



Wilderness Journal:

Parental Engagement with Young Adult Mental Illness*

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What is mental illness? “A group of disorders,” according to the National Alliance for the Mentally Ill, “causing severe disturbance in thinking, feeling, and relating.”¹ Disorder and disturbance. I shall add more words: muddle, heartbreak, and chaos. Is there any way even of describing—to say nothing of analyzing—the waste and pain involved? The answer is no. But we can tell our stories.

Something unusual happened when Jon was seventeen years old. With our three children, we had taken a vacation from a sabbatical at London University and were touring parts of the continent in our VW camper. We were in Cordoba, Spain, strolling one of its medieval streets. But Jon was on the opposite side of the street, shouting and cursing! To this day, I have no idea what triggered such behavior. He always had a temper, but this was something else: scatological language released in a torrent of fury. Several years later, Jon was a passenger in a car involved in an accident wherein the driver was killed. The surgeon who patched him up assured me he was all right. But “there was something strange,” he continued, “the language I heard from him when he came out of the anesthesia...awful...I’ve never heard anything like it. Thought you should know.”

As were Jon’s maternal and paternal grandparents and great-grandparents, I am a Lutheran clergyman. We are “church people”; it is fair to describe us as pietists (no cursing allowed), but hardly as puritans in the popular sense. The tirade in Cordoba was something unexpected and bizarre. It took years to accept powerlessness in the face of such behavior. Demon possession, as far as I am concerned, works as well as any other language to describe two other such outbursts in the ten years following the

*This essay grows out of a paper delivered to the Association of Mental Health Clergy, Chicago, May, 1987.

¹“Mental Illness Is Everybody’s Business” (Arlington, VA: National Alliance for the Mentally Ill).

first incident. As a parent first wrestling with such conduct, I resembled the man who survived a jump with a faulty parachute: free fall (clutching at straws), impact (destruction of plausibility structures), and coming to (coping and surviving).

Karen Lebacqz has described the dilemma of parents of a newborn infant afflicted with atrophy of intestinal tissue as a “wilderness experience.” Several elements are involved: (1) disruption of normalcy (they are at the hospital day and night); (2) recurring uncertainty (one day things look good, the next day is a crisis); (3) loss of control (the medical world takes over); and

(4) loss of identity (life no longer matters). The experience of such a crisis, the author suggests, bears similarities to the wandering of the ancient Israelite people.²

The wilderness model also adapts well to parents involved in mental illness. In order to mark the oases of the journey, I will use yet another paradigm. It is the testimony of a mother of a child with a developmental disability: finding out, holding on, and letting go.³

I. FINDING OUT

Eight years lapsed from the time of the street scene in Cordoba until a psychiatrist gave the enemy its name: affective schizophrenia. Without clinical details, here is a list of people and places I encountered in our wilderness trek:

People	Places
3 psychologists	3 colleges
4 psychiatrists	1 private psychiatric hospital
2 attorneys	1 state mental hospital
2 clergymen	2 private hospital psychiatric wards
3 mental health professionals	2 courtrooms
2 social workers	1 jail
12 (or so) high school teachers, college professors, and friends	2 halfway houses
	2 hospital emergency rooms
	1 shelter for the homeless
	1 drug rehabilitation center
	2 church outdoor ministry camps
	1 congregation

The pattern hardly matches the prevalent dreams of middle-class parents for their offspring: high school, college, graduate school, marriage, and a profession which affords upward mobility. Each person and place in my list represents a different lead, a new effort, and an attempt to start over. Behind it all was our effort to understand what was taking place. One day it was abnormal teenage rebellion; the next it was drug abuse or family dynamics and stresses.

Of all persons involved, the psychiatric profession seemed both to hurt and to help the most. Consider these examples:

²Karen Lebacqz, "Imperiled in the Wilderness," *Second Opinion*, Vol. II, The Park Ridge Center, Park Ridge, Illinois 60068, pp. 26-31.

³Mary Mantle, *Some Just Clap Their Hands* (New York: Adama, 1985).

- Finally I learned the identity of the doctor who was treating our son and pleaded for an appointment to talk about the situation. We spoke several times on the phone. No, a conference was not possible. I would have to be satisfied with a voice on the phone. An announcement was the final word. "If your son doesn't stop using drugs, he will destroy himself." (As if I did not already know!)
- We discussed our family history and the prospects for our son at an exclusive and

expensive psychiatric hospital. The physician dismissed us with these words: “Your son has a mental disorder—whatever *that* is.” (This for a fee of \$75.00.)

