Dan Weisburd talks about the formation of the Lieutenant Governor's Task Force for the Seriously Mentally III...

So my frustration came after a few trips up there [to testify before the state legislature in Sacramento]. I recognized that in my opinion, nothing works. Nothing. The medications don't work. Oh, they numb people out, they quell violent acting out, but no one gets better. No one gets well. And they had therapies where they didn't need to be accountable to anybody. Even when I was the conservator they wouldn't tell me what things were. And that didn't play very well for me.

So, I went up to Sacramento to see Grace McAndrews. She said "there is a person you've got to meet and she wants you to meet, and that's Rosie King [Rose King worked for several California politicians, and was the author of 2004's Proposition 63]. She was the chief of staff for Leo McCarthy [then the Lieutenant Governor of California], and she's experienced the same kind of terrible things that are driving you up the walls. But she's in an active [political] position. She needs some support so I told her about you, and she wants to meet you."

So I went in there with Grace. She introduced me to Rosie and she left. Rosie took me in to Leo [McCarthy]. And I didn't go up there to say "there are exceptions to what I am going to say." What I said was exactly what I went up there to say: "Nothing works — nothing we have encountered. We've met a lot of nice people, a lot of well educated people, a majority of semi-educated people, and there is a knowledge base that is very scant about the most complex part of the human anatomy. And my baby, our golden boy — he wants to be well. He wants to get back in with his friends."

When I said "nothing works," the Lieutenant Governor said to me, "Okay, I've looked at your resume, your business experience. You're obviously a solid experienced person. You really care and you've been damaged as much as my Chief of Staff has, with her three kids who are all mentally ill. So, you have two choices. You can have a Little Hoover Commission [an independent committee that investigates state government operations] and have the power of subpoena, and you can go to the press and you can point the finger at everybody who is wasting our money. We spend over a billion dollars a year for services for people with serious mental illness and you can point out who are the people that are wasting it and raise hell and maybe affect some change if nothing works. Or I can give you a Task Force.

READ THE FULL TRANSCRIPT BELOW.

**INTERVIEWEE: DAN WEISBURD** 

**INTERVIEWER: Howard Padwa and Kevin Miller** 

DATES: April 29 and July 8, 2010

### I. David's Early Life and Diagnosis: Trying to Find Help for a Son with Mental Illness in the Early 1980s.

KEVIN MILLER: So tell us a little bit about David and when you found out about his illness. [David Weisburd is Dan's son, who has been diagnosed with schizophrenia]

DAN WEISBURD: He's our first child, our eldest. His pediatrician said "everything he does is perfect. This child is perfect in every way." [He did great on] every test. He walked early. He didn't walk — he ran. In school he was superb. And then he started pulling the hair out of the top of his head. Now, what was that? Nobody knew.

HOWARD PADWA: How old was he?

DW: Kindergarten. So they tested him. His score was off the board, so they put [him] in what Elaine [Dan's wife, David's mother] had started when she was a school teacher—she had started the Highly Gifted Program in LA elementary schools. They broke the lockstep and let each child go at his own pace. David was hungry to learn, and his hair grew back when anxiety was removed. He performed top of the class. And so he went through the LA School System in the Highly Gifted Program. He had his problems going through various steps of maturation, but he was always a high flier academically.

Elaine and I had taken David to [an academic program in] Andover [Maryland] for his summer between the eleventh and twelfth grade to see how he would do in competition with the Ivy League kids. We knew some families who had kids at Princeton and those kids that went to prep school there had a leg up. I mean the schooling here in public schools is nothing compared to a good prep school.

Then we got a letter from a man who said he had been a philosophy professor at Harvard for twenty years [and he had taught David at the summer session in Andover]. He said that David was the best student of existential philosophy that he had ever had. [He said] "you must send him to Harvard, and I'm recommending we send a recruiter to your home to convince you that you owe it to this child." So everybody recognized very special stuff with Dave.

HP: Now were there any signs of him starting to not be well at that point?

DW: At the end of high school, he was shocked when a favorite teacher of his killed herself. She was beautiful and brilliant and gentle and a great teacher. But David was absolutely brilliant. He sat and played the piano for you while he talked with you about something. His gift with the language was magnificent.

So when David had his psychotic break at Harvard he called me and said, "Daddy, the whole Harvard football team, in the nude, chased me, and I jumped down three flights of stairs and they threw a grand piano at me. So, I thought I'd better check in to the hospital. The doctor wants to talk with you." And the doctor got on the phone and he said, "Mr. Weisburd, David is so much more ill than I can possibly tell you and we can't give you a definitive diagnosis because it takes about six months to be sure. But it looks like it could be schizophrenia and God forbid if that's what it is. We don't know what the hell to do with him. You should take him home." They said "we have nothing. We know almost nothing about the brain. [In] about six months someone can give you a definitive diagnosis. We're guessing this could be schizophrenia but that would be the worst possible scenario."

HP: And was this the first you had known of his being ill?

DW: It's the first that I knew that he knew he was ill. When I had gone to the Harvard-Yale [football] game [with him], all the kids sitting around [us] were smoking pot, and I got a contact high. Everybody had their little flask of liquor. So, David went out with me and we'd shoot pinball and go out and have something to eat. And you know I would say [to him], "David, you've got to get off this pot." I didn't realize until later, when I was doing studies, that the Finns had discovered in their Army records that cannabis causes schizophrenia. It's the Finns who keep records. We don't keep records of any consequence here in the United States.

I called the head of the National Institute for Mental Health, who had been, as circumstance would work out, a friend. And that was Herb Pardes, who went on to greater glory as President of the APA [American Psychiatric Association] and as head of Columbia's College of Physicians and Surgeons - a wonderful, bright, honest man. And I said, "Herb, they are talking about David" - who wanted to be a psychiatrist and who was brilliant, perfect on the SAT's and stuff like that. And Herb said, "What do you want from me?" And I said, "You are sitting in the cat bird seat at NIH [National Institutes of Health] and NIMH [National Institute of Mental Health]. Who is the best doctor of the brain in the world? I've been a little lucky in my career. I will spend my last nickel on this first born of mine." He said, "Save your money Danny. We know almost nothing about the brain. I'll give you a 'least worst' in California."

HP: And when was this? What year was this?

DW: 1980. October, 1980. Unfortunately the one he found for us *was* the worst. He was the head of psychiatry at St. John's [hospital] in Santa Monica, and it was a disaster.

HP: Well, if we could just pause at that moment first. If you can tell me a) as this was happening what you thought it was and what was behind it? And then b) when they told you the diagnosis - or what they thought it was - how it was explained to you? How did they explain what schizophrenia was at that time?

