

CHAPTER 1

Sensory Regulation and Dysregulation

Camille was having another complete meltdown. The sky was getting dark and it looked like rain. She began to panic with the first sign of a potential storm, even though she had never experienced a truly dangerous storm in real life. She would hide in her room with all of the curtains closed with the covers pulled over her head, screaming and in a complete panic until the sky started to clear. When she was in second grade, her parents were assured by the pediatrician that Camille would outgrow this fear and advised to ignore it, but the bizarre behavior continued to escalate. In third grade Camille saw a psychologist for 1 year to treat her storm anxiety, but with little benefit despite repeated exposure to storms and the experience of bad weather. In fact, the repeated exposure to storms (having her watch the storm from the window, listening to recordings of storms, watching movies about storms) seemed to cause her fears to get worse and her avoidance and acting-out behavior to burgeon. Camille is now in fifth grade and her anxiety is much worse, affecting her ability to maintain friendships, causing her to miss school, and exhausting her parents. Her therapist referred her to a psychiatrist for a medication consult because she was not responding to exposure treatment as expected. She was placed on an antidepressant medication, a selective serotonin reuptake inhibitor (SSRI) with little benefit, and her reaction to storms continued despite therapy and medication. Over time, her therapist stopped seeing Camille, as she felt unable to help her. Camille felt like a failure and her parents felt helpless.

Almost every mental health professional has had experiences with patients where treatment was not as successful as expected. Sometimes these cases are referred to as treatment resistant. Therapists may use evidence-based therapeutic approaches and still have poor treatment outcomes. Why does this happen? Although there could be many reasons why treatment does not progress as expected, such as poor compliance, family discord, environmental stress, and comorbid conditions, one important aspect that might be overlooked is the phenomenon known as sensory dysregulation. Sensory dysregulation is an emotional or behavioral disturbance that occurs when your nervous system is not perceiving or processing internal or external sensory stimuli accurately. The nervous system dysfunction causes either intense discomfort or the seeking of comfort in atypical ways. In children, the avoidance of discomfort or inappropriate comfort seeking to increase a positive experience can look like either anxiety or another psychological disorder. When sensory dysregulation is not identified as the problem or as contributing to the problem, good treatment can get derailed. Assessing for and treating sensory dysregulation in children helps psychological treatment progress more effectively, and the rate of relapse is reduced. Before describing how sensory issues can impact a child's functioning, we will give a brief, simplified review of the nervous system and the different functions that are governed within this system.

OVERVIEW OF THE NERVOUS SYSTEM

The nervous system sends electrical signals to different areas of our bodies to coordinate voluntary and involuntary actions, such as walking (voluntary) and digestion (involuntary), based on information received both from within our body and from its interaction with the environment. The nervous system encompasses two main parts: the central nervous system and the peripheral nervous system. The central nervous system consists of the brain and the spinal cord (which evaluate incoming information and give directions based on it), while the peripheral nervous system is made up of bundles of nerves that receive information from the environment

and communicate between the central nervous system and the rest of the body to achieve homeostasis (a relatively stable state of equilibrium). The nervous system is engaged almost constantly in two important homeostatic functions: arousal and calming. Arousal or activation in an individual is governed by the sympathetic nervous system and is responsible for reactions such as excitement, fear, and self-protection. Calming, relaxing, and vegetative functions such as digestion and falling asleep are governed by the parasympathetic nervous system. These two systems are also involved in how an individual regulates the body and maintains a sense of equilibrium or comfort in response to environmental stimuli. The nervous system regulates itself through three main processes: sensory, integration, and motor:

1. *Sensory.* The sensory function of the nervous system involves collecting information both internally and from the environment using the sensory receptors found in the eyes, ears, nose, mouth, and skin, as well as in the skeleton and the organs that monitor the body's internal and external conditions. This information is then passed on to the central nervous system for processing by the somatic and visceral sensory nerves.
2. *Integration.* Integration is the process by which the many sensory signals that exist at a given moment are passed into the central nervous system to be processed. These signals are evaluated, compared, used for decision making, discarded as unimportant, or committed to memory as deemed appropriate.
3. *Motor.* Once the sensory information has been evaluated, an action will be decided upon. The action required may involve smooth, cardiac, skeletal muscle, or glandular tissue depending on whether or not it is voluntary or involuntary. Appropriate actions depend entirely upon correct interpretation (sensory) and evaluation (integration) of the stimuli.

