

NAVIGATING THE LABYRINTH OF TREATMENTS FOR SCHIZOPHRENIA: SOME THREADS

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King Minos of Crete, to avenge the killing of his son, Androgeus, by Athenians, demanded that every ninth year Athens send a tribute of seven youths and seven maidens to be devoured by the minotaur, a terrible monster with the body of a man and the head of a bull who was confined in a labyrinth. At the third cycle of sacrifice, Theseus, son of Aegeus, King of Athens, volunteered to go alone to face the minotaur. Ariadne, daughter of King Minos, fell in love with Theseus and gave him some special threads to guide him back out of the maze. Theseus slew the minotaur, found his way out of the labyrinth by following the threads, married Ariadne and took her back with him on the voyage to Athens.

Schizophrenia is a terrifying and often devastating illness which causes one who suffers from it to act in bizarre and unpredictable ways. The schizophrenic is besieged by demons and voices and distortions in perception. Often unable to tell the difference between what comes from outside the self and what is coming from within, there is a feeling of desperate anxiety and powerlessness in not being able to rely on the mind, in not having a "self" and in being different in some terrible and inexplicable way from everybody else.

The schizophrenic's need for his or her family, therefore, is even more urgent than a normal person's. The family is virtually a life-line, a safety net, a precious source of love and acceptance and connection in a world where little solace, support or acceptance exists for those afflicted with this illness.

The family's dilemma is acute: how to free oneself from guilt, blame and grief in order to plunge fearlessly into the eye of chaos and relate to this member with love, acceptance, firmness and steadiness while at the same time maintaining one's own sanity and health. It is equally a challenge for the therapist who tries to help

the family, a challenge which, in my opinion, can best be understood as an invitation to grow and to develop in oneself those qualities such as compassion, understanding, courage, and awareness of the interconnectedness of all life that are the finest expression of the human condition. The family has little choice—it has simply been presented with the challenge—but the therapist does have choices, and, thus, this work is perhaps best selected by those who can welcome it as a sure-fire challenge to grow.

It so happens that, among other things, I am a family therapist and the mother of a son who has schizophrenia. I believe it was my son's schizophrenia and an early experience of family therapy that sparked my desire to become a family therapist. The latter seems to have been on one level a call to vocation and on another level an attempt to attain some mastery in a labyrinth of seemingly endless suffering, family disruption and fragmentation, conflicting theories, inadequate services and the general state of confusion and fear surrounding the nature and treatment of schizophrenia. It is my hope that in recounting some of my personal experiences with family therapy and schizophrenia, some threads will emerge that may be helpful in navigating this awesome and often terrifying labyrinth.

Our earliest experience in family therapy took place in 1974 at Yale-New Haven Hospital during my son's first hospitalization at age 17. Family therapy at Yale-New Haven in those days was quite primitive. It included all patients on the unit, their families, and numerous staff members and students as observers. Thirty to thirty-five people sat in a circle around the edges of a large rectangular room. The leader was non-directive. Patients came and went and nothing ever got resolved, but it was a forum, and I got a sense of the riveting drama of family life, of mysterious connections among family members and of the power inherent in the combination of forces present. Following upon that experience have come sixteen years of search and struggle to find treatment that could adequately address my son's condition and help us all. Our first formal family therapy was in 1977 during a period when he was living at home. By this point he had already been treated in a number of programs: work and environment therapy at a farm in Vermont, half-way

house and part-time job in New York City, and individual therapy with intensive educational and other supportive therapies while living at home. Since none of these treatments had seemed to help him, I seized on the hope generated by an article I read on strategic therapy, which was called "paradoxical injunction" in those days. I decided that this method must contain the magic that could help my son clear up his convoluted thought processes.

I sought out the best therapist using this method I could find. He was on the staff of one of the leading family therapy institutes and seemed to offer us boundless energy and confidence. He gave the impression that he was going to be the one to succeed where all others had failed. Involved in therapy were myself, my two sons and my second husband, who was my sons' stepfather. Their biological father had remarried and lived two-thirds of the way across the country. My daughter attended only one session because she was in college, also in a distant state. The therapy was weekly, and we were faithful in attendance for an entire year and compliant with every instruction from the therapist. We *believed* in him. Nevertheless, the therapy ended in disaster for us.