DW: It was really not explained to us. My wife is a voracious reader - they wanted her to be a story editor of Playhouse 90 [an anthology television series]. She reads like nobody I know. She's the head of two book groups. She is intellectually superior. [She researched and found that] there was almost nothing [good to read to learn about mental illness at that time]. We called one doctor in upstate New York who wrote one of the

more literate books on the topic at the time, but as fate would have it, we were told he had died two weeks before.

So, in 1980 we were in no man's land. We read some explanations about schizophrenia that were contradicted by other explanations of schizophrenia. I got to know Linus Pauling [a famous scientist] who for fifteen years was funded by the Ford Foundation to study schizophrenia. And he was at war with psychiatry when I was with him. They had defamed him and he felt that they didn't know what they were talking about. [In the late 1960s Pauling devised his theory of orthomolecular psychiatry, which suggested that mental illness could be treated nutritionally. Mainstream psychiatry never accepted his views]

HP: What were the main explanations that were floating around? I mean, even if they were contradictory? What were some of them?

DW: Oh God. You know, somebody said, "well this is a split of the brain and you've got rival forces warring so that's what the 'schiz' is". I mean I knew the theories of Bleuler [Eugen Bleuler, 1857-1939, the psychiatrist who coined the term "schizophrenia"] and we went back and looked at other historical theories too. We looked at how people were wrapped with frozen wet sheets and how people were strapped to beds [as part of treatment]. I got laws passed in California where they can't do that anymore.

HP: Were they still doing those things then [in 1980]?

DW: I don't know. They didn't [do those things] to David. But they were certainly putting people in "quiet rooms"—which is solitary confinement—and putting them in four-point restraints [physically strapping individuals to their beds], and leaving them there. *That* is terrifying for anyone—much less a person with mental problems.

Anyway, one of our key consultants when we were doing little children's films for CBS television's *Captain Kangaroo* [a children's television show] was Professor Emeritus of Child Psychiatry at UC Irvine, Justin Call. Justin called me and said, "Oh my God. I heard what's happened to David." He used to take David on skiing trips in a helicopter. They'd go out somewhere and ski down big mountain slopes, or he'd take David on his catamaran [a type of boat]. He loved David. He said to me, "Give up a week of your life. We'll check into a motel. I'll bring the popcorn, and we'll work around the clock for seven days and we will have a breakthrough, I guarantee it." But then after about twelve hours with David he threw his hands up and said, "Oh my God. This is nightmare. It is so much worse than anything I've ever seen. I'm so sorry I minimized it Dan."

KM: So what sort of treatment did you try to get for him?

DW: We had him staying in the house. The first psychiatrist we went to see, the one that Pardes advised, put him in the hospital for a few weeks. It was the most frightening experience for *us* [Weisburd and his wife]. The creatures who were the staff looked like they were out of Elm Street [reference to a horror movie]. I mean deformed, weird, angry, you know. I don't hallucinate. I'm not a drinker. And this is my baby! And I wanted help [for him]. [We were] scared to death, so we pulled him out of there.

[Then] I took him into Westwood to this psychiatrist's office. We had the right to pay for David being seen, and he [the psychiatrist] had no responsibility to tell us what

medication David was on, what his condition was, or anything that they talked about. [We thought] that was absurd. You've got a loving family who is the best avenue into learning about the person and they don't tell you anything or ask you. We took a lot of steps to try to change that. And things have changed...somewhat.

And you know something? When he came back with his break we didn't even know there was County Mental Health. They seemed hidden. Our first contact with LA County Mental Health was an amazing finding: a sign out in the Culver City area that said, "County Mental Health." It was just a set of mental health offices, and we went in there and there was nobody there. It was lunchtime, so everybody was off at lunch. And then we found a social worker there, and my wife asked this woman "what becomes of people like David when they come in for treatment?" And [she] described his behaviors. And she [the social worker] literally said, "Well, most of them die."

HP: So what did you do to try to help David then?

DW: Well there was that first psychiatrist. I had bought a Honda Accord for the kids to learn to drive. They were all of the age where they should be driving here. [But] I [had] lifted David's license because he was not in possession of his...whatever [faculties]. Then his psychiatrist got on my case. He said "You can't do that to him. You've got to let him socialize. This is Los Angeles and when you socialize you need to be mobile. Let him drive." Then he [David] had a head-on collision six blocks from our home one night. Luckily my attorney and his wife — two of our close friends — were having dinner with us.

The police called, and said "Sir, your son refuses to go in the ambulance. He's been in a head-on collision and has gone through the windshield of the Honda. This is the first person we've ever encountered who has lived after flying through the windshield. The people in the other car, a Ford Mustang, are all going to the jail hospital. They were all heavily drinking. He [David] said he was on his way to his drug peddler." David said that to them! [The police continued,] "He [David] is refusing to go into the ambulance and he is drenched in his own blood. Can you please get over here and help us? We don't want to use force on him, but he will die [if we don't get him care right away]."

David remembers that I came there screaming at him. [But] what I can tell you is honestly what happened. I showed up there. The police officer took me. They had it blocked off where he was...I put my arms around David. I didn't care if he was wet. I said, "Honey, you've got to come with me. I don't care if you come in my car. I don't give a damn if your blood gets on the seats. We've got to get you [to the hospital]" Meanwhile my attorney is getting a plastic surgeon because David is all lacerated, scalp wounds, shards of glass everywhere — in his skin, in his mouth.

So, we get him over to emergency at St. Joseph's [hospital] in Burbank. And the surgeon comes out after two hours and he says, "Oh my God I've not had an experience like this since I was in Yale." I said, "What was it?" He said, "David refused all anesthetic. I've taken thousands of pieces of glass out of everywhere down to his shoulders, and [at the same time] we had the greatest discussion of the philosophies of Immanuel Kant that I've ever had."

HP and KM: Wow!

DW: That's David.

Then one day here I heard a scream from my daughter. This was when she was still living here. David was in her bedroom and my daughter screamed, "Daddy, David is on top of Grandpa." Now this is my elderly father-in-law, who David loved. My daughter had taken some of David's records. David at Harvard had written a monumental paper on the piano players who accompanied Miles Davis. And there was a huge buzz about it around the campus. And so here was David saying "Beth [Weisburd's daughter] stole some of my records." Well the truth I finally found out - days later - was that she did take some of David's records, but David had taken some of hers, so she was asking Grandpa to get her records back from David. David was offended that Grandpa was taking his records and was on top of the old man.