The nervous system is constantly gathering and analyzing information garnered from multiple senses simultaneously, which allows one to experience one's environment as a complex but

coherent whole. This combining and interpreting of multiple pieces of sensory information simultaneously is referred to as multisensory integration (Stein, Huneycutt, & Meredith, 1988; Stein & Meredith, 1993) and informs the individual how best to respond to specific stimuli (Ayres, 1958, 1961). Every person has a unique interpretation of sensory stimuli, which is why one person may be thrilled by the experience of a roller coaster hurtling downward at 60 miles an hour, while another might be nauseous and/or extremely uncomfortable with either the motion of the roller coaster, the sensations of the loud noise, the wind hitting her face, or the intense visual overload provided by the experience. Either way, each person's nervous system has gathered and evaluated sensory information, and consequently has directed that individual to respond in a way that will maintain individual comfort (seeking the roller coaster or avoiding it).

SENSORY REGULATION, LEARNING, AND BEHAVIOR

Information processed by the nervous system is important for learning, memory, and behavior. For example, a person who is prone to feel chilled in 65 degrees would likely bring a sweater to go out for the day in the belief that it is a cool day, while another person might wear shorts and a T-shirt the same day believing that the same weather conditions constitute a warm day. The nervous system is a powerful generator of knowledge and memories that lead to subjective belief and action.

Misunderstanding sensory-based issues can derail treatment in a variety of ways. For example, the goal of therapy frequently focuses on identifying and changing irrational thoughts and beliefs. However, dysregulation of the sensory system can lead to beliefs and actions that are appropriate in the context of that individual, but can be highly inappropriate in relation to the surrounding world. It can be tricky in therapy when a child presents as having what seem to be irrational beliefs based on her sensory experiences because to her the beliefs are quite rational—for example, “I can’t stand the sound of thunder because it hurts my ears.” Many children cannot

articulate their feelings clearly, so the details about their discomfort do not get verbalized to parents or clinicians. A therapist may interpret this response to storms by assuming the child is afraid based on the irrational belief that “storms are dangerous.” The therapist would likely attempt to change the erroneous belief through cognitive challenging and cognitive restructuring. The child’s belief, however, is accurate (the sound of thunder does feel terrible and may indeed hurt her ears). The therapist could help this child by giving her a full understanding of her own nervous system and by developing new, creative ways for her to comfort herself in stressful situations (loud storms). Expanding the therapeutic understanding of childhood behavior leads to self-awareness, an ability to gain a sense of control when feelings are overwhelming, and confidence in being able to manage challenging situations in the future.

SENSORY REGULATION

The sensory nervous system works with all of the far senses—sight, smell, touch, hearing, and taste—as well as the near senses, such as proprioceptive (body position), interoceptive (internal organs), and vestibular (movement). A well-functioning nervous system gathers all pertinent information accurately, integrates it effectively, then makes decisions that lead to homeostasis. Sensory perceptions determine likes and dislikes in every way imaginable: decorating a house in a style that is pleasing to the eye, wearing perfume that is pleasing to the nose, listening to music that is pleasing to the ear, and so on. Each of us may have a different idea about what is satisfying to us. Our unique nervous system guides each of us to create a personally gratifying environment that suits our sensibilities.

The nervous system also alerts one to situations that are perceived to be uncomfortable. A loud rock concert is tolerable for some people, while spicy foods are inedible for others. Avoiding certain foods or loud music are just a few examples of how the system learns what is comfortable and what is unpleasant or offensive for each of us, and we make decisions accordingly.

The sympathetic nervous system also serves a safety function through activation or arousal in response to perceived danger. For

example, if you're driving on a highway at a steady pace when the surrounding cars are speeding, but the car in front of you comes to an abrupt stop, you would immediately hit the brakes, without any conscious thought. This motor reaction may also be accompanied by involuntary responses such as rapid heartbeat, tense muscles, increased blood flow to internal organs, or an adrenaline boost. The sympathetic nervous system prepares the individual for immediate action if needed, also referred to as the fight, flight, or freeze response. When sensory stimuli are inaccurately perceived by the nervous system, the sympathetic nervous system can get triggered, resulting in the fight, flight, or freeze response. The stimuli are then perceived to be dangerous, as the self-preservation response occurs.

