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The Puzzle of Trauma: Redefining PTSD in the *DSM*

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The Puzzle of Trauma: Redefining PTSD in the *DSM*

BY MARY SYKES WYLIE

Back in the late 1970s, a motley crew of Vietnam War vets, sympathetic psychiatrists, antiwar activists, and church groups undertook a crusade to have a hastily-assembled new diagnosis almost completely innocent of scientific research included in the *DSM-III*. Nevertheless, fueled by a sense of mission and responsibility to the huge population of Vietnam vets and buoyed by the accumulating everyday clinical evidence that their war experience had profoundly disrupted the lives of thousands and thousands of young men, this unlikely coalition prevailed. Once established as a distinct disorder in the official manual of psychiatric diagnoses, the otherwise unaccountable behavior of badass vets—their hair-trigger tempers, violence toward wives and girlfriends, drinking and drugging, difficulty getting and keeping jobs, social alienation—suddenly made sense. There was a reason for it and the reason had a name and that name was post-traumatic stress disorder (PTSD). By giving words—a verbal shape, a definition—to an amorphous constellation of symptoms, what had before been invisible became a part of standard professional discourse.

As a diagnosis, PTSD is quite straightforward. A person is exposed to a traumatic event or events “that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others,” causing “intense fear, helplessness, or horror,” and followed, down the line, by variations on intrusive reexperiencing of the event (flashbacks, bad dreams, feeling as if the event were reoccurring, etc.), persistent and crippling avoidance (of people, places, thoughts, or feelings associated with the trauma, sometimes with amnesia connected to important parts of the experience), and increased arousal patterns (insomnia, hypervigilance, irritability, and so on). Clear, brief, intuitively sensible, the definition of PTSD implies a kind of satisfyingly simple, dramatic, and implicitly moral story line: individuals are innocently minding their own business when—wham!—they’re slammed by a frightful, shattering, life-threatening happenstance, and are never the same again. The trauma may have “ended,” but not in the perpetually recycling memories and disrupted nervous systems of the victims.

Yet no sooner had PTSD been signed, sealed, and delivered, than many clinicians began to realize that the new diagnosis by no means encompassed the experience of all traumatized clients. Soon after the publication of *DSM-III*, Boston

psychiatrist and trauma expert Bessel van der Kolk recalls that a woman came to see him after she’d beaten up her boyfriend. “She said, ‘I have PTSD,’” he says, “but after I’d spent some time with her, I told her, ‘No, actually you don’t have PTSD, you have something else. You cut yourself, you space out a lot and don’t remember things, you shift personality, you feel lots of shame and self-blame, you get extremely upset by very small things—that’s not PTSD.’” Even though she *did* show signs of PTSD, her symptoms seemed to take off from there into unexplored territory—a psychological terrain very different from that of traumatized vets.

The patients he was seeing, almost entirely women, had multiple, often severe, and apparently global problems affecting their sense of identity and self-perception, their relationships, their ability to moderate emotion, even their physical health. They were, varyingly, clingy, needy, impulsive, enraged, depressed, despairing, or suicidal. They purposely hurt themselves—cutting, scratching or burning their skin, biting or starving themselves, pulling out their hair—drank too much, and did drugs. They couldn’t remember large blocks of their childhood, “lost” days at a time, often felt apathetic, disembodied, or as if the world was unreal. They might regard themselves as somehow innately stigmatized or defiled, as lonely outcasts whom nobody could ever understand, or as somehow special and completely different from others. Their sense of personal boundaries was porous, to say the least—they might share their life stories, full sexual details included, with virtual strangers. They frequently suffered from amorphous, hard-to-diagnose-and-treat physical illnesses—fibromyalgia, irritable bowel syndrome, chronic pelvic pain, headaches, “acid” stomach, back pain, as well as stranger complaints, like temporary blindness and tingling in the extremities. In short, the more van der Kolk learned about them, the longer the list of their symptoms—in fact, it sometimes appeared that there wasn’t a symptom, mental or physical, they *didn’t* have.

They also shared one other feature: they all reported histories of childhood incest. To van der Kolk, this was more than a little bizarre. The most authoritative psychiatry textbook at the time opined that not only was incest “extremely rare”—about one case in every million people—but when it *did* occur, it was often “gratifying and pleasurable”; at the very least, “the vast majority” of girls “were none the worse

for the experience.” Reflecting on the presumed rarity of incest cases, van der Kolk could only wonder, “Why are so many of them showing up in *my* office?”

