A President’s Perspective:
The Human Face
of the Diagnostic Controversy

I sit with 17-year-old Alan in my office and we chat about his college plans, his new girlfriend, and his desire to take up a career in medical technology. Five and a half years ago I had diagnosed Alan with DID (dissociative identity disorder) after he was brought to me by his birth mother and step father with whom he began to live at age 10. After ten years of neglect and abuse in the home of his birth father in another state, he moved to his new caring family in Maryland. When he arrived at his new home, Alan’s parents noticed that he talked to himself in different voices, went into cataleptic, unresponsive states when corrected for minor infractions, and had no memory for destructive episodes. When angry, Alan destroyed furniture, killed a house hold pet, and set a fire in a trash can in his school’s cafeteria.

Four years ago, Alan became a student at the day school at Sheppard Pratt Hospital where he received grade level education in small classes, several times a week therapy, family therapy, and benefitted from a
structured school program with clear consequences and rewards. His individual treatment course followed from a theory about his behavior that was implicit in his diagnosis. His behavioral and psychiatric problems were seen as adaptive responses to a disturbed and traumatic environment in which the development of integrative emotional functioning was precluded by inconsistent and abusive caregiving. His internal voices were seen as his mind’s coping mechanism with the binds, confusions and traumatic circumstances of his early years, symbolically personified in an internal microcosm of the external chaos and conflict. His therapy emphasized listening to the internal voices that held intense feelings about his abandonment, neglect and abuse and helping him express these feelings and conflicts directly. Alan’s betrayal by the circumstances of his early life were contained in a voice he called “Silent Rage.” “Silent Rage” was not silenced further by psychotropic medicine, but given a voice in his treatment so that the betrayal of his early years was shared and acknowledged with his treatment team. He was taught that his brain was adaptive and creative and he could learn now, as he had in the past, to adapt to the new circumstances of his life. Currently, Alan has full memory for his behavior, no longer hears voices commanding him to do destructive things, and has developed attachments to his new family. There have been no destructive episodes for over two years, and Alan is eagerly embracing a productive future.

In an office two doors away, a therapist is meeting with 17-year-old Suzie, who attends the same school, with access to the same plethora of special services. She receives twice a week psychotherapy, family therapy, speech and language services, and has the same small classes and environment of structured consequences. Suzie was sexually abused between the ages of 3 and 5 by a friend of her father, and began to display self-destructive behavior at age 11, including self-cutting, which resulted in three hospitalizations before the age of 16. Suzie hears voices, a male voice commanding her to harm herself, and other voices which argue about her. Occasionally, even at school, she enters cataleptic unresponsive states and hides in a corner sucking her thumb. Suzie has been diagnosed with major depression with psychotic features. Suzie’s treatment course follows from the theoretical model implicit in her diagnosis, just as Alan’s has. While her traumatic background is acknowledged, the problem is viewed as primarily a disorder in Suzie’s brain. Her brain simply will not behave itself, and her treatment team must help her control it. The rage and storm within her from the betrayal of her early years has been reinterpreted to Suzie as Suzie’s problem, a problem to be taken care of with chemical interventions and external
control. Most recently, Suzie was given her second ECT treatment to help her with her intractable depression, and she takes an antidepressant, antipsychotic and mood stabilizer. However, the voices have not stopped.

During her most recent hospitalization, the attending doctor suggested that maybe the long term consequences of her traumatic background had been overlooked, and after a consult with the trauma disorder program, a provisional diagnosis of Dissociative Disorder, Not Otherwise Specified was suggested. Now that Suzie has a new provisional diagnosis, it is possible that she too will find a way to give voice to her “Silent Rage” so that it is no longer directed against the self. Perhaps she can learn to reframe her angry voices as a protective strategy, and to break away from her close identification with the perpetrator, signified by the condemning, persecutory voice that she hears. Like most abuse victims, Suzie blames herself for her suffering, and perhaps the new psychiatric response will no longer provide subtle collusion with her own self-directed anger, but teach her to transcend her self-blaming posture.

Alan and Suzie are prototypical of hundreds of cases I have seen over the last ten years, which illustrate that the questions raised in this important issue are not simply a pedantic exercise. The way we resolve the controversies about diagnosis have profound implications for the lives of thousands of people who are entrusted to the care of mental health professionals. It is the patient to whom we owe our allegiance and it is for the patients that this diagnostic controversy has any relevance. Stories like Alan’s and Suzie’s convince me that diagnosis profoundly affects the way these youths are treated in our psychiatric settings and, in turn, the way these youngsters see themselves and their future potential.