I come in there — now you have to know I was in a specially trained group of Air Force officers. So I got David, and I knew when I pinned his arm behind his back, if I pulled up this way it would hurt so he would stop. Well, what he did — because David is physically quite strong — was bite me and draw blood on my hand. And when I reacted to that pain, he hit me with a fist and knocked my glasses into my eye and my face, and surprised, I fell back. He ran out of the house barefoot and disappeared. We called the police saying an altercation had happened, and there is a young man that should be on psychiatric medication. The cop said, "Forget about him. Let's get you into emergency immediately. The worst kind of bite anybody can have is not a dog bite, it's a human bite. You need shots. We'll find David."

Well, we didn't find David for four days. Then a call came through from a judge in Roseville, California just north of Sacramento. And he said, "Sir, your son was picked up for loitering. He was sleeping on a warm car hood in a carport at an apartment complex in the Sierra foothills in the snow, and he was barefoot and disoriented. He had no idea where he was." They had put him in a holding cell in the Roseville jail with a bunch of baddies. And the bad guys were trying to [sexually assault him]. And David was fighting them off, [but] he was badly bruised and bloodied...When he [David] came before the judge in court the judge said "I will remand you to your father's custody provided you go to a psychiatric hospital for treatment, or I will throw the book at you and you will get nine months for loitering and the altercation in the holding cell - and you'll be in prison with those same baddies. What is your choice?" And he [David] looked at the judge stone sober, and he said, "I'll have to think about it." What that said to me is that he hated mental health care more than he was afraid of the bad people who were after him. And that was accurate.

DW: (Later, back in Los Angeles), I went to a place that I was told was one of the best board and care homes. I had my son in there. The problem they had was that they had two diverse populations - one was young people with schizophrenia and the other was old people with Alzheimer's. And the problem people were not the people with schizophrenia. The problem people were the elderly people who were angry at their condition and were violent, and acting out violently with their canes. They would hit and hurt some of the mentally ill people. But...it was run by the friend of the then director of mental health for LA County. They had beautiful drapes on the windows. They had round the clock nursing and they had matching bedspreads that matched the drapes and good carpets on the floor and a piano and it looked like, "Wow" [impressive] when they showed it to you.

It looked like two relaxed populations who had their separate things they could do in the day, but you didn't see what really went on. One day I decided I wanted to bring David home for a weekend. I went in there and he was lying in a bed of urine, paralyzed by his medication, which we immediately had him taken off of. I had to rush him to the hospital because he had been poisoned by overdoses of his medication given to him by a nursing staff that apparently thought, "more was better."

(Then) David was in one place run by lovely people who were students of Fuller Seminary. David would walk out of the class and go in the hallway where there was a piano. David is a pianist, so he would play and smoke. [But] you weren't supposed to smoke in the hallways and when a class is on they don't want the piano played.

HP: Right.

DW: [That is] legitimate, [but then they said] "he's bad for the milieu." They wanted him out. [They said] "we don't want him here anymore." And they had a meeting with the head of LA County Mental Health and the various staff members — some of the best people in LA — and they said, "if a person is not appropriate for the settings that we offer in our program, then that person must leave. We don't need to alter the program. It works."

Then I said, "Are your other people as ill as David? David's here because he is seriously mentally ill with schizophrenia. It's a bona fide mental illness. I've talked to a few of these other people [staying at the facility]. They are here with conditions but they are nowhere near [as ill as David]. You've got the wrong mix. He's only walking out of the class because he doesn't want to disrupt it with his voices. He's got a problem. And he becomes your problem [when he stays in your facility]. What are the problems for these other people? Some of them I would say — and I'm not trained in it, but I've seen plenty of it now — they don't have what he's got." He shouldn't have been accepted or maybe they shouldn't have been [accepted as the place for David to stay].

So I grew very suspicious [of mental health services provided by the county] because I realized the county didn't [even] do too good of a job picking up the garbage at our house. There wasn't enough money for this and there was a shortage in that. And [policymakers would say] "we'd better cut the mental health budget." I didn't even know there was a mental health budget at this time. I heard that kind of talk going on both in Sacramento and in Los Angeles and I was thinking, "Wow, maybe the county doesn't do much well. Maybe we should have a mental health authority of some kind that can be restructured from the beginning."

# II. Spreading Awareness; Working with The California Alliance for the Mentally III; Becoming an Advocate for Change.

HP: Why don't we discuss a little bit about how you came to be involved with NAMI [the National Alliance for the Mentally III—an advocacy group of family members of individuals with severe mental illness]. Tell me how you heard about them and some of the work you did with them.

DW: My wife heard about CAMI, the California Alliance for the Mentally III, and she went with a friend who also had an ill son, that was Susan Dempsay [an advocate who worked with CAMI]. Susan's son was also like David, flirting with pot and some other

drugs that were very much in vogue at the time. Elaine went with Susan up north to a conference where she met Jay Mahler [a leading member of the consumer movement in California] who she struck up a friendship with. He reportedly was someone with a serious mental illness. She thought he was in much better shape [than David] so maybe there was hope. He was very articulate and handsome and dear. And Elaine said [to me], "You've got to meet this young man. He's wonderful and you know with any luck maybe David can show that kind of recovering ability." And I met Jay and I met some other people and went to some meetings at a little support group of Susan Dempsay's, a former school superintendent who was the president of the LA chapter of CAMI [Don Richardson] and Dick Van Horn, who was the Head of the Mental Health Association [currently Mental Health America] here. And we couldn't have been more fortunate than to have picked those people.

DW: They were very dear, especially Richardson's wife, Peggy. But David wasn't getting better. We couldn't find any real care. Then I met a woman named Helen Teischer, who at the time was the President of CAMI in California. She asked me to come speak to Bronzan's committee [Bruce Bronzan was a representative in the California State Assembly from 1982-1993. As Chairman of the Health Committee, he was a leading advocate for mental health services in California] I didn't know who Bronzan was. He was a young legislator and he spoke well. He and I developed an alliance: he asked me if I would be his torpedo witness, and he would bring me up to every hearing that they had. He would say, "Dan, can you discipline yourself and only talk about housing and how impossible it is to get good housing, and the reasons that it is impossible to get it?" Or about therapies that worked, he would ask me "Have you looked for therapies? What has worked and what hasn't? Talk about that and restrict yourself to that and that's what we'll bring up as a bill of some kind."

HP: Right.

DW: So we got along very well. And I felt he was very sincere in what he was trying to do. After Helen [Teischer] heard what I was saying at Bronzan's committee meetings, she suggested to me that I should address a conference for the Alliance of the Mentally III. She said, "My God Dan, I want to run you for President of the state organization."