But they weren’t just showing up in his office. In the popular ferment generated by the feminist movement of the ’70s, women were beginning to tell stories previously never mentioned in public, revealing the appalling *ordinariness* of rape, wife-battering, child abuse, and incest. Therapists willing to take seriously what their female patients were telling them—which a decade earlier would have been widely dismissed as hysterical fabrications—began learning about an unsuspected and nasty underside of American domestic life. At the same time, two young therapists—psychiatrist Judith Herman and psychologist Lisa Hirschman—were hearing an astonishing number of childhood incest stories from *their* adult patients. In spite of being told by their supervisors that these stories were most likely fantasies, they began studying the phenomenon and produced first an article in 1977 for *Signs*, an obscure feminist journal, and then *Father-Daughter Incest*, a pathbreaking book published in 1981.

Like van der Kolk and many other therapists who were just beginning to peer into this newly opened Pandora’s Box, Herman and Hirschman soon discovered that the PTSD diagnosis was simply too narrow to encompass the extent and, frankly, the messiness of what needed to be described. PTSD didn’t remotely account for the length and intensity of the abuse these women had suffered, their complex, heterogeneous symptoms, or the damage done to their personalities, capacity for relationship, and physical well-being.

But then, neither did any other diagnosis. Presenting themselves with a muddle of symptoms, such women might be treated for depression, anxiety, agoraphobia, panic, multiple personality disorder and, of course, borderline personality disorder—already a notorious grab bag for troublesome female patients who seemed to have everything wrong with them, but nothing definitive. Even worse, these women were often implicitly blamed for being “manipulative,” their problems considered inherent to their fundamentally malicious nature. Advocates for these female patients, like Herman, argued that there was a moral and psychological imperative to agree upon a new diagnosis that actually made sense of these patients’ experience. Giving what these women suffered a *name*, she wrote, would help grant “those who have endured prolonged exploitation a measure of the recognition they deserve.” As had happened with PTSD a decade earlier, words would make their suffering real—or perhaps, force people to finally acknowledge what was already all too real. “As long as we live in a world in which there are no definitions and no language for what’s wrong with people, we can’t do anything about it,” observes van der Kolk. “When a diagnosis ignores the reality of what people suffer from, we’re living in psychiatric la-la land.”

The Power of DSM

In 1980, the *Diagnostic and Statistical Manual’s* third edition

(*DSM-III*) established the field’s first standardized, empirically based listing of psychiatric disorders. It became the “bible” of psychiatry—the single, authoritative arbiter of legitimate diagnoses. If what ailed van der Kolk’s patients was ever to be recognized by official psychiatry, it had first to be defined and presented effectively to the gatekeepers of *DSM-IV*, scheduled for publication in 1994.

The *DSM* is the book that everybody loves to hate and hates to love, but can hardly do without—it’s all we have, the one organizing principle standing between the mental health field and sheer diagnostic chaos. The manual’s economic, institutional, and social power—its necessity—can hardly be overestimated. Not only is a *DSM* diagnosis required for private insurance reimbursement, government payment for mental health treatment, and research funding, but it also constitutes psychiatric law for the court system, regulatory agencies, schools, social services, prisons, juvenile detention facilities, and pharmaceutical companies. Absent inclusion in the *DSM’s* authoritative pages, a disorder doesn’t exist. The diagnoses it contains aren’t written by the hand of God, but they might as well be.

“What happens is this,” says psychiatrist Frank Putnam, an expert on dissociation in children and adults, himself a hardy veteran of many trauma-related psychiatric battles, “you need a diagnosis to bill—that’s the way the world works. Most of the interventions we do at my center aren’t billable—we lose about \$220 for every kid we see. You can’t just treat somebody without giving a formal diagnosis.” As a result, according to Putnam, “the *DSM* has become the tail that wags the dog.” Furthermore, without an official diagnosis, there can be no money for research. “If the diagnosis doesn’t exist,” says van der Kolk, “you can’t study it—you can’t go to NIMH and ask to be funded to study a nonexistent diagnosis.”

In the late ’80s, van der Kolk became one of the central players in the laborious spade work for getting some sort of “complex PTSD” diagnosis into the *DSM-IV* to be published in 1994. He and his colleagues worked with Bob Spitzer, the “father of the *DSM*,” to define a new diagnostic entity, which Spitzer inelegantly called “diagnosis of extreme stress, not otherwise specified” (DESNOS). As co-chair of the *DSM-IV* PTSD Committee field trial, van der Kolk was commissioned by the American Psychiatric Association to conduct a study to examine the validity of DESNOS as a psychiatric diagnosis. Between 1990 and 1992, his study group reviewed hundreds of studies demonstrating the connection between childhood trauma and psychiatric disorders in adults, hypothesized plausible symptom criteria sets for the new diagnosis, used a battery of assessment instruments to test it on more than five-hundred patients at five outpatient psychiatric facilities—basically comparing people with extensive histories of childhood abuse with adults traumatized by natural disasters. The goal: “to see if people who had been traumatized by long-term interpersonal childhood violence looked different from people who had been traumatized by one-shot traumas.”

