H., & Hepworth, J. (1994). Medical family therapy: An emerging arena for family therapy. *Journal of Family Therapy, 16*(1), 31–46. doi: 10.1111/j.1467-6427.1994.00775.x
- Domingue, B., Cutler, B., & McTarnaghan, J. (2000). The experience of autism in the lives of families. In A. Wetherby & B. Prizant (Eds.), *Autism spectrum disorders* (pp. 369–393). Baltimore, MD: Paul H. Brookes Publishing Co..
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism: International Journal of Research and Practice, 13*(4), 375–387. doi: 10.1177/1362361309105658
- Freedman, J., & Combs, G. (2008). Narrative couple therapy. In A.S. Gurman (Ed.), *Clinical Handbook of Couple Therapy* (3<sup>rd</sup> ed., pp. 229–258). New York, NY: The Guilford Press.
- Goin-Kochel, R.P., Mackintosh, V.H., & Myers, B.J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism, 10*(5), 439–451. doi: 10.1177/1362361306066601
- Gray, D.E. (1995). Lay conceptions of autism: Parents' explanatory models. *Medical Anthropology, 16*, 99–118.
- Gray, D.E. (2001). Accommodation, resistance and transcendence: Three narratives of autism. *Social Science & Medicine, 53*, 1247–1257. doi:10.1016/S02779536(00)00424-X
- Gray, D.E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability, 27*(3), 215–222. doi:10.1080/1366825021000008639
- Gutstein, S.E. (2009). *The RDI book: Forging new pathways for autism, Asperger's and PDD with the relationship development intervention program*. Houston, TX: Connection Centers Publishing.
- Harris, S.L., & Glasberg, B.A. (2003). *Siblings of children with autism: A guide for families* (2<sup>nd</sup> ed.). Bethesda, MD: Woodbine House, Inc.
- Hartley, S.L., Barker, E.T., Seltzer, M.M., Floyd, F., Greenberg, J., & Orsmond, G. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology, 24*(4), 449–457. doi:10.1037/a0019847
- Herbert, M.R. (2005). Autism: A brain disorder or a disorder that affects the brain? *Clinical Neuropsychiatry, 2*(6), 354–379.

- Hertz-Picciotto, I., & Delwiche, L. (2009). The rise in autism and the role of age at diagnosis. *Epidemiology*, *20*(1), 84–90. doi: 10.1097/EDE.0b013e3181902d15
- Higgins, D.J., Bailey, S.R., & Pearce, J.C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, *9*(2), 125–137. doi: 10.1177/1362361305051403
- Hillman, J. (2006). Supporting and treating families with children on the autistic spectrum: The unique role of the generalist psychologist. *Psychotherapy: Theory, Research, Practice, Training*, *43*(3), 349–358. doi: 10.1037/0033-3204.43.3.349
- Itzhak, E.B., & Zachor, D.A. (2009). Changes in autism classification with early intervention: Predictors and outcomes. *Research in Autism Spectrum Disorders*, *3*, 967–976. doi: 10.1016/j.rasd.2009.05.001
- Jepson, B. (2007). *Changing the course of autism: A scientific approach for parents and physicians*. Boulder, CO: Sentient Publications.
- Kogan, M.D., Blumberg, S.J., Schieve, L.A., Boyle, C.A., Perrin, J.M., Ghandour, R.M. et al. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics*, *124*(4), 1–11. doi: 10.1542/peds.2009-1522
- Lebow, J.L. (2006). *Research for the psychotherapist: From science to practice*. New York: Routledge.
- Lokshin, S.B., Gillis, J.M., & Romanczyk, R.G. (2005). *Helping your child with autism spectrum disorder*. Oakland, CA: New Harbinger Publications, Inc.
- Lord, C. & Risi, S. (2000). Diagnosis of autism spectrum disorders in young children. In A.M. Wetherby & B.M. Prizant (Eds.), *Autism spectrum disorders: A transactional developmental perspective* (pp. 11–30). Baltimore, MD: Paul H. Brookes Publishing.