The central formulation of the therapy was strictly systems: my son was a sacrificial lamb to save the marriage. (I was baffled about this from the beginning since the marriage in question, my second, came into being after my son developed schizophrenia.) The focus of the sessions was on this current marriage, my family of origin, my relationship with my sons, and on my oldest son's sacrificing of himself for the benefit of the rest of us. Much of the time was spent by the therapist devising ingenious ways to help me handle my son's outbursts. There was a lot of reframing.

For a while therapy seemed to be helping. Although nothing really had changed with my son, we believed that things would improve because we were working together as a family. But eventually the sense of progress was undermined by a sudden change in course taken by the therapist. He began to reframe my son's condition as "spoiled" and urged him to grow up. He recommended my son leave the day program he was attending and give up the therapist he was seeing there. His medication, which was handled

by an M.D. colleague on the staff of the family therapy institute, was radically reduced and then discontinued altogether. The family was told that treatment was ending lest we become too dependent on therapy.

My son's behavior deteriorated alarmingly. He pushed me down during an argument with his sister. Frightened, confused and demoralized by the turn of events, I kicked him out of the house, an action I believed at the time was required of me by the therapist. For days my son was on the street, begging money for hotels and sometimes, unbeknown to me, being allowed by the super to sleep in the basement of our apartment building.

Eventually his father said he could come out West where he (father) lived. The therapist reframed this as success because it brought father into the picture. When I pleaded with the therapist and his colleague for medication for my son so we could get him on the plane, they prescribed Valium for both of us. What transpired out West was a very sad year of suffering, stress and failure for both my son and his father.

In retrospect, it is hard to find any positive results from that year of therapy since my relationship with my son stayed at the level of a power struggle. In terms of family therapy and schizophrenia, however, this first official experience did reveal some important guiding threads. First of all, we learned that nobody knows what causes schizophrenia. There is now clear evidence of a genetic factor, but that is not the whole answer. In face of the mystery, we can only look to what helps. It is neither accurate nor helpful for parents to believe they caused their child's illness, nor is it accurate or helpful to imply that they can cure it if they will only change their behavior.

In my own experience, as long as I believed that I caused it by the mistakes I made in parenting, I was helplessly invested in an over-responsible role with my son. If I caused it, then I could cure it. If I was such a toxic parent, then I had to redouble my efforts to do the right thing. Setting limits to protect myself and the rest of the family was impossible since I couldn't trust my own instincts and felt unworthy to have needs of my own. Given all this confu-

sion and heartache, there was no way I or anyone else in the family could give my son what he needed from us.

Another guiding thread from this experience concerns the attitude and expectations of the therapist. It became clear that he or she must be prepared to be in the moment without expectations or need for change, while at the same time believing in the possibility of recovery, no matter how slow the pace may be. I will have more to say about this attitude later on.

A year after the therapy ended, following the sudden death of his father in an automobile accident, my son returned to New York City in a very bad state. Thus began a descent into the darkest inner chambers of the labyrinth. My son could not be contained anywhere despite the best efforts of a series of devoted and sincere mental health professionals. There were residential programs and hospitals, time living in an SRO (a shabby single room occupancy hotel), weeks on the street, a period haunting the entrance to our building, and finally commitment to a state hospital that was a hell-hole beyond description. There was a brief respite from the state hospital in a research program, but after a week he was shipped back to the state hospital in restraints. There was a stay of about a year in a bleak custodial long-term residence where most of the residents were developmentally disabled. During all this time I worked with more mental health professionals than I can count or remember, but nowhere did we find any real help or guidance in navigating the labyrinth of suffering and defeat.

Eventually there was the enormous relief of finding a residential program at another farm in Vermont where my son was accepted, treated with great kindness, and where the staff worked patiently and affectionately with him, handling his outbursts with amazing forbearance.

The relative peace and distance afforded me by this good fortune made it possible for me to begin to include psychotic people and their families in my work as a family therapist at a Mental Health Center in northern New Jersey. By this time I had learned some basics: first of all, the therapist needs to call forth qualities of fearlessness and compassion beyond the ordinary range. Families with a schizophrenic member are battered families, pushed to extreme

states in their efforts to cope with their member who is in extreme states of mind. A therapist must be prepared to be comfortable with the intense feelings engendered by struggling with prolonged grief and extended exposure to irrational and often explosive behavior and situations that frequently verge on the edge of disaster.