The answer was a dramatic: yes, indeed they did. The participants with a history of interpersonal childhood sexual and physical abuse were “vastly different” from the disaster victims with simple PTSD. The former showed the same mish-mash of symptoms van der Kolk, Herman, and other therapists had seen for years in patients with histories of seriously abusive childhoods—inability to regulate their emotions, self-destructiveness, dissociation, amnesia, suicidality, shame, hopelessness, despair, wide-ranging somatic complaints, and so on. These people almost always *also* had PTSD symptoms, and yet, according to van der Kolk, “What brought them to treatment was *not* their PTSD symptoms, but their DESNOS symptoms.” In short, to the advocates for the new diagnosis, the evidence seemed inescapable that DESNOS was real.

Then began a voyage into the Byzantine politics of DSM. The DSM-IV PTSD Committee voted 19 to 2 in favor of accepting the new diagnosis in the new manual. It looked like a slam dunk. And then . . . nothing. “The diagnosis went up the chain via various DSM committees and then disappeared—it didn’t make it into *DSM-IV*,” van der Kolk says ruefully. “It was over-ruled at higher levels,” Herman wrote cryptically in her groundbreaking book *Trauma and Recovery*. But why? It appears that what most bothered the critics of DESNOS was its diagnostic messiness—its tendency to leak into so many other disorders. DESNOS seemed to smash virtually *all* the boundaries between diagnoses that the publishers of the *DSM* had been at pains to keep separate since the *DSM-III* “revolution” in 1980, which neatly both medicalized mental disorders and divided them into distinct, non-overlapping categories.

More than a decade later, epidemiologist Dean Kilpatrick, editor of the *Journal of Traumatic Stress*, wrote an editorial to a special section on complex trauma that seemed to reflect the viewpoint of the DESNOS naysayers. It was true, he argued, that PTSD didn’t capture all the significant post-traumatic problems that could occur, but so what? Disease “classification systems aren’t designed to include every symptom associated with a disorder,” but the *least* number required. “Also . . . the fact that the PTSD diagnosis does not capture all responses to traumatic events is not a problem per se because there are numerous other Axis I and Axis II disorders that capture many of the other features that DESNOS and complex PTSD advocates think should be measured.” In short, was there really a need for a kind of super-diagnosis that included everything and the kitchen sink, when lots of other perfectly good diagnoses were already available?

To the proponents of DESNOS, this critique and concern for clashing with the goals of the existing diagnostic category system entirely missed the point. Without understanding what Judith Herman called “the underlying unity of the complex traumatic syndrome,” many deeply troubled and profoundly victimized people would continue to receive one unrelated diagnosis after another, or all piled up on top of each other, while the traumatic origins of their suffering remained unaddressed.

Renewing the Battle

In 2001, the Cummings Foundation convened a group of child psychiatrists, public policy experts, and representatives from the Department of Justice, Department of Health and Human Services, and Congressional staff to consider the deplorable state of services to traumatized children, a service sector that consumes billions of taxpayer dollars with very little to show for it. Led by Senator Edward Kennedy’s office, this initiative led to the establishment of the Congressionally mandated National Child Traumatic Stress Network (NCTSN), which, during the past nine years, has welded together 53 clinics and academic institutions nationwide to develop and implement effective interventions for traumatized children and adolescents. Soon, the researchers and clinicians working in the NCTSN ran into the same problems Herman, van der Kolk, and their numerous colleagues had confronted a decade earlier: while children can develop plain PTSD symptoms as a result of a single traumatic incident, the children who’d sustained prolonged abuse, neglect, and violence—the vast majority of children treated in the NCTSN—suffered from something that went beyond PTSD.

These very troubled children with histories of abuse weren’t easily pigeonholed into any other existing diagnoses: the standard treatment system wasn’t working—it just didn’t fit the circumstances of abused children, any more than it had worked for adults with histories of chronic childhood abuse. These children often collected impressive diagnostic records—four, five, six, and more different diagnoses before they reached their teens; the more traumatic stressors, the larger the number of diagnoses. As a result, they received treatments geared to one or another diagnosis, like bipolar disease or conduct disorder—consisting of medications, behavioral modification, exposure therapy—that often didn’t work, or even caused more damage.

Alicia Lieberman, director of the Child Trauma Research Project at San Francisco General Hospital, remembers one 18-month-old referred to her during the mid-80s by a child care center because he was so hard to manage. He regularly ran away, bit and pushed other children, refused to take naps, and often sat in a corner crying and rocking. The last straw came when he threw a chair through the window, bit the teacher who tried to restrain him, and then ran away. In addition, Lieberman soon discovered, he woke up at night screaming, cried for his mother in daycare, and alternated between being sad and despairing or angry and defiant.