- “Why do you bring this situation to me?” (Implication: “Can’t you see how busy I am?”) “You will have to tighten up at home.” We were wondering at the time if kicking holes in the wall, ripping telephones from their sockets, and smashing the thermostat—all before our eyes as we attempted to “set parameters”—was not unusual teenage behavior. (Imagine the irony—years later—when we listened to the same psychiatrist inform an audience that recent theory shifts blame away from family dynamics to biological causes of the illness.)
- “I think I can help Jon.” For seven years this doctor has accepted state medical coupons for a modest fee. He was the one finally to venture Jon’s diagnosis. By psychotherapy and medication, he has enabled a four-year stabilization and maintenance period without a serious crisis. For the first time, we found someone to lean on.

With the best intentions and good will, most of the other people and places involved also helped, but, in the final analysis, they proved as impotent as I to cure or rehabilitate. Eight years to find out. Eight years of false hopes, confusion, guilt feelings, and helplessness. Once reality was grasped, however, a new phase opened.

II. HOLDING ON

On a manic high, Jon is talkative and a bit agitated. He bolts from a room for no reason. Sitting through an entire movie or sports event is out of the question. Sleep disruption always makes it difficult for him to get started after he awakens. Nighttime alcohol abuse combined with daytime smoking and caffeine consumption set the pace. During a swing into depression, he slows down, remains silent, and avoids eye contact. He loses interest in being around people at all.

With symptoms of schizophrenia, Jon finds it increasingly difficult to concentrate; his thoughts jump from one association to another without making much sense. Then come the “voices.” Hallucinating, he hears others talking about him; they bid him do certain things. Whispers come from friends, relatives, or Satan. Since many with paranoid symptoms are preoccupied with religion, God also speaks to him “in his head.” While the feelings that he is being watched, followed, persecuted, or controlled are delusions, the consciousness of them is utterly real to the young man. On the one hand, he asserts his grandiose identity as anyone from rock star to President. On the other hand, he swings in the opposite direction: blunted

in emotions, he is indifferent to occasions when the rest of us express joy or surprise. He also becomes confused in his sense of self because his body feels too big or too small; some parts are numb while others are overly sensitive; he recoils from anyone’s touch. Fine tuning (drug therapy) restores a fragile balance. How long it lasts is difficult to predict.

Until one becomes system-wise, involvement with the mental health services (federal, state, county) is like dancing with an elephant. Parents, while waltzing to the music of evasion and confusion (“We don’t handle that here”), see the body and spirit of a son or daughter crumble. Amidst the chaos, family members lose their innocence about the sufferings produced

by these intractable, baffling disorders. They are loaded with demands for rescue: Can you front me some money? Will I go to jail? Episodes of various degrees of seriousness generate an atmosphere of crisis and emergency. Caught between the needs of the ill person and the bewildering, elusive services available through public agencies, the family eventually acts as its own doctor, nurse, and social worker. Churches recoil in fear and ignorance. Society, for the most part, ignores the dilemmas faced by the impromptu caretakers and bids them continue on with their funerals without end. Brokenness is the word.

How did this come about? In the early 1960s the success of new antipsychotic drug treatments had political results. President John F. Kennedy called for the establishment of geographically defined community mental health centers across the land to replace reliance upon mental hospitals. “Deinstitutionalization” had begun. Inclusion of the word “health” in the name of these new centers was supposed to diminish the negative public stereotyping suggested by its opposite (illness). Despite this objective, “health” actually became a smokescreen for the incurable sickness involved. Gradually, public education and the needs of the “worried well” for consultive services got most of the attention. The primary mission to treat serious mental disorders took second place or was forgotten.⁴ The situation therefore hides the plight of those people who suffer from chronic mental incapacities and need help the most. Denial of unsolvable problems spawns freedom from responsibility for them. Who has ultimate accountability in providing adequate treatment in today’s mental health care system? I still wonder. People fall through the cracks.