I had learned that parents do not cause schizophrenia and that the first job of a therapist is to make this abundantly clear. I had learned that one needed to relate to the person underneath the seemingly bizarre behavior—that the schizophrenic person has exactly the same feelings and emotional needs as everybody else. In order to do this it helps tremendously to have read some of the excellent first-hand descriptions of psychosis that are available and describe what the experience is like from the inside (e.g., *Experience of Patients and Families: First Person Accounts*, 1989). What seems like bizarre behavior will then become understandable.

I had learned that people with schizophrenia are generally exquisitely sensitive to emotional currents. Since they are apparently bombarded by external and internal stimuli in a way the rest of us are not and therefore have great difficulty with sequential thinking, focus and boundaries, they rely on their emotional antennae for a grasp of what's going on. The schizophrenic is almost always the best expert in the family on what is really going on emotionally with every other member of the family.

I had also learned that siblings in these families also suffer tremendously and commonly share certain problems which therapists must be aware of. Siblings almost always have a pervading deep fear of also going crazy, which parents may not be aware of as they usually do not share this fear. There is anger at the inevitable suction of parental attention created by the schizophrenic brother or sister and at the impossibility of ever getting an equivalent emotional intensity from the parents. The pressure of turmoil and grief is so intense that the tendency for siblings as well as parents is to become either over-responsible or cut-off. There is also shame since schizophrenia is still commonly stigmatized and poorly understood by the public at large, despite the fact that it affects about 1% of the population worldwide and about one family in five.

Our day hospital unit at the mental health center where I worked

had an excellent staff who had been working hard to put together all the different interlocking parts required for the effective treatment of severely disturbed clients, i.e., good day treatment, vocational training, residential services, and hospital liaison. What was lacking was the family component. Families had been called in only when the staff wanted something from them or when there was some problem at home, and often the contact was adversarial in tone.

I started seeing the families of these clients as a matter of course as part of the regular treatment. What I learned right away was the obvious: the most effective intervention was to have everybody important associated with the client's treatment in the room at one time, especially whenever there was an issue that seemed to be blocking movement. This meant the sessions would often include the family, the client, the family therapist, the residential counselor, the vocational counselor, and the day hospital therapist or relevant worker. Scheduling was difficult but definitely worth the effort. Just going to the trouble to get everybody together sent an important message. An issue that had been slipping through the cracks of the various components could be handled in one session, bringing all relevant staff members onto the same wavelength immediately. This is the forum where the client can be listened to respectfully and carefully, where he or she can be drawn out and where feelings and ideas can be explored. The importance of the family therapist's role in this cannot be overestimated.

My most important revelations about family therapy and schizophrenia came from an unexpected source. About six years ago, I saw an ad for a weekend introductory workshop at the Option Institute in western Massachusetts. The ad promised to teach a simple, gentle dialogue process that would help one become happy not two years or ten years from now but *now*. That sounded pretty good to me. I had been struggling so long and so hard to cope with what was going on in my family that I certainly hadn't had much time to be happy. My second marriage had recently ended and I was definitely ready for a little more happiness. I enrolled.

The Institute is run by Barry and Suzi Kaufman who cured their son, Raun, of autism after three years of intensive work by family

members and volunteers using a method the Kaufmanns developed based on their previous work with the dialogue process. In simplified form, the process is based on the following: the principle of complete self-acceptance, that is, accepting ourselves exactly the way we are at any given moment without judgement or blame (and therefore accepting others without judgement or blame or agenda that they should change); the principle that each person is his or her own best expert; and the principle that our beliefs cause our unhappiness, and if given the opportunity to unearth the set of beliefs underlying the problematic issue, we have the choice to change the beliefs and thus affect our state of mind.

The dialogue process is designed to help us bring to light the complex of beliefs usually just below conscious awareness which is keeping us stuck in the current problem. A “mentor” follows the lead of the one exploring his or her problems and asks questions designed to uncover these beliefs. The mentor must be sufficiently trained in a crucial attitude of self-acceptance so that he or she can extend this acceptance to the person who is exploring. Questions must be asked in a non-judgemental context and with no agenda for change on the part of the mentor.

Experience with this process was liberating for me. It helped me see that at any given moment I was choosing to feel as I did and thus could change it in an instant if I wanted to. I could let go of anger, of grief, of guilt, shame, whatever. And paradoxically, of course, one lets go by first bringing whatever it is to awareness and accepting it, by having compassion for oneself. I began to see how my beliefs and the feelings they caused prevented me from being open in the moment and thus from being happy or really living at all, since the present moment is all I have.