HP: And what was the organization doing at that time?

DW: The organization was showing up. There were some nice people up there [at CAMI's headquarters in Sacramento]. I'm blanking on some of the names but they would come to hearings and speak on behalf of the families because people didn't want to waste money on "non-productive citizens." [referring to how many legislators viewed individuals with mental illness at the time].

Some very forceful, well-spoken people were in Sacramento when I went. I met Tony Hoffman and his wife, Fran [Tony and Fran Hoffman, early leaders of CAMI]. They had rented a little apartment for an office and put in a cheap steel case desk and hired a young woman who had been working with the mentally retarded and who was well spoken and bright. She was from Nebraska, an attractive and decent person, Grace McAndrews. She was just a secretary to them, but had the smarts to understand what the legislators were talking about, and read the bills [McAndrews would later become the Executive Director of the National Alliance for the Mentally Ill's California chapter]. And so I had gone and met them, and then Helen Teischer was very convincing. She was a

lovely old woman with a very sick son, and she was also a gifted speaker. She said, "Please, keynote our conference and say some of the things that you said for Bronzan because our people need to hear that. You ignited our people who heard you."

Out of respect for Helen, I agreed to be the keynote — and I spent an inordinate amount of time developing the content. I wanted it to be a rallying cry for all those family members who did not abandon their mentally ill loved ones.

I called the speech "We Carry The Torch" — to illuminate the darkness, to show the way. It was filled with hope and it focused on *recovery*, not merely the use of powerful meds to block symptoms. We wanted rehabilitation, and even *cures*. We wanted a place at the table when treatment planning takes place. [We said] "We will no longer be kept in the dark by 'treatment providers' who had never cured anyone." Our voices would be clear and demanding. We would stand for *hope*, and only support those in public service who gave us their respect. We would be fair, but demand the same in return.

Also, around that time we had made *Interrupted Lives* [a 1984 documentary about mental illness narrated by Burt Lancaster that Weisburd and his wife wrote and directed]. When we were on the air we had what was reportedly eleven million viewers -- which was unheard of -- but it was all because of Burt Lancaster's star power.

HP: And this was on PBS?

DW: Yeah. And because of Burt and his celebrity and his Oscar win and his openness about having a son who was severely mentally ill with schizophrenia. Star power meant something and we got him and he was terrific.

HP: What about it do you think struck a chord [with audiences]?

DW: There was hope in it. You know, I had met Bill Anthony and the idea of rehabilitation made sense you know. [William A. Anthony is the Executive Director of Boston University's Center for Psychiatric Rehabilitation, and was one of the first researchers to promote the value of the recovery model for the treatment of mental illness] You just don't relegate people to a junk heap because they don't respond to a medication that really isn't backed up with much research. It's [in a voice mocking doctors who overprescribe medication] "We make pill. You buy pill. And maybe it will work. And if this pill doesn't work we'll try another one."

HP: And what were the pills then?

DW: I can't even name the different pills, but everybody got into it [the business of psychiatric medications]. As you peeled the onion you found there were more and more mentally ill people. And when you can sell a pill and cross label [to treat conditions other than those it was designed to treat] you say [mocking psychiatrists who overprescribe medication] "well, you're having headaches, or maybe your just ducking it. Maybe you have depression and that's why you're not going to work regularly. It might be the alcohol you're drinking to mask it. You should try one of these pills because though it was designed for schizophrenia, it might be able to get to that portion of the brain that we don't know that much about yet, but it might affect the serotonin which is a chemical that's in the brain. And we're not sure exactly whether you can interrupt the flow of serotonin but we find that maybe there is a reuptake mechanism that's happening and

we can interfere with that." Well, the brain is smarter than the people compounding the chemicals. And the brain creates a different response than was expected.

Meanwhile people at various universities had discovered me. UCLA, USC and UC Irvine were all asking me to come and speak with young medical students because the best medical students, when they made their choice of a discipline to stay with, were not choosing psychiatry. In fact, they said, in *their* language not mine, [that] "the dregs in the class chose psychiatry."

HP: That's interesting.

DW: [University faculty told me] "The best ones chose brain surgery and neurosurgery and then there are various levels, but psychiatry isn't the most rewarding. They are really pill pushers."

HP: Most rewarding in terms of the-

DW: Satisfaction and success. If you save somebody's brain and they can become active in the world again, wonderful. But if you are just nurturing people who go from one tragedy to another it is not very satisfying, so maybe you change.

DW: People like Biff Bunney [William Biff Bunney, the former co-chair of the psychiatry department at the University of California, Irvine] introduced me to Steve Potkin [a professor of psychiatry at the University of California, Irvine]. They were recruiting him to be their director of research, brain research. They were a relatively new department to UC Irvine. He met Elaine and me and we all went out to dinner together and we really clicked. We liked each other. Then he joined UC Irvine and that became a special place to us. Then he became David's doctor for fifteen years after many failures of other doctors.

His [Potkin's] wife [Michelle Trudeau] then called us one day and said, "I'm the National Science Reporter for National Public Radio and I don't know if you ever listen to 'All Things Considered' [a National Public Radio show] but we would like to do a segment on the family experience of living with somebody who has schizophrenia. Would your son David be willing to be interviewed by me? And would your wife, Elaine be willing to be open about her feelings? You seem to be quite public about your feelings. I'd like to cut together the three of you and then paste it together with some of my observations about you and about the state of care and so on." And so Michelle did a story about us on National Public Radio and we got three thousand letters. Mailbags dumped on us. It took us over a year. I answered every letter.

HP: Wow.

DW: She was masterful in her interviewing. Suddenly we were on the air and we're getting calls from people all over the country who because somebody let our phone number get out.

HP: And what were these calls? What were—

DW: Old friends who said "they didn't say your last name but we knew it was you. They said the son was David. We knew that was Elaine." Old college friends of hers

and people I hadn't seen for years and relatives and old neighbors and people who didn't know us who were asking us, "Could you come talk with us? We have a small NAMI group. And people don't know how much the families suffer and how frustrating it is to have systems that don't work. They won't talk to you about your child's medicine. They won't tell you what it is. They won't let you come see them in a locked facility. The doctor won't explain what treatment your child is getting." And so I realized that I had a voice that could articulate what a variety of people were saying to us. That leadership was thrust upon us.