What if Suzie’s therapist had found in a diagnostic and statistical manual a way to describe Suzie’s self-injury, cataleptic states, regressions, and voices, in the section on dissociation, under a major dissociative disorder diagnosis, as suggested by Dell (this is sue), or under passive dissociative disorder, as suggested by Coons (this is sue). What if, this hypothetical DSM facilitated a way to see Suzie the way Alan had been seen, as having developed an adaptive process that led to fragmentation of the self? Might Suzie’s treatment have taken a totally different course as Alan’s has? Of course, one can never know for sure, but as a consultant to cases like Suzie’s, I have seen important therapeutic changes made after the treatment changed direction to frame the problem as a posttraumatic adaptation. For at its best, a diagnosis provides a mutual
language of therapeutic dialogue. This therapeutic dialogue provides the framework for the patient to see himself/her self in new ways that can facilitate powerful changes.

Diagnosis can be seen as a mutually agreed on narrative, an abbreviated “story” that distills the essence of a problem. This problem and its resolution can then be examined within a context where the therapist and patient share mutual assumptions. While Dell acknowledges that the classification of even mammals is “fuzzy” at best, how much more “fuzzy” are classification schemes for human behaviors! But an additional irony separates psychiatric classification from its cousins in the natural sciences. Unlike classifications of mammals, the ultimate goal of our classifications is to facilitate changes that result in the category no longer having any relevance. In other words, as therapists, we seek to name the thing in a way that the name soon outlives its usefulness. Thus, there is an inherent tension between scientific classification, which best remains static in order to verify and validate one’s classifications, and therapeutic classification, which implies an evolving and temporary state in which potential change is always possible. The challenge for us is that our naming and classification does not come to an end in itself, and the “stories” that we tell about our patients with our “naming” of their disorders are stories that potentiate growth and recovery. Within this perspective, the most accurate diagnosis is the one that tells the story in a way that potentiates the greatest change.

What “story” does the current DID diagnosis as described in DSM-IV (American Psychiatric Association, 1994) tell us about the potential for change? Surely the words “presence of two or more distinct identities” (APA, 1994, p. 487) conveys the sense of an immutable condition. For Alan, I did not show him these criteria, or even communicate them to his family, as the way this diagnosis is described in DSM-IV would not assist Alan with a story about himself that would move him to a new understanding. In my education to Alan about the nature of his diagnosis, I relied on my clinical and theoretical understanding of trauma and its consequences, gleaned from reading both scientific and clinical literature, and from my clinical experience. I certainly did not emphasize that his disorder was a problem of “distinct personality states” (“each with its own unique way of perceiving, relating to and thinking about the environment and self” [APA, 1994, p. 487]) as the DSM-IV definition would advise me. This would be countertherapeutic to the messages I am trying to teach him, about his own capacity for change and the importance of integration of his disparate self-views. In fact, I worried that the DSM-IV conceptualization of DID was so potentially misleading in its
emphasis that I never told his diagnosis to his teachers in the school who work with him daily, for fear they would start to either look for “alters” or ridicule him or myself for our mutual understanding of this disorder. Had the diagnosis been “major dissociative disorder” as suggested by Dell, might I have felt more comfortable communicating this? Perhaps.

The ultimate agreed-upon iteration of the diagnostic criteria of the dissociative disorders, is not yet clear, but Paul Dell has moved our field for ward in urging a re consideration of the implications of our current diagnostic criteria. As Putnam (this issue) and Steinberg (this issue) suggest our criteria must rely heavily on the research that has already been done, as well as venturing out in new directions. As Coons suggests, these criteria must emphasize the polysymptomatic nature of dissociative disorders, and as Spiegel suggests the criteria must emphasize a careful description of the phenomenology as well as intensity of the symptoms.

This issue has taken a bold step for ward in helping us define what that ultimate iteration might look like. We must not forget that our patients are the ultimate beneficiaries of our diagnostic clarifications. It is they who will use these conceptualizations to define themselves and the nature of their struggles towards health. The diagnostic controversy debated in this is sue provides an important stimulus to spur the development of an increasingly refined shared language. That shared lan guage will likely encourage the evolution of increasingly more compassionate and competent treatments. I am grateful to all of the contributors to this issue for moving us along this important path.

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REFERENCE