Toward the beginning of my son’s illness I had begun meditating. Quite simply, I needed more strength to cope with the crisis, and I suspected that I had more inner resources than I was in touch with. Meditation did help and put me in touch with an inner world previously untapped, so I kept it up in one form or another. Most recently I have been studying Buddhism and doing the simple Buddhist meditation practice of following the breath with the mind and witnessing the thoughts, feelings and perceptions that arise and

constantly change. I have been helped greatly by the Buddhist teaching of *karuna* and *maitri* or loving kindness which, in order to be extended outward, must *first* be extended to oneself. This is very close to, or perhaps the same as, the Option Institute's teaching of self-acceptance, of non-judgement.

From one of my teachers, the Vietnamese Zen Buddhist Monk Thich Nhat Hanh, I learned what for me was a revolutionary truth: one must be happy oneself to be able to alleviate the suffering of anyone else. If you are not happy, all the thoughts, feelings and beliefs associated with the unhappiness will cloud your mind and prevent you from being fully present with another's suffering. If there is action to be taken, the unhappiness prevents you from seeing what the most skillful action would be, what Buddhists call "skillful means."

The Option Institute's dialogue process shares these same insights but approaches the situation from a cognitive rather than a meditative position. In the cognitive approach, the dialogues process uses intellectual inquiry to ferret out hidden belief systems. Once brought to light, one can consciously choose to let go of constricting beliefs and to substitute more positive or even limitless ones in their place.

In the Buddhist meditation practice of "conscious breathing," as Thich Nhat Hanh calls it, one focuses awareness on one's breath and allows thoughts, feelings and perceptions to come and go, or to stay if they are persistent, without judging them or trying to force them in any way. Loving kindness is extended to oneself and to one's mind. Thich Nhat Hanh speaks of "sponsoring" one's anger and advises us to cradle our anger in our arms like a baby, to protect it. The Zen master Soen Sa Nim advises us to cultivate "don't know mind," which is another way of saying that one tries to promote an attitude of acceptance and non-judgement.

If one *really* fully accepted oneself, there would be no reason to be unhappy; in fact, happiness would be the natural state. This is not to deny that there is real suffering in the world. We are talking here about different paths towards the alleviation of suffering and different methods for training oneself to work with suffering. It all

fit together for me, and served as a necessary introduction to the work that followed with my family.

Although I originally went to the Institute for myself, I was immediately attracted to the inspiring work they did in their family program. My family participated in two separate five day programs there, one in 1986 and one in 1988. The work was brilliant and resulted in a radical restructuring of the way I experienced my son and in an important breakthrough for my son. It also affected the staff of the farm in Vermont where my son was living. The director was so impressed by the change in my son she began to train at the Institute herself, and then to provide training there for her staff.

The Kaufmans work primarily with autism in their family program, and families with autistic children come from all over the world for the five-day training program. They also work with families who have other kinds of problems, tailoring their work accordingly. For us, they designed a program that was fine-tuned in staff meetings two or three times each day, depending on what developed in the previous session. Since it is beyond the scope of the customary family therapy weekly hour to work this intensively with families, my intention is to describe the work in such a way that threads can be detected which may be used in any therapy with families with a schizophrenic member.

The most radical thing about the Institute's approach is that autism, schizophrenia, or any other situation commonly thought of as tragic or unfortunate is not viewed in that way. It is not judged but is accepted completely. This means the child with autism or the person with schizophrenia is not seen as imperfect or damaged, but simply as a person, as perfect as any other. This engenders an attitude of respect and acceptance that simply cannot exist if there is a judgement that schizophrenia is "bad" or an agenda that requires the person to change. This is not a passive acceptance akin to indifference but an active acceptance combined with strong nurturing and an invitation to change. My son was treated with absolute respect. The dialogue process of questioning was used consistently with him. The following excerpt from my journal describes this on the first day of the first five day program: (I will call my son "Will." Suzi is Suzi Kaufman.)

Will interrupts and Suzi shifts to him—then spending the better part of an hour in dialogue with him. They laugh quite a bit and he answers every question she asks him. Talks about himself with great awareness and about his schizophrenia, hallucinations, etc. with some distance. At no time does he become unintelligible or go off into crazy talk. I keep thinking ‘but he won’t be able to tolerate this.’ The themes that emerge are:

1) Will always feels he must change how he thinks or feels at any given time, on any given occasion; 2) Will’s voices become a theme and he is asked why he feels he needs to listen to them or answer them; 3) Will is searching for the right way to be with the family—doesn’t want to be always taken care of—doesn’t know whether to ‘dive into the family’ or to stay separate.