In Lieberman’s office, the boy clung fearfully to his mother’s jacket, unwilling to leave her side, to which his mother responded harshly, “Stop manipulating me. You’re just pretending to be shy!” Asked about her son’s extreme nail-biting—Lieberman could see he bit his nails to the quick—the mother said brusquely, “He just does that to bug me.” He was frightened by any loud noise. When a bell rang outside the office, Lieberman had to take him outside to see that it was only a bell to calm him down.

There were obvious attachment problems, Lieberman said—the mother rejected the child and attributed malicious motives to his behavior. When asked about her own background, the mother revealed that she'd had a lifelong history of childhood abuse and chaotic, unstable relationships as an adult. She'd become pregnant with her son when her boyfriend raped her at gunpoint. He then abandoned her when she told him she was pregnant. Now she was convinced that the boy was the father's genetic double—a small version of her rapist. The boy had witnessed a lot of domestic violence between his mother and a succession of partners. His bruises made it clear that he was being knocked around, and he certainly was being emotionally maltreated.

“This boy started me thinking about the whole problem of comorbidity with trauma,” Lieberman said. “He could meet the criteria for depression, anxiety, oppositional defiant disorder, and PTSD. But if we only picked one of the disorders, we wouldn't be alert to the wide range of symptoms—we wouldn't be seeing the whole child. This case made me think that we needed to move beyond single diagnoses to something that could encompass different domains at once.”

The ACE Studies

Since *DSM-IV*, a massive body of neurobiological research has accumulated revealing how protracted childhood abuse and neglect can cause pervasive, devastating, and lasting biological and psychological harm. Researchers in developmental psychopathology have shown that childhood maltreatment and neglect are associated with structural and functional abnormalities in different brain areas, including the prefrontal cortex (logic and reasoning), corpus callosum (integrating the right and left hemisphere), amygdala (fear and facial recognition), temporal lobe (hearing, verbal memory, language function), and hippocampus (memory). Last year, for example, researchers found a reduction in the visual cortex of young women sexually abused as children (but not in controls), which may help explain why abused children are quicker to recognize and stare at angry faces than non-abused kids, and why they pick up anger even in faces with ambiguous expressions, while missing other emotions. Abuse also disrupts the neuroendocrine system, altering the production of the stress-regulating hormone cortisol and neurotransmitters like epinephrine, dopamine, and serotonin—chemicals affecting mood and behavior. Chronic trauma weakens the immune system and sets up children for illness far down the road. The Centers for Disease Control has recently reported, for instance, that trauma's disruption of cortisol levels leaves abused children vulnerable to chronic fatigue syndrome later in life.

Some of the most astonishing and far-reaching evidence for the lifelong and malign repercussions of childhood trauma has come not from the mental health field, but from the study of epidemiology. In 1995, internist Vincent Felitti, a preventive medicine specialist with California-based HMO Kaiser Permanente, and Robert Anda, an epidemiologist

with the Centers for Disease Control began the Adverse Childhood Experiences (ACE) Study to track the relationship between childhood maltreatment, neglect, and other family loss or dysfunction and adult mental and physical health.

Drawing data from an extensive and detailed survey of 17,337 Kaiser members undergoing standard yearly physical exams, this unprecedented study (and more than 60 others by numerous researchers based on the same data) found that a majority of the participants surveyed had experienced some form of serious family dysfunction, emotional, physical, and/or sexual abuse and neglect. Not only that, but the studies showed direct correlations with these “adverse experiences” and a remarkably large proportion of all the physical, mental, and social ills that beset society.

It's by now glaringly obvious to mental health professionals that child abuse significantly increases the risk for mental and emotional disorders—and associated risks for alcoholism, drug abuse, and smoking—though the ACE Studies nail the case beyond denial. Who knew, however, that childhood adversity was major risk factor for many of society's most prevalent biomedical illnesses and causes of death—heart and lung disease, diabetes, liver and kidney disease, some cancers, sexually transmitted diseases (including HIV), and autoimmune diseases, for example? Or that being abused or neglected as a child increased the likelihood of being arrested as a juvenile by 59 percent, as an adult by 28 percent, and for committing a violent crime by 30 percent? The total direct and indirect costs of child abuse—hospitalization and mental health care for children, as well as increased health care costs for adults who were abused as children, child welfare services, law enforcement, special education, juvenile justice system, criminal justice system, and lost productivity—amounted to \$103 billion in 2007 in conservative estimates. In light of all this, it's been asserted that child abuse is the largest single public health issue in America.

Lobbying DSM-V

In order to study the symptomatology of the children seen within the NCTSN, van de Kolk and his colleague Joseph Spinazzola organized a complex trauma task force. Between 2002 and 2003, they conducted a survey (via clinician reports) of 1,700 children receiving trauma-focused treatment at 38 different centers across the country. They found more evidence of what two decades of research had already revealed: nearly 80 percent of the surveyed kids had been exposed to multiple and/or prolonged interpersonal trauma, and of those, fewer than a 25 percent met the diagnostic criteria for PTSD.