The unstable, oftentimes confused and frightened client, set free from the asylum or state hospital, is now asked to relate to a wobbly, politicized, undependably staffed, and underfunded series of offices. There are the mental health centers (without hospital units), the bureaucratic social and health service locations (state and federal levels), the local food banks, the housing authorities, the “rescue missions,” and, usually at the bottom of the list—just before nights in the street or under a bridge viaduct—the church shelters (provided space is available). Maybe an all-night bus ride or a shabby eatery provides survival. It is enough to test the mettle of the most sane and healthy individual around!

⁴Phillip Boffey, “Advancing on Schizophrenia,” *New York Times*, 16-20 March 1986 (series of four articles). See also E. Fuller Torrey, *Surviving Schizophrenia* (New York: Harper & Row, 1983) and Phyllis Vine, *Families in Pain* (New York: Pantheon, 1982).

One wonders what the public response would be to heart disease treatment if delivered in the same way: First, a bureaucratic, red-tape cluster of national “cardiac health centers” requires those with this disease to present just cause (difficult to obtain) for hospitalization if a “cardiac breakdown” occurs. Then, once under treatment, doctors see patients for perhaps fifteen minutes a month for medication (who knows its long-range side-effects?) at the center. It is up to clients to get there on their own, even if this means walking for miles. A cardiac episode requiring hospitalization specifies stabilization and discharge in five to ten days unless the patient is ruled a criminal (having somehow wound up in jail overnight along the way) or is admitted as an “involuntary commitment.” Meanwhile, at the “State Cardiac Hospital” authentic criminal patients are housed on the same grounds as everyone else. As for the hospital itself, perhaps an accreditation probationary status for understaffing, etc., is in effect. How would Americans

respond to such health care for heart disease? By a public outcry. Local and congressional investigations and media attention would boost a rocket of change. Funding would appear. Citizens across the land would not tolerate such a national disgrace.

Government judiciaries and mental health centers fail to provide an adequate alternative to hospitalization as envisioned in 1963. Too many of those eligible for “community based care” continue to drift into a revolving door syndrome: from psychiatric ward to an apartment to the street or shelter to a congregate care facility, back to the street or jail, then to the hospital once more. Here civil libertarians add fuel to the fire. In temporary hospital courtrooms attorneys and judges plead, advise, and decree—and then wash their hands of it all, even when the proceedings take place in psychiatric wards in the presence of the nodding, stupefied, and tranquilized client about to be released. At least, libertarians reason, society has defended the individual’s civil rights. But, given the quality of the life these civil liberties afford upon release, it is easy to conclude that ideology has replaced both compassion and common sense. On the western frontier you died “with your boots on.” Today, people will die with their “civil rights on.”

I advocate a change: Instead of the criterion “danger to oneself or others” for involuntary hospitalization, make it “unable to care for oneself.” This is easy to demonstrate. Ask any sibling or parent. In case after case, the seventy-two hour involuntary commitment time is not sufficient for stabilization. Imagine an exhausted parent coming for a hospital visit and being told his still hallucinating son has been released ten minutes earlier to hitchhike home. Periodic legal review (30-90 days) would control the “putting someone away” threat.

Presently, the whole apparatus of public care drifts; responsibilities shared on different care levels become responsibilities denied on every level. Clients pay the price. Forgotten and lonely congregate care inmates (in nursing homes, and various inns and lodges) in need of wholesome companionship spend their days before the TV or staring at the walls. And make no mistake: Facilities of this sort operate in industrial areas, wasted central cities, or out in the countryside—certainly not in “respectable” neighborhoods.

It is not my intention to minimize the difficulties faced by mental health professionals in advancing therapy strategies and procedures. Diagnoses are multiple and often baffling. In cases where substance abuse is involved, victims appeal to the system for rescue from the effects of illicit drugs upon the mind; yet afterwards they will stoutly resist further rehabilitative measures. By such behavior, some circumnavigate the path to recovery and enter their own “revolving door.” But when “the organ of decision (the brain) is also the organ of disease,” we might expect as much.⁵ Moreover, the case system is overloaded by demands made upon it. Constantly trying to “get out from under” the load, it holds its breath for the next funding decision. Little wonder I felt at times like an unwelcome intruder when I approached a desk for *any* news—good or bad—of what was going on.