Everything described until now explains, in a rather simplified way, how the nervous system operates when it is working normally. However, sometimes sensations are experienced in either an exaggerated way or as insignificant when compared to how others experience them. These incorrect signals are sent to the central nervous system, and the system may respond as if they are accurate, for example, hearing a balloon popping and experiencing it as if it were a rifle firing right next to your ear. Furthermore, when there is a breakdown in the integration of sensory information (unimportant information is not discarded or the system experiences a sensory overload), mistakes in action or reaction can also occur. Children with these actions or reactions can appear in the therapy office misdiagnosed with a variety of different disorders, which will be discussed in detail in Chapter 8.

There is limited research about how internal sensory experiences evoke external behaviors or symptoms, but what does exist indicates that sensory sensitivities can impact behavior and functioning. For example, people with Tourette syndrome report heightened interoceptive awareness and a hypersensitivity to external stimuli for all five of the far senses (Belluscio, Jin, Watters, Lee, & Hallett, 2011; Eddy, Rickards, Critchley, & Cavanna, 2013; Woods, Miltenberger, & Flach, 1996), and people with obsessive-compulsive disorder (OCD) report hypersensitivity and intolerance of external stimuli (Wu, Lewin, Murphy, & Storch, 2014). Taylor, Conelea, McKay, Crowe, and Abramowitz (2014) found that people with greater self-reported sensory intolerance had a higher lifetime

incidence of tics and OCD than those without sensory intolerance. Miller and colleagues (Miller, Reisman, McIntosh, & Simon 2001; Miller, Robinson, & Moulton, 2004) found that poor sensory regulation is correlated with problems with attention and poor emotion regulation. Calkins, Fox, and Marshall (1996) and Fox, Henderson, Rubin, Calkins, and Schmidt (2001) reported that sensory reactivity in children was related to fearfulness. Finally, Hopkins and colleagues (2008) described how sensory dysregulation was significantly related to both internalizing and externalizing symptoms.

SENSORY DYSREGULATION

When sensory information collected by the nervous system is inaccurately read, processed, integrated, or evaluated it can lead to a disruption in homeostasis, mood, or behavior and result in reduced or impaired participation in activities of daily living (Miller, Nielsen, Schoen, & Brett-Green, 2009). There are three possible types of breakdown in the sensory system: sensory modulation difficulties, sensory discrimination problems, and sensory-based motor disorder. Sensory modulation difficulties—difficulty regulating responses to sensory data—are the type that will primarily be described in this book.

Within sensory modulation difficulties, three main subtypes have been identified:

1. Sensory overresponsive: responds too much, for too long, or to stimuli of weak intensity.
2. Sensory underresponsive: responds too little or needs extremely strong stimulation to become aware of the stimulus.
3. Sensory seeking/craving: responds with intense searching for more or stronger stimulation (Miller et al., 2009).

All of these phenomena involve difficulty regulating responses to sensory stimuli. The children discussed throughout this book demonstrate how these problems processing sensory information can lead to, mimic, or exacerbate anxiety and other psychological disorders, and how children who are dysregulated respond

atypically to cognitive-behavioral therapy (CBT) treatment for anxiety.

Eight-year-old Brad was about to sit down to eat dinner with his family. He took one look at his dinner plate and started to cry, became angry, and left the kitchen upset. His parents were perplexed. They enforced the family rule that if he did not return to the kitchen, he could not eat dinner. Brad went without dinner that night. At bedtime, Brad told his mother that green peas were touching white potatoes and he could not eat knowing that they had touched. His explanation was that it didn't look right. From that point on, Brad felt it necessary to examine the dinner plate before committing to eat dinner with the family. All of the food had to be separated so that the different colors did not come in contact with each other. He was not able to eat in restaurants or at his grandparents' house or go to dinner at friends' houses because he was too concerned that the dinner plate would not look right and he would not be able to eat. The thought of eating away from home would send Brad into an anxious state where he would cry, throw things, and refuse to leave the house.