Instead, these children showed pervasive, complex, often extreme, and sometimes contradictory patterns of emotional and physiological dysregulation. Their moods and feelings could be all over the place—rage, aggressiveness, deep sadness, fear, withdrawal, detachment and flatness, and dissociation—and when upset, they could neither calm themselves down nor describe what they were feeling. To soothe

themselves, they'd engage in chronic masturbation, rocking, or self-harming activities (biting, cutting, burning, and hitting themselves, pulling their hair out, picking at their skin until it bled). They often had physical problems—sleep disturbances, headaches, bad digestion, unexplained pain, oversensitivity to touch or sound—as well as difficulties with language processing and fine-motor coordination. They were clingy and dependent, even with the person who abused them. They often loathed themselves, felt defective and worthless, and distrusted other people. Not surprisingly, they couldn't concentrate, performed poorly in school, and made few, if any, friends. "These kids have serious problems with affect regulation, dissociation, attention, concentration, risk-taking, aggression, impulse control, and self-image—they hate themselves," says van der Kolk. "But they don't have PTSD."

Studying a similar group of young adults at New York University, researcher Marylene Cloitre found that *emotional* abuse and neglect—the absence, failure, or distortion of the child's relationship to a primary caregiver—did as much, if not more, damage than actual physical abuse. "The severity of a particular trauma—assault, accident, whatever—determined PTSD symptoms," van der Kolk says, "but the child's relationship to the abuser determined everything else—anger, suicidality, self-injury, disturbed relationships, tendency to be revictimized." At the heart of emotional abuse or neglect is a failure of parental attachment and attunement, not to mention overt hostility, which is worse in its way than physical abuse because it does such a number on the developing brain and nervous system of a child. "You need presence, you need mirroring, you need someone out there who knows what you see, so you can know what you know, and speak what you speak," says van der Kolk, before quoting attachment pioneer, John Bowlby: "What cannot be communicated to the mother by the child cannot be communicated to the self of the child." If a child doesn't get this sense of "presence" from a trusted adult, she can't connect with her own felt inner experience and, ultimately, can't develop a sense of her own authentic self.

Van der Kolk illustrates the lesson with the example of an alcoholic father beating a child, who later says to his mother, "Daddy hit me. I hope that he'll just go away and never come home again." The mother, afraid to leave her husband or even rock the domestic boat, simply denies what happened—"No, no, Daddy really loves you a lot—he's just had a bad day and is tired." In such a situation, particularly if there are lots of such situations, "You lose the capacity for internal representation of what really happened, for finding words that represent your felt, physical experience. Your capacity to feel your inner realness is impaired." Such children are left with a bone-deep sense that "something is very wrong with the way I am." It's this damage done to a chronically abused child's budding sense of personal identity and coherent selfhood that particularly distinguished this "trauma syndrome" from garden-variety PTSD.

In 2005, the complex trauma task force, chaired by van der Kolk, began working in earnest on constructing a new diagnosis, called Developmental Trauma Disorder (DTD), which, they hoped, would capture the multifaceted reality experienced by chronically abused children and adolescents—a kind of "DESNOS, Jr.," only with more emphasis on developmental and attachment issues. Finally, in January, 2009, they submitted to the DSM Trauma, PTSD, and Dissociative Disorders Sub-Work Group, an elaborate criteria set (DSM-speak for symptom list) for DTD: exposure to prolonged trauma, causing pervasive impairments of psychological dysregulation (of emotions and bodily functions, of awareness and sensations, of attention and behavior, of their sense of self and their relationships), as well as at least two symptoms of standard PTSD, and multiple functional impairments (with school, family, peer group, the law, health, and jobs or job training). They also requested support for a field trial to develop accurate assessment tools, test the criteria, and address still-unanswered questions. With their proposal, they included supporting evidence from 130 research papers representing 100,000 children.

According to van der Kolk, the DSM committee responded that the complex trauma task force had "inundated" them with too much data, but not the right kind: they needed to submit *other* kinds of data concerning 17 issues, including possible genetic transmission, environmental risk factors, temperamental antecedents, bio-markers, familial patterns, treatment response, and so on—almost none of which, van der Kolk notes, is known about any currently existing psychiatric diagnosis. After a two-week, night-and-day, largely sleepless extravaganza of work, spearheaded by Wendy d'Andrea, a post-doctoral student at the Trauma Center, the NCTSN task force resubmitted the proposal, with an even bigger barrage of supporting materials, including combined data on 20,000 traumatized children gathered from various sources—among them, 4,500 children from the NCTSN, 7,000 from the Illinois child welfare system, and almost 2,000 collected by Julian Ford from a juvenile justice center. Participating Chicago NCTSN director Bradley Stolbach did the preliminary analysis, which convincingly showed that kids suffering from long-term trauma are indeed different from those suffering single-incidence trauma. In addition to the data on these 20,000 children, they analyzed and submitted more than 300 research articles. They also enclosed a joint letter from the National Association of State Mental Health Directors, representing 53 states, urging DSM to adopt the new diagnosis. Says van der Kolk, "I'd guess that we gave DSM more documentation supporting DTD than ever before provided for any other psychiatric diagnosis."