III. LETTING GO

For me, the eventual diagnosis—finding out—was the key to holding on. Light began to overcome the dark side of the dream, and I discovered life after mental illness. Words like “stabilization” and “maintenance” became terms of survival. Contact with other parents in the same situation was water in the desert. Volunteer work at the local mental health center became

therapy. Self-pity is the earliest casualty in contacts like these.

St. Paul learned to forget the ugliness of past struggles because he chose to “press on” to a distinctive quality of life and a future prize (Phil 3:13-14). I still need to let go as the apostle managed to do. I seek to break out from:

Anger. There is enough around for everybody. Insofar as Jon was responsible, I am outraged with him for throwing his life away. It hits me whenever he “comes back” for fifteen minutes, and I see once more what he had going for him. I rage at drugs in this country. The understaffed and bureaucratic system still irritates. What appalls me even more is the fact that, in this country, we spend \$16,000 in research for every victim of AIDS, \$300 for every victim of cancer, and only \$7 for each victim of schizophrenia.⁶ I am also fed up with the stigma of mental illness and the vicious stereotyping promoted by movies and TV.

I am angry at myself for being duped by so many for so long during those eight years. I am disgusted that my church trumpets justice in distant lands and ignores Lazarus on its doorstep. Had enough? So have I. I want to let go of it all, and guilt besides.

Guilt. “If only...” If only I had known about my local mental health center. Then I could have called them the night I phoned the police instead and watched *five* sheriff’s deputies drag Jon from his home. If only I had been a better parent. If only we had managed a brain examination (CAT scan) when, at age sixteen, Jon’s head shattered the windshield of the car

⁵Dr. John Talbott, “The MacNeil/Lehrer Report,” *PBS*, 1 April 1987. Cf. Nancy C. Andreasen, *The Broken Brain: The Biological Revolution in Psychiatry* (New York: Harper & Row, 1984).

⁶The National Alliance for the Mentally ill maintains the latest statistics.

he occupied. If only I had not sinned. If only God had heard our prayers. (No—let it go and press on.)

Ignorance. Today, I employ acronyms like CCF (congregate care facility) and words such as tardive dyskinesia (involuntary hand tremors, an occasional side-effect of drug therapy). Ten years ago, I was more or less like everybody else when it came to knowledge of mental illness. This means I was one of “them,” the ones bearing their backpacks of ignorance. Listen to them as they display some common assumptions:

Prejudice

“Nervous breakdowns are a cop-out and a sign of a weak personality.”

“Mentally ill persons are dangerous.”

“It’s up to the state to take care of *those people.*”

Reality

Chemical imbalances of the brain can produce symptoms of psychoses.

The vast majority are passive and often prefer solitude.

Mental health professionals are eager for individual and group volunteer efforts from synagogues and churches.

Today, silent as Trappist monks, Jon and his board-and-care housemates sit before a humble meal. From such “least of these” (Matt 25:45) and their eerie nobility I also have

something yet to learn.

Cheap faith. With apologies to Dietrich Bonhoeffer and the notion of “cheap grace,” I posit “cheap faith”: the trust that, given my Christian status, God will pay special attention.

The best advice I got was from another father whose daughter was mentally ill. “I spent thousands,” he said, “before I decided to let the system take over. It works. Give it time.” This man gave not only practical advice; together with his wife he also comforted us and became what I suspect the Bible means by a helper (1 Cor 12:28). They helped us dismiss our romantic visions of miracles, divine or medical. Grace has intervened. Both sets of parents are grateful that emergency room trips with our loved ones (slashed wrists and empty medication bottles) were on time. Today, Jon is one of my closest friends. How many parents of “normal” children can say the same about their young adult offspring?

What does a parent dream about for a child? For the majority, I submit, it is not a place of renown in politics, entertainment, or sports. Rather, the dream concerns life in the long run. One hopes for a child’s happiness and that he or she somehow will help others along the way. Fame is fine, to be sure, but is it not more of a gift or a surprise than anything else? The unexpressed dream, perhaps, is an ancient one: you plan to overcome mortality through your children.

Mental illness puts an abrupt end to this and snuffs out other dreams of how life was meant to be. The result is loss, not unlike bereavement. You wander in the wilderness and watch your child die in a socially unacceptable way. Early on it was like putting funeral plans on hold. Yet eventually we lowered our expectations and managed to let go of a few of the cultural dictates of success. It was then we caught our first glimpse of the banks of the Jordan.