This was all news to me. In all the years I had spent trying to “take care of” Will and to cope with his behavior, I had never known how to elicit what was there all the time behind his crazy talk and explosive behavior.

Another quote comes from day one, during the afternoon session in which we all did an exercise of looking into a mirror and sketching ourselves:

Will finished first with the least struggle. Then we were each asked to talk about what we thought of while sketching and how we thought the picture represented us. . . . For Will, it got into a whole long dialogue about how he *hates* how he looks. Can’t remember his adjectives about himself, but they were extreme. He continued to answer directly every question Suzi asked him, and eventually I began to relax. He would sometimes go into his private crazy-sounding meanings, but Suzi would follow him right in and question why he thought that, usually with a joke—but always respectful.

Here is a description of an exercise we did on day two:

First Will and I did an exercise in which we were to describe attributes and weaknesses of each member of the family. Will elected to do the writing. I felt myself in the role of leading the exercise—moving it from point to point—and felt uncomfortable with that; kind of bossy. I began to notice that in each case, Will’s adjectives and statements about the person in question were lightning quick and far more poetic than mine. At times, I would feel the need to translate some of his more poetic phrases into more conventional language. I became vaguely uncomfortable with this approach without knowing exactly how to correct it. At one point he took me on about something I said that made him feel childish—and this led to a whole discussion and exploration of what it is in my manner that treats him like a child. He was very careful of my feelings—said ‘unknowingly and out of your experience of the past, you are too helpful.’ I knew exactly what he meant—all the subtle ways I am impatient with him or have low expectations—and interestingly, I think I’m aware when I do this because in some way it feels like a terrible strain, very uncomfortable. He used as illustration how I don’t expect him to empty the cold coffee out of his cup, when actually he intends to move his own legs, get up and do it.

After the exercise, Will was taken for one-on-one work with another staff person, and my other son and I were given feedback. (Steven is the staff person giving feedback. Ned is Will's brother.)

The feedback in general was that neither of us really listened to Will very closely, taking it for granted at times that we knew what he meant without questioning him and drawing him out. Three different times Will had thrown the ball to Ned on the subject of his anger, saying 'my anger is my liberation' and 'my anger liberates my mind.' Steven's point was that Ned could have drawn him out to explain more what that was all about. The implication was that Will gets a great deal out of his anger: exhilaration, freedom to express things he otherwise edits, a chemical change, etc., etc. Steven also was highly enthusiastic about Will and how he expresses himself—poetically, clearly, creatively—and thinks he's a 'gem.' Recommended we respond much more enthusiastically to these qualities. I think this is what happened for Will yesterday—he felt respected, appreciated, responded to—and it really changed his behavior. Steven said Will told him that nobody talks to him the way people here did. Nobody really listens to him.

From day two:

There was a lot of time spent on how to deal with Will's anger. The first and most important principle being to change one's attitude and *not to be afraid*. Now of course, giving up my fear did not seem like an easy proposition, but the more we talked about it, the more they questioned me about it, the more they acted out other possible creative and humorous responses to Will's anger, the more I felt my fear draining away drop by drop. I could absolutely see that Will gets such a major dramatic reaction from me whenever he is angry that it could only serve two purposes: 1) to make him feel powerful and 2) to escalate the negative trend.

Also on the second day we dealt with the importance of not giving Will a "genetic" message, i.e., that schizophrenia is a genetic brain disease and therefore something over which he has no control. Ned and Steven engaged in a dialogue about this:

The essence of Steven's point was that that gave Will a message that he had no control. Ned was coming from a position of believing that schizophrenia entailed considerable brain damage. I listened in fascination. . . . I saw their struggle as a metaphor for the struggle going on in Will, and I decided that I was going to do my best to shift my position to Steven's—and to do it without having any expectations insofar as possible.

From that time on, I adopted the belief that no matter what the etiology of schizophrenia is, Will does have some measure of control and recovery is possible. Many people do recover. According to the latest long-term studies, somewhere between two-thirds and three-

fourths of people with schizophrenia recover fully or improve significantly. For someone who has been ill as long as Will and whose hallucinations and delusions are not greatly alleviated by medication, recovery would require a monumental effort, but the studies also show that it is not possible to predict who will recover. At the same time, I equally accept that he might not recover, that it is mostly out of my hands.