They were again turned down. It was, as Yogi Berra once famously said, "déjà vu all over again." The DSM subcommittee, chaired by Matthew Friedman, executive director of the National Center for PTSD, wrote that "the consensus is that it is unlikely that DTD can be included in the main

part of *DSM-V* in its present form because of the current lack of evidence in support of the diagnosis and the lack of prospective testing of your proposed diagnostic criteria.” The DSM trauma subgroup didn’t necessarily refute the reams of supporting data—they just didn’t seem to think any of it was particularly relevant. Yes, they agreed that the data cited by the DTD task force showed that chronically abused children had more symptoms than others, but so what? That didn’t mean they were inappropriately diagnosed or treated under the current system, or that this new diagnosis was required to fill a “missing diagnostic niche.” There was just no consensus in the child trauma field that DTD would be clinically useful.

Furthermore, there were no “published accounts about children with this disorder” and “no research had been performed using the particular, specific criteria,” nor “studies on differential responses to treatment.” In any case, there was only “scant evidence” that interpersonal trauma (i.e., family-based trauma) has a unique influence apart from non-interpersonal trauma. Nor was there much evidence that chronic childhood abuse disrupted children’s development, which was “more clinical intuition than a research-based fact.”

Finally, what seemed to make the DSM subgroup figuratively recoil in horror was the sheer *muchness* of the diagnosis. “The range of symptoms covered in the proposed criteria is too broad, . . . it would supersede not only PTSD, it would supersede all internalizing and externalizing disorders that appeared following interpersonal trauma and poor rearing. Nearly any problem that followed childhood mistreatment would have to receive this new diagnosis.” They found it “most worrisome” that the proposed DTD symptoms showed so much overlap with borderline personality disorder.

To this fusillade, the complex trauma group responded with a polite, but barbed, rebuttal. They were hardly addressing a “diagnostic niche,” they replied but a substantial proportion of the one million children who are confirmed every year to be abused and neglected, plus the half-million living in foster care. There was also a great deal of consensus, thank you very much, from thousands of clinicians who treat chronically traumatized children—if the DSM subgroup liked, the NCTSN task force estimated that it could assemble a petition to DSM in favor of such a diagnosis signed by 10,000 clinicians.

As to “no published accounts about children with this disorder” and “no research . . . using the particular, specific criteria,” nor any treatment studies, well, of course not: this was a *proposed* diagnosis, which didn’t officially exist yet, and so—in that great Catch-22 tradition of DSM—couldn’t qualify for the funding of exactly this kind of research, which was why the trauma group sought official DSM recognition in the first place. The complex trauma group wrote that they had extrapolated the specific criteria from the vast body of relevant research and data on traumatized children. That was basically the way all diagnoses began—with a literature and data search and discussions among leading experts, who came to a consensus about a plausible set of criteria, which

could then be field tested. The only difference was that *this* proposed diagnosis began with a much larger database than had any other diagnoses.

Finally, to the quarrel with the symptom overlap, the trauma task force responded briskly, “That is exactly the point—currently all these symptoms are relegated to a host of seemingly unrelated diagnoses, while they clearly cluster in children with histories of chronic abuse and neglect.” Borderline personality disorder was a perfect example, since numerous studies had shown that the vast majority of BPD patients “have histories of severe abuse and/or neglect starting before age 7.”

To the DSM reviewers, the avalanche of literature submitted by the trauma task force may have been circumstantially very interesting, suggestive, and epidemiologically dramatic, but it was still unconvincing as the basis for the pared-down precision of a legitimate diagnosis. “Correlation does not imply causation,” is the standard mantra in science (a criticism raised about the ACE studies, as well.) A risk factor, even if it precedes an event, isn’t necessarily a cause.

Commenting on his group’s rejection of the task force’s proposal, Matthew Friedman, the chair of the DSM trauma work group insists that, “I encouraged them to submit their diagnosis to DSM. Their proposal was reviewed by many people from different work groups who generally felt the evidence was not compelling. Their research was almost entirely retrospective, collected from different places, under a variety of conditions, using different kinds of measurements. They need to identify in advance, not retrospectively, what the criteria should be, develop the diagnostic instruments to assess them, then go into the field and rigorously apply it to see whether the criteria they propose are accurate, whether they hold together diagnostically and constitute a diagnosis that is sufficiently differentiated from others.”