### III. The Journal of the California Alliance for the Mentally III

HP: So tell me a little bit about the founding of The Journal [the Journal of the California Alliance for the Mentally III, which Weisburd published from 1989-2000]

DW: When Elaine and I were looking to learn about serious mental illness and David – whether or not he was going to be diagnosed with schizophrenia and so forth – we found there was a paucity of reading matter. Elaine reads twenty times faster than I do, but there was nothing. And there were so many voices who experienced things differently, whether it was a Jay Mahler or Don Richardson. Or if it was a doctor who worked fifty years in psychiatry who felt psychiatry was on a wrong track, abandoning communication between patient and physician and taking a journey together rather than just pushing a pill and banking it.

So I thought, "I know I'm a good writer. I know that when I've written something or made a speech and I just wing it, it has body to it. It is not superficial." Then I thought, "What if I could just be a conductor and I could attract people to a complete orchestra to play not my composition, but to play their part?" The best thing I could do was to pick the window we look through for this issue to look into the mental illness experience at all levels. Whether it [is a broad question, such as] is recovery possible? What is recovery? If you never get totally recovered can you live a life that has [meaning]? Or what makes suicide take place on so many different levels? How many people deal with someone who is thinking of suicide or mourning forever the child who killed herself who was a person with such wonderful potential? What is "Wellness?" What is it to be a nurse in the mental health field? Has that evolved? What have you seen? Are you disappointed? Are you excited? What is it you know?

But first I had to learn some — I was so naive. The only thing I had published in print was when I was the editor of the Mt. Vernon Junior High School Minuteman. And I had won that office in an election because I told a dirty joke and the principal chastised me before the second assembly and all the kids rose to my defense. And I made a paper that had some provocative things in it even. So, here I was now with a dream of something to do, knowing I was a good writer but knowing where my pitfalls were. So, I brought in the most talented graphics person I knew. I brought in what I thought was a decent board that had no power, but they knew people [who could contribute to the publication]. They could not censor anybody, but if they knew somebody they could suggest as a writer or a theme that we were going to do would be of interest to them. I even had a couple of issues about religion or spirituality for people like Jay [Mahler] who felt he was on a spiritual journey with his illness. And so I wanted to have a lot of people help us branch out and reach out for talent. I also knew that if it was going to be quarterly, I needed to be in communication during any single year with over a hundred writers. There was no pay for any of them except when I hired a writer with a specific

assignment. I hired my God-daughter — Laurie, Gary Marshall's daughter--who is a fine writer.

Most of the writers who wrote for us and were professionals were thrilled to work for a non-peer reviewed publication because they could dare to tell *their* truth. Whereas when you write for a peer reviewed publications, you have to...shall we say "toe the line?"

HP: Fit into the literature, devote half the article to your methodology.

DW: Exactly. And you have to stay as part of the herd. You can't bolt too far. A lot of them wanted to bolt. They wanted to tell or speculate down a road of their own creation and we were letting people do that. People wanted to write again for it when they've had the experience.

We didn't have much money. It was all from donations and slowly I began to reach out to foundations and stuff and raise millions of dollars for it so that the Alliance [CAMI] people who had subscribed to it would [only have to] pay ten dollars or something.

HP: Is that what it went to? Was it mostly the people in CAMI or did it have a wider readership?

DW: Oh, it went all over the world. I've been invited everywhere to go [to discuss *The Journal*] It was in Indonesia. You know, it was in Israel. They [the people who read the publication] were mostly professionals out there across the world. We've gone to some conferences where Elaine and I made friends with people who had something to say who don't think like the United States about mental illness.

HP: So it was in publication for how long?

DW: Eleven years.

HP: Okay, and then what brought it to an end?

DW: Uh, let's see if I can say this without expressing too much bias. A lot of the leadership in the Alliance [CAMI] changed and became much more representative of a segment of the population that believes in forced medication [forcing individuals with mental illness to take psychotropic medications]. They had a lot of very aggressive followers of Fuller Torrey and I felt no affinity for where they were headed. [E. Fuller Torrey is a psychiatrist who founded the Treatment Action Center, and is a leading advocate of forcing treatment on people with mental illness in some circumstances]

HP: And was this at the state or the local level?

DW: State and local, and even national. A lot of the people on the local level had mixed feelings about whether people should have the option to say no to a medication. I didn't share that view. And I feel it was a big mistake to have vested *The Journal* in the Alliance for the Mentally III, because it transcended that rather quickly. In fact what I should have done was found a way to put it in a university. But now, here suddenly, we had people that wanted to dictate what you do. Not only dictate, cut out what they didn't want by gluing [members of CAMI who glued shut pages of *The Journal* in order to censor articles they did not want to be published].

But I didn't have the right to take it away [from CAMI]. I had gifted it [donated it to CAMI]. It wasn't their money I worked with. And I didn't take a huge stipend for me, but as we went on I got paid something and I brought in a former head of the number three advertising agency in the country — who was a graphics person who is a dear friend. So I learned a lot of things...and I really learned the value of Freedom of the Press.

# IV. The Lieutenant Governor's Task Force; A.B. 3777; The Creation of Integrated Service Agencies

HP: So you were involved with CAMI and you are working on these various things. Now tell me how you came to work with the Task Force [The California Lieutenant Governor's Task Force for the Seriously Mentally III], and then the work that you actually did.

DW: I got more and more frustrated with the quality of care that we were able to get for our son. There were times when I had to do some traveling for my work that paid me something, and sometimes that required me going out of the country. One time I asked a friend of mine who is African-American and a United Methodist minister to act in my stead, and visit David in a locked facility. I was authorizing it. And I was his conservator at that time, so my authorization was "legal." He [Weisburd's friend] tried to go, but then he said to me, "they didn't want to let me in to see David, and I'll tell you Dan, in my honest opinion the people who run the place are sicker than David and the clients there."

HP: Was this a board and care or at the hospital?

DW: It was a board and care. But it was a locked facility. And you know, I knew the owner and he gave a lot of money to CAMI and NAMI, which buys favors — just as it does in government.

HP: Yeah.

DW: It's one hand...

HP: Washes the other?

DW: That's how a free society works. So my frustration came after a few trips up there [to testify before the state legislature in Sacramento]. I recognized that in my opinion, nothing works. Nothing. The medications don't work. Oh, they numb people out, they quell violent acting out, but no one gets better. No one gets well. And they had therapies where they didn't need to be accountable to anybody. Even when I was the conservator they wouldn't tell me what things were. And that didn't play very well for me.