- Lord, C., Rutter, M., Dilavore, P., & Risi, S. (2002). *Autism diagnostic observation schedule*. Los Angeles, CA: Western Psychological Services.
- McAdams, D.P., Reynolds, J., Lewis, M., Patten, A.H., & Bowman, P.J. (2001). When bad things turn good and good things turn bad: Sequences of redemption and contamination in life narrative and their relation to psychosocial adaptation in midlife adults and in students. *Personality and Social Psychology Bulletin*, *27*(4), 474–485. doi: 10.1177/0146167201274008
- McCarthy, J. (2007). *Louder than words: A mother's journey in healing autism*. New York, NY: Penguin Group, Inc.
- Minshew, N.J., & Williams, D.L. (2007). The new neurobiology of autism: Cortex connectivity and neural organization. *Archives of Neurology*, *64*, 945–950.
- Mundy, P. & Newell, L. (2007). Attention, joint attention and social cognition. *Current Directions in Psychological Sciences*, *16*, 269–274. doi: 10.1111/j.1467-8721.2007.00518.x
- O'Brien, M. (2007). Ambiguous loss in families of children with autism spectrum disorders. *Family Relations*, *56*, 135–146.
- Petalas, M.A., Hastings, R.P., Nash, S., Lloyd, T., & Dowey, A. (2009). Emotional and behavioral adjustment in siblings of children with intellectual disability with and without autism. *Autism*, *13*(5), 471–483. doi: 10.1177/1362361309335721
- Pinsof, W.M., Breunlin, D.C., Russell, W.P., & Lebow, J.L. (2011). Integrative problem centered metaframeworks (IPCM) therapy II: Planning, conversing and reading feedback. *Family Process*, *50*(3), 314–336.
- Ramisch, J. (2010). Marriage and family therapists working with couples who have children with autism. *Journal of Marital & Family Therapy*, 1–12. doi: 10.1111/j.1752-0606.2010.00210.x
- Rhoades, R.A., Scarpa, A., & Salley, B. (2007). The importance of physician knowledge of autism spectrum disorder: Results of a parent survey. *BMC Pediatrics*, *7*(37), 1–10. doi:10.1186/1471-2431-7-37
- Rutter, M., LeCouteur, A., & Lord, C. (2003). *The autism diagnostic interview, revised (ADI-R)*. Los Angeles, CA: Western Psychological Services.
- Safer, J. (2002). *The normal one*. New York, NY: Bantam Dell.

- Schall, C. (2000). Family perspectives on raising a child with autism. *Journal of Child and Family Studies*, 9, 409–423. doi: 10.1023/A:1009456825063
- Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation*, 38, 195–206.
- Sears, R. (2010). *The autism book: What every parent needs to know about early detection, treatment, recovery, and prevention*. New York, NY: Little, Brown and Company.
- Shah, K. (2001). What do medical students know about autism? *Autism*, 5(2), 127–133. doi: 10.1177/1362361301005002003
- Steward, K. (2007). *Helping a child with nonverbal learning disorder or Asperger's disorder* (2<sup>nd</sup> ed.). Oakland, CA: New Harbinger Publications, Inc.
- Swedo, S. (2009). Report of the DSM-5 neurodevelopmental disorders working group. Retrieved March 1, 2011, from <http://www.psych.org/MainMenu/Research/DSMIV/DSMV/DSMRevisionActivities/DSM-V-Work-Group-Reports/Neurodevelopmental-Disorders-Work-Group-Report.aspx>.
- Werner, E., Dawson, G., Munson, J., & Osterling, J. (2005). Variation in early developmental course in autism and its relation with behavioral outcome at 3-4 years of age. *Journal of Autism and Developmental Disorders*, 35(3), 337–350. doi: 10.1007/s10803-005-3301-6
- Woodgate, R.L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18, 1075–1083. doi: 10.1177/1049732308320112
- Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C. (2003). Prevalence of autism in a US metropolitan area. *Journal of American Medical Association*, 289(1), 49–55. doi:10.1001/jama.289.1.49