According to Charles Zeanah, psychiatry professor and executive director of the Institute of Infant and Early Childhood Mental Health at Tulane University and a critic of DTD, the whole debate is a classic case of the old division in science and philosophy between lumpers and splitters (lumpers focus on commonalities between different phenomena, splitters on the distinctions between them). The DTD diagnosis is the very embodiment of the lumper spirit, while the *DSM* is essentially defined by its splitter ethos. “Some people [the DTD camp] look at traumatized kids and say, ‘wait a minute! These kids have way too many symptoms other than PTSD caused by trauma, so we need a bigger tent,’” says Zeanah. “Maybe, but the concern is that the diagnosis becomes so big, so inclusive of everything that it just turns into ‘psychopathology, with no further specifications.’ You could take two kids with the same disorder who bear almost no resemblance to each other and they might both be assigned the same diagnosis—maybe that tent is a little *too* big. One risk factor can have a multiplicity of outcomes, but that doesn’t mean you have to call all of those outcomes by the same name.” The ACE study is a case in point, he argues,

a relatively narrow set of circumstances early on apparently resulting in a host of physical and psychological disorders later in life—suicide, alcohol abuse, drug addiction, depression, among many others. “But we don’t call them all the same thing, says Zeanah. “We don’t lump them altogether under the name ‘ACE disorder.’”

Another source of mutual hard feelings between DSM members and the non-DSM world of clinical practice is the issue of who actually takes care of these patients. The most influential shapers of the *DSM* are overwhelmingly epidemiologists and other researchers, whose databases rest on responses to prepackaged rating scales, rather than on clinical encounters. Even *DSM-IV* chair Allen Frances, in one broadside on the “psychiatric civil war” now being fought, wrote to the *The Psychiatric Times* last summer that “almost everyone responsible for revising the *DSM-V* has spent a career working in the atypical setting of university psychiatry,” their clinical experience “restricted to highly select patients who are often treated in a research context.” The gist of Frances’s remarks was that scientific work coming from this rarified environment—including the *DSM* itself—didn’t generalize well for the typical clinician-in-the-street, so to speak.

It seems likely that most DSM members disagree with and resent the imputation that they don’t get or even care about multiply troubled people beyond their own pristine research samples. “I really bristle when people make the distinction between researchers and clinicians,” says Friedman with some passion. “I’m a doctor, I treat patients, and I want to have the best diagnosis I can. Most of us in this business *are* also clinicians, who have been seeing patients for a long time. The researcher-clinician dichotomy is false. What all of us working on *DSM-V* want to do is take the best scientific evidence we have and synthesize it into a diagnostic classification scheme that makes it easier for people to identify clinically significant constellations of symptoms, resulting in better diagnosis and better treatment. It has to be useful to the clinician in the trenches.”

Nevertheless, at the heart of the rejection of his task force’s proposal, van der Kolk sees not the weighing of different kinds of evidence and the disinterested workings of science, but the more elemental forces of professional politics. “The most likely explanation: academic laboratories are funded to study particular disorders,” he says. “If you say that your disorder is part of a larger picture, which includes elements from several other diagnoses, then you’d have to rearrange your lab, your concepts, your funding, and your rating scales—and you also have to confront the fact that if children are terrified and abandoned by caregivers, this will affect their brains, minds, and behavior. That seems to be too much to ask.”

Though temporarily stymied, the NCTSN task force is no means defeated. Enlisting the support of the foundations that fund the treatment of traumatized children, who don’t want to see their investment wasted on inadequate treatments for inadequate diagnoses, they’ve been able to raise

the money for a DTD field trial and enlisted the sites that are able to carry out the required research. In addition, there are murmurings that, since so many maltreated children are also poor, DTD sympathizers in Congress would like to enable Medicaid to bypass DSM entirely and pay for treatment geared to some kind of complex trauma diagnosis for children. “We’re still going ahead full throttle,” says van der Kolk. “I feel very optimistic.”

Looking toward the Future

What difference would it make if DTD made it into the promised land of the *DSM*? One answer is that it would open the way (not to mention the money spigots) to focus research and treatment on what van der Kolk and his colleagues believe are the central principles organizing the protean symptoms of chronically traumatized children: pervasive biological and emotional dysregulation, failed or disrupted attachment, and a hugely deficient sense of coherent personal identity and competence. These issues transcend and include almost all diagnostic categories, but treatment that doesn’t put them front and center, say advocates for DTD, is likely to miss the mark.