So, I went up to Sacramento to see Grace McAndrews. She said "there is a person you've got to meet and she wants you to meet, and that's Rosie King [Rose King worked for several California politicians, and was the author of 2004's Proposition 63]. She was the chief of staff for Leo McCarthy [then the Lieutenant Governor of California], and she's experienced the same kind of terrible things that are driving you up the walls. But she's in an active [political] position. She needs some support so I told her about you, and she wants to meet you."

So I went in there with Grace. She introduced me to Rosie and she left. Rosie took me in to Leo [McCarthy]. And I didn't go up there to say "there are exceptions to what I am going to say." What I said was exactly what I went up there to say: "Nothing works — nothing we have encountered. We've met a lot of nice people, a lot of well educated people, a majority of semi-educated people, and there is a knowledge base that is very scant about the most complex part of the human anatomy. And my baby, our golden boy — he wants to be well. He wants to get back in with his friends."

When I said "nothing works," the Lieutenant Governor said to me, "Okay, I've looked at your resume, your business experience. You're obviously a solid experienced person. You really care and you've been damaged as much as my Chief of Staff has, with her three kids who are all mentally ill. So, you have two choices. You can have a Little Hoover Commission [an independent committee that investigates state government operations] and have the power of subpoena, and you can go to the press and you can point the finger at everybody who is wasting our money. We spend over a billion dollars a year for services for people with serious mental illness and you can point out who are the people that are wasting it and raise hell and maybe affect some change if nothing works. Or I can give you a Task Force. You run the names by me so you don't choose any convicted felons. Put on some people from the legislature — a sprinkling of them — and some clients and some family members and the best people you know you can get involved.

So, I picked some people from the private sector of industry to get that crowd. I knew the Vice-Chairman of Times-Mirror [the Times-Mirror Foundations]. He was a good friend of Dick Van Horn. I knew the President of Levi Strauss. He was one of American's great marketing people. We would have our meetings either at the Times-Mirror boardroom — which is like the UN — or Levi Strauss, which is the San Francisco version of the same. Or we'd meet periodically at a Capitol room [at the State Capitol in Sacramento].

Rosie said to me, "You know who you really need? There is a guy who I had with Lanterman-Petris-Short to do the LPS Act [the 1968 Lanterman-Petris Short Act, which established the rules for mental health commitment in California]. Now he's got an independent company, but I bet we could hire him away for a time to be your Chief of Staff, and that's Art Bolton. The man can write. He's brilliant and he can structure ideas in a way that can be codified into law. You can speak dramatically and talk about it, but he can write it as law. If the two of you can get along — you are both hard guys — let's see what happens." [When she said that, my first thought was that] I didn't want another guy. I wanted to control this thing. But as it turns out, he saved my life. What a dear, brilliant, fine man.

There was a lot of disagreement because these people [on the Task Force] for the most part knew they were from different positions, but they knew what they thought was necessary. I'd say to Art after we'd have a tumultuous meeting with the Task Force "I must be the world's worst chairman," because I'd come out of meetings where there was such turmoil. But he said to me that "the thinking process is working." [Art reassured me] "It isn't dull like the legislature. Give me a day and I will get down. I've taken notes and recorded it. Let me feed it back to you and see if that's what you had in mind." And he nailed it, and amplified it [when he wrote up his reports].

HP: What was all the turmoil about?

DW: Disagreements about who should be in charge of what. The clients wanted clients in charge of everything. Some people wanted to spend less than what we were spending — that came from the Republicans. You can get more or less but you can't get more *for* less — [then] you get less and more of it.

And we had spirited discussions with disagreements. Some of the disagreements came out of the personalities, some came out of the fact that the people who were in the [mental health treatment] industry needed to bottom line on what the idea was going to do. Like a legislator said to me "can you say that with this integrated service agency we will have 40% less hospitalizations? Because that's what we've got to say to get the bill passed." Well that would be BS [not true]. You'd be making up a number. I couldn't sign off on that. So we would fight over things like that. [People would say] "if you can't say that there will be 10% less recidivism into our jails we're not going to get the support of the criminal justice system." So you had to start making up numbers that expressed a hope, with no honest belief that that's what it would deliver. [After all] Why [say] 10%? Why not 97%?

HP: And then where did the idea of the capitation scheme come from? [The legislation that resulted from the Task Force's work featured a capitated funding scheme, where organizations received a given amount of money to provide all services for their clients].

DW: You know, somebody figured out numbers. All of these schemes of putting numbers on things became necessary, but we weren't spending enough on each individual because we didn't have the parts of a system that would give people what they needed. So, how can you say eighteen dollars a day or a thousand and twenty dollars a day? You can't, because what's it going to be spent on? Who is on the take? And I realized early that you can't be against all the people who are delivering substandard work, because that would be cutting out jobs in California. If you cut out jobs you've got the unions on your neck. You've got you know segments of the earning populations.

HP: Yeah.

DW: But that's not about my son getting better. That's how they get paid. You know, people knock the people who lobby, but at least they have sheets of paper that give some knowledge about something. Unless you have experienced a child of yours who people judged as perfect, totally deteriorated and doing absurdities that you never would have thought you'd see in your lifetime, you don't know how devastating it is. But you can't be against jobs in California. The [findings of the] initial paper that the Task Force had printed was not going to [support] a continuation of County Mental Health. It was almost like charter schools. It was kind of like "if you didn't do a service for a mentally ill person that day you wouldn't get paid." It was piece work. It was a concept that "we don't pay for you to have a job and occupy a chair. We pay for services for people with serious mental illness. All the expenditure has to be that. No big administrative stuff where you can't figure out what they do hands on."

The Lieutenant Governor let me use his office. He wanted to stay in San Francisco with his family. He said, "Put your feet up on my desk. My secretary is the best secretary in the Capitol. She'll type anything for you." [But] I couldn't work in his office. You looked out those gorgeous windows on those beautiful gardens, and I dreamed. So, I'd go back to the crappy hotel where I stayed for very little money, and there was a lousy desk

that was uncomfortable. I would do my work quickly, get it to the secretary to type it up, and go back home to mamma. I didn't need to play "I was Lieutenant Governor." I chose to have a Task Force largely because I could get some of the best people in this state to want to come on it. Not just legislators who don't know a hell of a lot about mental health and probably won't learn about it. People who had felt the pain [of trying to get help for loved ones from the mental health system].

I don't know how much contact you've had with politicians, but when there is a good Irish politician, they are the best. I'm telling you. I traveled the state with him. We had fourteen town meetings. We took over the Chambers of the Supervisors. He gave me unlimited power. I said, "What power do I have?" He said, "Run the names by me of who you want on the Task Force so that I can check them out and be sure you haven't put a convicted felon on because that would give me political problems. I want to be governor." And I did have a convicted felon. How was I to know? We got rid of her and put a professor from UCLA who was also black, but hadn't killed anybody.