When I was with him, I began to try to bring as much of my mind as possible into the present moment in order to appreciate who he was just as he was, in order to be able to explore more what he meant by the clues he was always giving us in conversation, and in order to enjoy as much as possible whatever was given in each moment. To help with this, I continued to go for dialogue sessions at the Institute and spent some time training to work in their family program.

The Kaufmans believe that the most important work they do in their program for autistic children is with the families and other caretakers involved with the child. They teach families how to be happy—a radical proposition given our usual set of beliefs about autism and schizophrenia. This is an educational rather than a therapy experience for families, although the results are therapeutic. From a position of happiness and acceptance, one's way of relating to one's child or family member is transformed. When this is the case almost anything can happen.

During the remainder of the time, there were other insights. I was able to taste and feel my controlling position with Will to such a degree that I was able to start to give it up. I also began to see how I pulled Ned in to protect me from Will. Ned was able to examine for the first time his terror that there was something wrong with his brain and that he, too, would go crazy. Some profound shifts in the family system and in our belief systems got started which continue to deepen and bear fruit in the present.

An example from day four, which continues to inform our lives:

Each of us was to face each of the others and tell them what about them we didn't trust and what we did trust. It was hard—but good. I could see Will take in what was said

to him, rather like a thirsty plant after a drought. He was absolutely brilliant, sincere and direct, especially with Ned. We were all very accurate about each other and basically told each other the same things, i.e., it was hard for us to trust the other would do what's best for him/her—though in almost every other way we trusted each other. Will's statements were the best—most poetic and to the heart of the matter. I felt, as I have so many times here since Monday, a new and profound appreciation of him as a person. More and more 'schizophrenia' fades into insignificance.

That first program at the Institute was the beginning of many changes. No longer in the grip of a tragedy, I began to lighten up, and yes, to get happier. Family members were freed to pursue their own lives. We had seen how dramatically Will responded to this short period of treatment, and we felt that with a similar kind of help over a longer period he had a chance at recovery. The Option Institute was not set up to provide long-term treatment, so it was necessary to look elsewhere for treatment that could continue the work started at the Institute.

At this writing, Will is in Canada in a program following the model set forth by Edward Podvoll, M.D. in his recently published book (1990). Will has been there for seven months, and there are clear signs of continued improvement. He has also been helped somewhat in the past year-and-a-half by the drug Clozapine.

The program, as does the Kaufmans' approach, provides for a great investment of time and energy by a team of people working with one individual. Most of the team members in Canada are Buddhists. They view their work with Will as part of their Buddhist practice and as an opportunity to develop further the qualities of the spiritual warrior: mindfulness, courage and compassion. It is beyond the scope of this article to fully describe this program. I will touch on aspects of it here that pertain to the family and to attitudes cultivated in doing the work.

Team members alternate spending three-hour "shifts" with Will. During the shifts, the attitude and quality of presence that is cultivated is called "basic attendance" by Podvoll. He describes the discipline of basic attendance as dealing "with the intricate function of synchronizing mind with body and environment. It is the concerted effort of a whole group of people who practice basic at-

tendance—with the patient and with each other—that constitutes the work of a healing team” (1990, p. 247). This attitude and presence, which Podvoll also describes as gentleness, kindness and warmth, is very similar to the Option Institute’s attitude of respect, complete acceptance, enthusiasm and nurturance. The basic premise of both is that recovery from psychosis is a difficult process requiring great courage and persistence on the part of the psychotic person and that the motivation for this effort must be very strong. The Kaufmans speak of kindling motivation in an autistic child by an attitude of acceptance, non-judgement, humor, playfulness and energetic appreciation of the child exactly as she/he is. Podvoll says that recovery from psychosis is much more likely to come about through the catalyst of human intimacy. He named his group “Windhorse,” a mythic horse in the Shambhala tradition symbolizing a cheerful, uplifting and healing energy. Again, this energy that the Windhorse households are designed to elicit seems to me related to the energy of motivation which the Kaufmans speak of.