Take the pervasive emotional dysregulation, which, according to many experts, could be almost a single-word synonym for the effects of chronic trauma. “What appear to be the symptoms of other disorders are often better understood as extreme dysregulation of emotional states,” says Julian Ford, associate professor of psychiatry at the University of Connecticut Health Center and a coauthor of the DTD proposal. “Some youths diagnosed with oppositional-defiant disorder are extremely angry, negativistic, and defiant in large part because they’re attempting to defend themselves against what they perceive to be coercion or threats, based upon prior traumatic experience in which they actually were coerced, threatened, or severely harmed.” Such a kid doesn’t respond well to common behavioral interventions stressing “consequences,” which just reinforces his defensiveness and anger. Similarly, a traumatized child already on edge with fear and unable to concentrate in school will not be helped by a diagnosis of attention-deficit disorder and a prescription for Ritalin, a stimulant that will just rev up her already hyper-aroused nervous system even more.

The official recognition of DTD, the thinking goes, could allow therapists and researchers to bypass standard diagnoses and hone in specifically on dysregulation, and on poor attachment and on inadequate sense of self if they exist, as well. One intervention that does this, developed by Ford, is TARGET (Trauma Affect Regulation: Guidelines for Education and Therapy), which focuses on helping adolescents and preadolescents to understand something about how trauma affects the brain and nervous system, acquire the self-soothing skills that can help them manage their own stress reactions, and gain a sense of self-confidence and trust in their own resiliency. Another program, the Attachment, Self-Regulation, and Competency (ARC) practice, originating at

the Trauma Center at the Justice Resource Institute where van der Kolk is founder and medical director, focuses on building secure attachment relationships between caregivers—who may be child protective-services staff, foster parents, residential counselors, or parents—and traumatized kids. It teaches children and teens how to identify, modulate, and communicate emotion and bodily sensations, and helps them develop a stronger sense of personal identity and competence. The Trauma Center also provides a variety of nontraditional approaches— theater groups, yoga, mind-body, sensorimotor psychotherapy, expressive art therapy, neurofeedback—that promote the integration of psychology and biology to reconnect minds and bodies torn asunder by trauma.

While showing great promise and early success, multifaceted approaches like these tend not to be simple, short, or cheap. Nor have many of them been subjected to “gold standard,” random-outcome research that would incline large state service systems to pick them up and pay for them—even if there *were* an official diagnosis for which they could become the treatment of choice.

Were DTD to go into effect, its supporters believe it would be a game changer. Just as the creation of PTSD “transformed the health care system for individuals exposed to traumatic stress and led to an explosion of specialized research and practice,” says psychologist Bradley Stolbach, “the inclusion of [DTD] in *DSM-V* . . . will be a powerful catalyst for transformation of the systems that serve children.”

Finally, the frontline mental health troops—overwhelmed and underpaid social workers and therapists serving in poor communities—seem to respond with a collective “At last!” when they hear about the new diagnosis. Eugene Griffin, psychologist, attorney, and clinical director of the Illinois Childhood Trauma Coalition, recalls bringing Frank Putnam to talk to his staff about complex child trauma in 2004—what it looked like and its long-term consequences. “The day [Putnam] presented, veteran social workers said things like, ‘I’ve been around 20 years and that’s the best description of our kids I’ve ever heard. We could have told people about these kids 10 years ago.’ They got it right away.”

Meanwhile, van der Kolk’s own commitment to DTD is as much moral as scientific and clinical. “There are 10 times as many kids getting abused in America than there are soldiers fighting in Afghanistan and Iraq,” he says, “and their maltreatment is strongly correlated with our huge jail population, high crime rates, poverty, and school dropouts, not to mention suicide, depression, obesity, and a host of other issues. But none of this is in people’s purview—the connection between these vast social problems and the way we raise our kids isn’t being made.” Van der Kolk would like to see a massive public crusade against child maltreatment based on the model of the anti-smoking campaign begun by Surgeon General C. Everett Koop in 1982. “We need someone important in public life to have the courage to stand up and take a very visible stand on something like this—it has a huge impact on both science and society.”

Unfortunately, the issue remains an uphill fight. Politically and socially, child abuse continues to be a taboo subject. Van der Kolk recalls sitting at a dinner next to former Surgeon General David Satcher in 1999, who told him about a new plan to address the adolescent suicide epidemic in the United States. “That’s just great,” van der Kolk replied, and began telling him about the Trauma Center’s interventions to stem an adolescent suicide epidemic in South Boston. Mentioning the ACE studies and the astonishing correlation between child abuse and suicide, van de Kolk added, “I’m so glad you’ll be making this connection publicly, so that the issue of child maltreatment will get more attention.” Satcher responded, “Well, no, we left that out of the report—it’s way too sensitive a topic.”

We’ve come a long way in our understanding of trauma. No one any longer denies the fact that wars can ruin the lives of soldiers and their families. But when it comes to physical and emotional violence within the family, advocates like van der Kolk insist that society continues to avoid the grim evidence. As he puts it, “We don’t seem ready to acknowledge that the largest danger to our women and children isn’t Al-Qaeda, but the people who are supposed to love and take care of them.”

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