I said, "I don't want power of subpoena." He said, "You don't have it but nobody knows you don't have it. So don't tell everybody you don't have it and when you ask for something. Be polite, but [say firmly that] you want the Board of Supervisors chambers in Los Angeles on March 12<sup>th</sup>. Call there and give them a reasonable amount of time — like at least two weeks and say what hours you want it, and that you are holding a town meeting. And if they question whether you have the right to, tell them 'please call Lieutenant Governor McCarthy. This is at his request."

And I would get threatening calls from labor unions like the Prison Guards. "We're going to kill you in the Senate, Weisburd...We have McCarthy in our pocket. We are his number one donor. So change your tune." Then I would say "thank you very much. I appreciate the call." Then I called Leo and I said, "I got a call from so and so who is represents himself as the head of the union, and he's got you in his pocket and he's your biggest contributor. So, I've written out my letter of resignation. I don't want to be trouble for you, but I'm not going to fall for his crap. So, can you do anything about it?" "Yes," he said, "what was he complaining about?" And I said, "Well read pages two through thirteen of my report. That's what he's complaining about, and we're not going to budge." So, Leo called me back and he said, "I like it. I'll call." He said, "I'm totally for you and you have a free hand and if you need anything else call me. And if the people threaten you, tell them you're going to call me and I'll tell them you have the power to do what you are doing."

Well, our town meetings were a hit. What ennobled me was Leo showing up suddenly to see how they were going. And he was delighted.

HP: And what were they like? What did you do? Was this to be a fact-finding mission?

DW: Yes. It was the people. Everybody who attended had a chance to say what was on their minds. It was a democracy. Some were professionals. Some were mental health directors. Some were family members. Some were clients. And they all got heard. It was arduous, but it was revealing. When we allowed the people to be heard, they were saying beyond what I said. I was learning. We were refining what we thought should happen. The main thesis that I had — and this wasn't going to work in the State of California — was that county government is entrenched. It is going to continue, and

nothing would change even if I had a gang of a thousand people agreeing with me. They are not going to change county government. It is there. Their retirement policies are there. There vacations are there. Everything but good services for people with serious mental illness are there.

HP: So you had the hearings. How did that lead to the creation of the ISA model? [ISA — Integrated Service Agency — an intensive case management model created by California Assembly Bill 3777, which emerged out of the Task Force's work]

DW: It got broken down into instructions for a bid proposal; if you read [California Assembly Bill 3777, Chapter 2] it kind of spells it out in loose form, not tight. And there was ample room left to be creative. One of the high points that people would receive was for their creativity — how they would plus what we were asking for. One of the things we were asking for at the beginning was — every program David had been in, in the beginning, in various places, you could get kicked out. For the ISA, you could never lose your membership. You would be a member. In fact, it [a client's membership] wouldn't even be terminated after you did something that was vile. They would care about you. If you went to jail or into a hospital they would accept you back when you got out.

HP: If they disappeared [lost contact] for six months?

DW: You couldn't kick them out. Well, *now* they get rid of people. They've changed that.

HP: Yeah, you know a lot changes, nothing stays the same.

DW: So, essentially the proposals came in, and that's a lot to read. I had two boxes of proposals. One of them had to be in a small community — the specification called for one to be rural. That was a shame because the rural proposals were poorly written. And the proposal that came from the Pacific Clinics [a community mental health provider in Southern California]—choice. [it was excellent] The proposal that came from Mental Health Association—choice.

I had written a proposal years before for a film we did with Burt Lancaster with Dick Van Horn, sitting on the floor late at night at an Episcopalian Church, and it was for the community support branch of the National Institute for Mental Health. And Dick and I wrote well together, and Elaine polished well, and we got it. So I knew Dick was a very good writer and a very good conceptualizer and all around good fellow. I knew David Pilon [currently the President and C.E.O. of Mental Health America of Los Angeles], who Dick tells me wrote most of it. He is terrific. I didn't know how they were going to staff it but I knew the people. [Then I thought] do I recuse myself because I know Chris Amenson [Dr. Christopher Amenson, a psychologist and administrator at Pacific Clincis] and the good stuff that comes out of Pacific Clinics? No. I care about what this is going to be so my caring in my mind makes me impartial.

HP: And what was it you were looking for specifically?

DW: We were looking for somebody who was willing to risk, to do something different than had been done before, that would allow a better life for people. [We wanted the ISA to go to providers] who spent their days interacting with people, and cared about offering

them supported education, job skills, more awareness of what is going on in the world around them, recreation. A life that the three of us [like everybody else] try to build for ourselves — work being one part of it, education being one part of it, health consciousness being another. So we were looking for "how do they create a community?" The name "The Village" came out of the Van Horn proposal. It wasn't part of anybody else's proposal.

So, you know the list of things that people came up with when we looked at their bids [focused on the question of] how they would carry the concept of an integrated service. It wasn't "you go this place for one thing and that place for another and so forth."

HP: So that was a key thing you wanted? Was it to be more of a one stop shop?

DW: Well yeah, it's got to be because they [people with serious mental illness] are not capable of running all over the place. I mean one of the things they did that made David mobile, was to help him get a bus pass. People were being killed by the blue line [a public rail system]. The blue line goes racing down in an open street and people who are mentally ill and on mind-altering drugs for their mental health have been badly hurt crossing and not knowing a train was coming. So, how that was being handled was [one of the criteria].

There were half a dozen judges, I being one. And there was a point system, one to a hundred. And at the first tally something was grossly wrong. Pacific Clinics was way above everybody else, and Van Horn's bid — which was at least as good — was down near the bottom. In checking the ballots with the chair of that effort — with Vince Mandela [of the California Department of Mental Health] who knows where all the bones are buried — we found that one of our judges had voted zero points for Van Horn, and that same judge had voted one hundred points for Pacific Clinics. We had a shill as a judge. I could have easily voted a hundred points for Chris Amenson, but you can say the same thing about Van Horn. The other stuff did not come close to those two. Those two should have been the two winners.

So how were we going to get this to a place where there was a level playing field? There wasn't [a way]. I was deeply offended that somebody would play a trick like that. So we came up [to Sacramento] and we counseled with somebody. And we came up with the solution that we were going to throw out the highest and lowest bid number, ranking and it worked out that Dick's won by one point. And even that was kind of unfair if you change the rules of the game in the middle of it, but the dirty zero was terrible. So you know I'm sure that happens with all kinds of things all the time.