Brad's nervous system was telling him that it is wrong when different-colored foods touch each other. It caused him such discomfort that he could not tolerate it, and he responded in a way that allowed him to ease his physical and emotional feelings. Unfortunately, Brad's reaction was also intense, as if his life depended on his food looking right. This example illustrates how faulty processing of sensory data can lead to irrational beliefs and emotional and/or behavioral dysregulation such as anxiety, avoidance, and dysfunctional behavior.

THE SENSES AND HOW THEY RELATE TO DYSREGULATION

The following section will provide a brief overview of three types of sensory dysregulation: overresponsive, underresponsive and sensory seeking. In Chapter 2 we explore these phenomena in more detail.

Touch

- *Overresponsive children* typically avoid touching objects or people, and avoid being touched by other people. They can have extreme reactions to getting dirty, to certain textures of clothing or food, and to unexpected touch. They may also avoid getting their hair brushed, having a bowel movement, brushing their teeth, and playing in sand.
- *Underresponsive children* have to experience heightened or intense touch to register the sensation. They may hit or push children, hug tightly, wear clothing or shoes that are very tight, or bang objects (such as computer keyboards while typing) and typically are not being bothered by cold or hot sensations.
- *Tactile seekers* may seek out tactile sensations that seem strange such as touching all kinds of objects, touching people constantly, tapping, rubbing objects or people, and seeking out stimulation in inappropriate amounts or unusual ways.

Sight

- *Overresponsive children* can quickly become overwhelmed when there is too much in their visual field (toys, words, people, or things). They may have poor eye contact, appear inattentive, or even cover their eyes, especially when the lights are bright. Other times they may be hypervigilant or fearful of additional stimuli being put into their environment.
- *Underresponsive children* may not notice messes or visual overcrowding and are not bothered by bright lights. They may dislike empty space or prefer clutter.
- *Visual seekers* will seek out lots of color or patterns, they may not be bothered by messes or even prefer them, and may be more comfortable with, seek, or create chaotic environments.

Sound

- *Overresponsive children* may cover their ears to close out sounds. They may become highly reactive to common

sounds that others may not even notice, like someone chewing crunchy food such as a carrot, the sound of a vacuum cleaner, the ticking of a clock, or the engine of a loud car.

- *Auditory underresponsive children* may not hear certain sounds that bother others, may not react to auditory cues, and may not notice competing sounds that would irritate other people (e.g., the radio and television on at the same time).
- *Auditory seekers* may like very loud music or prefer to have several sources of audio input going at once.

Smell

- *Overresponsive children* may strongly object to odors that others may not notice, such as an air freshener, certain food cooking, or a ripe banana. Reactions may include screaming, vomiting, or avoidance.
- *Underresponsive children* will not notice unpleasant smells and never complain about things smelling bad.
- *Olfactory seekers* may seek out smells or investigate the world through smell. You may see these kids smelling things in their environment, including books, pens, their underarm, a friend's foot, something they found on the floor, or their finger after touching something that another child might deem unpleasant.

Taste

- *Overresponsive children* may be unwilling to eat food with certain textures or temperature and may spit out food, gag, vomit, or cry when presented with certain foods.
- *Underresponsive children* will eat virtually anything without complaint, including foods such as strongly flavored fish, spicy sauces, and bitter tastes such as lemon.
- *Taste seekers* may explore new things with their mouth or tongue. They may lick objects, put them in their mouth, or even swallow them despite their being offensive to others or even dangerous.

SENSORY DYSREGULATION VERSUS SENSORY INTEGRATION DYSFUNCTION

The term “sensory integration dysfunction” was first used by an occupational therapist named Jean Ayres (1966b, 1972b) to identify and describe individuals with atypical responses to sensory stimulation and was later described in the book *The Out-of-Sync Child* by Carol Stock Kranowitz (2005). The clinical condition is now known as sensory processing disorder (SPD). While earlier studies examined the functioning of individual sensory processes separately, current research on this phenomenon focuses on multi-sensory integration, studying the interaction of two or more sensory modalities concurrently.