In the cognitive approach, people are trained for the work by an intensive process using the dialogue method and feedback during many hours in the playroom with autistic children. In the contemplative approach, people are trained in basic attendance through mindfulness/awareness practices of various kinds. I have found both approaches complementary in cultivating an attitude, a state of mind, that without any doubt has contributed to my well-being and to Will’s recovery process.

I was fascinated, while training in the playroom with autistic children, by the convergence of the two paths. To be fully accepting, spontaneous and playful with an autistic child one must have a mind empty of judgements, doubts and agendas. Autistic children are so extremely sensitive (one could almost say psychic) about people in their environment that as soon as you have an agenda or a judgement they sense it and retreat further into their inner world. An opening with them invariably comes in the moments when the worker (or player) is fully present and able to be spontaneous, creative, joyful and accepting. Only then does the child seem to feel safe

enough to take the risk of emerging a little from his/her isolation. I found this discipline to be remarkable *in vivo* training to attain empty mind with the child as an instant barometer of one's state of mind.

Although the focus of the work in Canada is individual, the family component continues to be vital. My relationship with the two team leaders is cooperative. From the beginning we "hit it off" and agreed to speak plainly and openly to each other. We consult regularly, sharing feedback and information. We plan family visits together. When I visit in Canada there are structured meetings of different configurations with Will and the entire team of about ten people. There are also informal social gatherings with team members and their families, a mingling of my family and their families and an awareness of the interdependence of all of us. The therapeutic household is seen as a small community devoted to healing in all directions. Thus, the effort to promote Will's healing promotes the healing of our family and of the team members. The healing radiates outward to the team members' families, to their places of work, and to places beyond in an ever-expanding circle.

The specific clinical family work of most importance was work I did with Will's principal therapist, Jeffrey Fortuna, on disentangling from enmeshment with Will. Enmeshment, a common condition of family life, is almost always much more extreme in families with a psychotic member, where daily events are often literally a matter of life and death. By the same token, cut-offs are also more common. The really difficult thing is to stay connected but not enmeshed.

I had been aware of my own intense enmeshment for a very long time and had worked on it, I thought. I seemed helpless, however, to really get to the heart of it, despite all my training, until the first program at the Option Institute when we began to get help as a family seeing everything in a different light. When Will moved to a Windhorse household in Canada, work on separation was able to be coordinated in great detail with what was going on in his life. What had kept me "hooked" all those years was fear that Will might

die if I didn't stay in a caretaking role. Jeff Fortuna helped me, in a step-by-step process, to set the necessary limits. Again, an entry from my journal describing a phone consultation with Jeff gives a flavor of this.

Jeff talks of the symbiosis in Will's life—'leakage' everywhere. Impossibility of boundaries. Leakage in phone calls to both Jeff and me, leakage in his mind where "the Lord" has unlimited access, leakage in my relationship to Will. We begin to work on my relationship with Will—both in the areas of phone calls and my crossing boundaries by trying to be therapist to Will. This coincides with my underlying and somewhat veiled desire to have my own life now—yet feeling a little guilty still. I spoke of a 'conspiracy' I notice in myself not to tell Will about how I enjoy my life away from him. . . . Jeff and I agree that I will restrict my phone contact with Will to prearranged times—will discuss spacing with Will—and will refuse to talk at other times. Jeff counsels me to have basic trust, that there are others now to take care of things. This hit home. We agreed that my task is not to freak out and start to believe I'm indispensable.

Will's phone calls to me had been a major avenue of enmeshment, and I had tried for years unsuccessfully to restrict them. This time it worked amazingly quickly. Will participated in deciding how to gradually increase the time between calls—and now we talk once a week on Sundays, something we both look forward to. The tone of the calls is entirely transformed. I no longer feel impatient and inconvenienced, and Will seems relieved and pleased by the more adult exchange.

While the work on separation took very concrete forms, as in limiting phone calls, it also proceeded in subtler ways for me. Another excerpt from this period describes a phone consultation with Jeff prior to a visit home Will made.

In preparation for Will's visit, I look at my sense of dread before these visits. Now, however, it's considerably lessened and I feel a general, delightful relaxation about the whole situation with Will. Nevertheless, Jeff says that when I feel dread it's 'outmoded symbiosis' and time to sit up and breathe.

Mindfulness practice has helped me become more aware of ways in which involvement with Will kept me from pursuing my own life. One could speak of an interconnected healing process that profoundly affects us both, radiates out to the other family members

as well, and touches everything we do in the interconnected web of life.