The concept of sensory dysregulation described in this book is identical to sensory dysfunction in terms of its mechanism, but sensory dysregulation also refers to the emotional and behavioral outcomes of a nervous system that is not functioning within the normal range. Sensory dysregulation is the result of a disturbance in the sensory system (including sensory integration dysfunction and/or SPD), but it goes on to encompass dysfunctional emotions and behaviors that are complex to both conceptualize and treat. This book is not intended to replace or to diminish the work being done within the occupational therapy realm; rather, it is an attempt to expand the understanding of the sensory system to mental health practitioners and explain how it governs far more than just a child’s reactions to certain stimuli. This book describes how emotional and behavioral dysfunction can be the result of a glitch in the sensory system and how incorporating the evaluation of the sensory system into routine clinical conceptualization and treatment can help to enhance and improve outcomes in many complicated cases.

AUTISM AND AUTISM SPECTRUM DISORDERS

This book intentionally leaves out autism and autism spectrum disorders (ASD) co-occurring with sensory dysregulation, not because this is not an important relationship, but because it is critical. All

people with autism or ASD have sensory dysregulation issues, while a much smaller percentage of people with sensory dysregulation issues have autism or ASD. In order to successfully treat autism and ASD, one must be specifically trained. This book will not attempt to tackle this complicated and important treatment, not through oversight, but by design. The focus of this book will be to address sensory dysregulation when it occurs outside of autism and ASD and enters the realm of anxiety and other disorders of infancy and childhood.

Johnny is a 5-year-old boy whose mother brought him in for evaluation after his kindergarten teacher expressed concerns about his unusual behavior. She reported that he is constantly touching, rubbing, smelling, and licking objects in the classroom, including his classmates. She stated, "It is as if Johnny does not know what an object is unless he has touched, smelled, and tasted it." His teacher seemed frustrated and annoyed when speaking to Johnny's mother, who was well aware of his strange habits. Since he was an infant, she remembered Johnny putting things in his mouth. She also reported that he has an unusually high tolerance for pain and will walk into the house with blood dripping down his leg from a cut that he does not even notice. Currently he is also unusually rough with his peers, not in an intentionally mean way, but in a roughhousing way that sometimes gets out of hand. Johnny is a talkative child who seems to want to do the right thing, but he continues to engage in behaviors that get him into trouble. Johnny shows remorse for his behavior but is unable to consistently correct his behavior. Johnny does not meet criteria for autism or an ASD.

Johnny is a good example of a child with a sensory-seeking nervous system, one who craves sensory input through smell, taste, and touch in a more excessive way than is usual. This is also evident in his high pain threshold, also an example of an underresponsive nervous system. Sensory dysregulation can cause not only obvious social difficulties, such as is the case of Johnny, but also more subtle and hard to identify interpersonal difficulties that may get misidentified. Over time, these interpersonal difficulties can develop

into patterns of interpersonal conflict or avoidance, or problematic behaviors that start with sensory dysregulation problems but can become full-blown psychological disorders. The following is an example of how sensory dysregulation affects the relationships of a high school girl with a sensitive nervous system in a much more elusive way.

Thirteen-year-old Sarah was having trouble with her friendships again. She had always had a small group of close friends who understood her quirky nature and were forgiving of her hot-and-cold reactions to seemingly benign situations. They thought of it as her being “Sensitive Sarah.” At lunch one day, Sarah was sitting at a table, with her friend Alice’s back to her as Alice talked with Amy. Alice and Amy were laughing and talking together for almost the entire lunch. Sarah felt certain that they were purposely excluding her and that they must have known how upset she was, yet neither one of them said anything to her about it later in the day. This upset and eventually infuriated Sarah. She came home and disappeared into her room. Sarah did not come out of her room for the rest of the night. The next day Sarah claimed she had a stomachache and refused to go to school. She began to avoid Alice, Amy, and other girls, without explaining her feelings. Her friends were confused and, after a while, stopped calling and texting her to get together. Sarah felt isolated and angry. She began to believe that her friends were purposely hurting her feelings and therefore not worth it. Sarah began to withdraw socially and tried to avoid school whenever possible, claiming that she felt sick.

Even by teen standards, Sarah’s reaction to feeling left out seems extreme. Sarah was unable to interpret this typical social situation because she has difficulty integrating multiple stimuli: a loud environment, the intense smell of the food, the visual chaos in the cafeteria, and the subtle social cues. In combination, all of these stimuli contributed to Sarah’s confusion about her friends’ behavior and resulted in her experiencing intensely hurt feelings. Rather than asking her friends if she could join in on the conversation, Sarah became overwhelmed and shut down emotionally. Her faulty assumptions perpetuated her hurt feelings and sense of isolation.

Sarah was also unable to both calm herself down and to talk to her friends about her feelings.

Accurately decoding situations contributes to emotional stability and regulation. The decoding process is an intrinsic function of the sensory system. Faulty decoding led Sarah to misunderstand her friends' behavior. This misunderstanding caused her to assume that her friends must have purposely ignored her, known how she felt, and not done anything to make her feel better. In addition to a faulty read of her environment, which made her anxious and angry, Sarah lacked the skills to manage those overwhelming feelings. Her emotional response was intense and confusing, which made her want to avoid similar experiences and ultimately caused her to withdraw from engaging in other relationships. Sarah's response to her friends' lunchtime chat is a good example of how a normal event can become a catalyst for emotional dysregulation and problematic behavioral responses that can have long-lasting implications.

DEVELOPMENT AND DYSREGULATION

According to Ayers (1966a), human development is dependent on three important neurobiological precepts:

1. Development follows a predictable sequence.
2. Abnormal development may reflect the expression of more primitive behavior.
3. Maturation is dependent on interaction with the environment.

When there is a disturbance in the evaluation, processing, or integration of sensory information, as described throughout this book, these neurobiological precepts can be interrupted. Camille, the child who was bothered by the sound of storms, clearly demonstrated primitive behavior (hiding, screaming, crying) and an inability to mature in her reaction to the sensory stimuli associated with storms (continued resistance and avoidance of storms). Typical therapy did not provide relief for Camille or her family because the origin of her resistance was not identified or addressed.

THE MISSING PIECE OF THE PUZZLE

Problems with sensory regulation coupled with anxiety and problematic behavior create a perfect storm for confusion and disruption of the family, frustration in therapy, and potential treatment failure. Consequently, it is always a good idea to screen for the presence of sensory difficulties during the initial intake. If present, specific treatment for these issues can make a significant difference in the ultimate outcome of treatment. Understanding a child's nervous system helps shed light on what may be causing the problem, as in the case of Brad, who was not able to eat food with comingled colors. Not knowing about his sensory sensitivities, a therapist might treat him as if he had an eating disorder or OCD, while the true etiology of his symptoms is sensory in nature. Treating Brad with exposure therapy alone might cause him to feel overwhelmed, frustrated, and misunderstood, and would possibly result in treatment resistance and noncompliance with therapeutic recommendations.

A unique and creative treatment approach that combines treatment for anxiety (exposure), direct treatment for symptoms of an over- or underresponsive nervous system (sensory interventions and coping skills training), and counterconditioning techniques will be described in detail in this book. Brad's treatment might include the practice of gradually mixing colorful objects, introducing sensory soothing techniques during exposure to color mixing, and teaching calming thoughts and relaxation skills, all of which will be explained in detail in later chapters. You will see how Brad will become more flexible with eating, and how these therapeutic skills will build his confidence and help him better understand his nervous system. Ultimately, treatment will enable him to effectively manage his responses and provide him with tools to maintain emotional stability in the future. In addition, his family will benefit from therapy by becoming more understanding and taking a more compassionate and supportive approach with him, without accommodating his anxiety or negatively reacting to symptoms of sensory dysregulation.

This book describes sensory dysregulation and explains how mental health professionals treating children with anxiety and other disorders as well as sensory dysregulation can improve their

diagnostic conceptualization and treatment of these hard-to-treat children. The book outlines how children with sensory issues may be misdiagnosed or improperly treated and illustrates how these issues can complicate the clinical picture. Numerous creative strategies are offered for successful management of the dysregulated nervous system. With early intervention, children can develop important lifelong skills that will lead to creative problem solving, better emotion regulation, reduced anxiety, increased functioning during stress, improved family relationships, more empathy toward others, and successful management of their nervous systems.

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