Will's healing process continues. The story of the individual work being done with him is another story. He is still entrenched, but less so, in his habits as a "mental patient." He is still dogged by voices and other distortions of perception that no medication has been able to eliminate, but he handles this with more ease and awareness. He is still angry at times but is a *lot* less angry and much more in control of his explosiveness. He is also humorous, highly intelligent, poetic, loving, unusually fair-minded and gifted in art and music.

As I was leaving on my last visit to Canada, Will thanked me for "all the affection and all the support." It felt good and natural, yet it had taken a very long journey to get there. No family therapy has "cured" him, but there have been dramatic differences in the family work we have experienced. Most of it did not help and therefore served to further entrench Will's condition.

The family work that did help us find our way out of the labyrinth taught us to listen carefully and respectfully to Will, to draw him out, and to explore with him what he really means by things he says. It taught us to nurture him by expressing love more fully and by greeting his accomplishments with enthusiasm. It taught us that unless we fully accepted ourselves and learned to be happier, we could never fully accept Will and help him to be happier. It taught us that as long as we needed Will to change we would always be giving him the message that he was not O.K. the way he was, which would tend to further entrench him in despair and self-hatred. It taught us to believe in the possibility of recovery and to go for it 100%—and not to need it at the same time.

Will is a teacher, challenging us to the hilt, giving us an opportunity to develop the best in us. He is teaching us how to let go of fear and helping us to understand the meaning of acceptance and love. He is giving us a deeper insight into how interconnected family members really are, and what really matters after all.

EPILOGUE

The final piece of work on disentangling from symbiosis took place in an unexpected way after writing the main body of this article. After spending one year in the Windhorse household, Will decided against everybody's wishes to return to the farm in Vermont where he had lived for several years previously. Both the Windhorse team and I felt that a monumental effort had gone into establishing the household and that, after a difficult period of adjustment, the program had really begun to bear fruit. I wanted the progress he was making to continue, but Will was adamant. I had one of the most intense experiences of dread I have ever felt—so intense that it was a clear signal to me that I was off base, was too attached, and had better sit up and breathe and LET GO! Grateful for my contemplative training, my family systems training, and for the Option Institute's teaching to go for recovery 100% and not to need it at the same time, I let go, supported his decision, and respected his reasons for making it. Will, far more able than in the past to discuss his feelings, told me how scary it was for him to go against my wishes. I told him it was okay for people who love each other to disagree. The relief we both felt gave me the impression that something had profoundly shifted.

Will returned to Vermont with a sense of going home. He had missed his family on the farm, had been lonely in Canada and felt too far away from the U.S.A. and his biological family. He returned with greatly increased skills in working with his mind and with an entirely new attitude. Whereas he had previously complained constantly about the farm and begged me to take him somewhere else, he now recognizes his good fortune in having such a place to return to and knows that he is there by *his* choice. His new attitude makes it possible for the staff at the farm to work with him at a much higher level. He has an art teacher in Vermont who is very important to him, and his painting is blossoming. And most wonderful of all, he is happy and feels, for the first time, that he has a life.

REFERENCES AND SUGGESTED READINGS

- Anonymous. First person account: Problems of living with schizophrenia. *Schizophrenia Bulletin*, 1981, 7 (1), 196-197.
- Experience of patients and families: *First person accounts*. Arlington, VA: NAMI Publication No. 2 (Second Series), 1989.
- Dearth, N., Labenski, B., Mott M., and Pellegrini, L. *Families helping families: Living with schizophrenia*. New York: W.W. Norton & Co., 1986.
- Fortuna, J. Therapeutic households. *Journal of Contemplative Psychotherapy*, 1987, IV, 49-73.
- Hatfield, A. Psychological costs of schizophrenia to the family. *Social Work*, 1978, 23, 355-359.
- Kaufman, B. *To love is to be happy with*. New York: Ballantine Books, 1977.
- Podvoll, E. *The seduction of madness: revolutionary insights into the world of psychosis and a compassionate approach to recovery at home*. New York: Harper Collins, 1990.
- Terkelsen, K. Schizophrenia and the family: II. Adverse effect of family therapy. *Family Process*, 1983, 22, 191-200.
- Vine, P. *Families in pain*. New York: Pantheon Books, 1982.
- Willis, M. The impact of schizophrenics on families: One mother's point of view. *Schizophrenia Bulletin*, 1982, 8 (4), 617-620.