HP: So now, looking at how the ISAs have unfolded over time, what would you say you are most pleased with and what are you most disappointed with?

DW: I'm pleased that it still exists. I think the concepts are solid. I think that the best thing that was done was a lot of the hiring initially of some of the key people, the woman they put in charge.

HP: Martha Long [former Executive Director of the Village].

DW: Martha Long was wonderful. Her personality helped the residents. [But since then] the mix of people has shifted. I don't think a huge percentage qualify as seriously

mentally ill [any more]. I think they've got a lot of other problems going on, but how they selected people and the people that they let go [is something I don't understand]. See, the members were supposed to be there as long as they wanted to be members. Now most of them are terminated at some point. Why has that happened? The rationale somebody told me was that they did this "to let more people have that experience." Well, if you don't outgrow your serious mental illness, and if they don't really know how to blend [into society] and make possible a life it doesn't have to rooted within the walls of an old telephone building [where the Village is located].

Anyway, I'm pleased with those things they do and that it still survives. I'm pleased that they staffed initially wonderfully with a great nurse, and with Mark Ragins [the head psychiatrist at the Village], a psychiatrist who is a maverick who *thinks*. He's *alive*. So what I like about it is continued. It was initially staffed very well.

What they could do to make me feel happy is much more individual tailoring for the members that they do have. They need more options for how they spend their day. Working and schooling are the best therapies there are. Socializing has a place, but not as a primary activity. They can sit and talk about how sick they are forever. All you have to do is sit a bunch of clients down to talk about experiences they've had. They could go on forever talking about their experiences with the illness.

HP: How is it that school and work are the two best things [for individuals with mental illness]? Some skeptics may say what if they are too sick for school or too sick for work.

DW: Well, I'm not saying that college level — I'll give you an example. David is not involved with a computer at all. When he was at his heyday at Harvard I bought him an Adler portable typewriter. He typed a hundred and twenty words a minute. Any good secretary can do that. Okay, so people were saying to David "why don't you go and take a class with the elderly in the park about computers. They don't go fast. They've got slower brains." So, David goes there and he completes the class and gets his little certificate and I said, "Well what did you learn buddy?" He said, "We learned how to get the menu." I said, "What is getting the menu?" He said, "I'm not sure how to tell you about this." I said, "Well, you can go into the best restaurants in the world and get a menu, and then there are choices you make about what you get from what they are offering. Or you could sit in the best restaurant in the world and starve to death. You've got to somehow get beyond a certain point and make choices."

So what can be done to have the Village grow and tailor more things to individuals? They are all different. Nobody is the same. Have they abandoned bringing in a lot of seriously mentally ill? My sense is yes. But the depth of my sense of what goes on is shallow. I have not looked over the books and asked to see things. I don't want to be a provocateur. I had a dream. It was put into action with some very wise choices in the beginning. Paul Barry [the current Executive Director of the Village] I admire. He's very capable and he's trying hard. Budget stressors are enormous, just as in every business.

The Village budget was cut back and cut back. They took in a bunch of people that were homeless and kept them in the basement. Well, homeless people are different than the seriously mentally ill. The reason why my Task Force was called the "Task Force for the Seriously Mental III" was [that it was] not for "the Seriously Mental III and Homeless People." If the seriously mentally ill was homeless, that's fine. But they have got to be bona fide person with a *serious* mental illness, not the aberrant stuff that is laid over.

Homelessness is terrible, but so is a mind disorder. And if your staff is up to their snuff on brain disorders — even with our scant knowledge — they can do a lot more. If you had a staff [full of people like] Mark Ragins you would be blessed.

HP: And what is it like there now?

DW: [Well now] they've got security there, armed security because there were weapons, there were knives, but they needed to get the money. Steinberg [California State Senate Pro Tem Darrell Steinberg, who has spearheaded efforts to enhance services for the homeless mentally ill citizens of California] was given an honor because he had a bill so they got more space in the old telephone building and they let people sleep downstairs and stuff. But it is a different population. They [the homeless] are streetwise. Most of the seriously mentally ill aren't that.

### V. On Stigma; Work With Law Enforcement

HP: So tell me a little bit about the work you've done on stigma, and helping change the way society views individuals with mental illness.

DW: You know stigma is a very hard thing to work against. Some people say stigma is when people misuse a word by saying "Oh we're having a schizophrenic weather problem," you know? Or when they say, "That's crazy. What you are saying is crazy." It's very hard to alter the language. What is easier to do, and I was asked by a psychologist friend of ours to do this, was go a meeting with the Program Practices and Standards people of all the [television] networks. They are the censors at all the networks to try and sensitize them to the stigmatizing things that were going on.

For example, one of the best programs at that time was *Hill Street Blues* [a police drama that was on the air in the 1980s], and they had an African-American man who had a German shepherd dog. The man was mentally ill. And not only did they have to kill the man, but the cops, the good guys, they had to kill the dog too. And I thought, gee that's by David Kelley [a successful Hollywood writer]. He is such a great sensitive writer, in my opinion one of the finest writers we've ever had in television. Why couldn't Practices and Standards talk with him about changing that ending so that the police weren't shown as terrified of a mentally ill person, and so you would learn to like that person? It was good dramatic effect, but what was it conveying to the public about serious mental illness? Now [we need] to get beyond the people who control access to the network and broadcast because [while] television has an amazing affect on the vast majority of people, now it's got to be on Twitter or something.

HP: Yeah.

DW: There was a circumstance where the people at St. Joseph's [hospital] were proud of some of the work that I had been doing what with the Journal coming about. They decided I was going to be honored as one of the "Beautiful People." They have a "Beautiful People" award. And one of the other people that was going to be honored was the producer of *ER* [a television drama about a hospital emergency room]. So I'm called upon to accept an award, and we had never watched *ER*. Since we were going to be honored and the producer of *ER* was going to be honored and then the people in their emergency room were being honored, I thought, "Well, I'd better do a little courtesy view of the program." And what I saw curdled my blood.

They had a psychiatrist in the show. This is the night before I'm going to be on the dais with the producer. And he [the psychiatrist on the show] says, "There isn't a day that goes by when I don't have to come in and work with a mentally ill person who either urinates on me or vomits on me. I'm sick and tired of having those people in the ER. When they come in tie them down in four point restraints and hit them over the head with a hammer." And Elaine looked at me and I looked at her and she said, "Can you talk to the producer of that show? Here you are running around making speeches in various places, but look what they are getting on the air! Can you say something at this event? Seven hundred and fifty people [are going to be] in this big auditorium at the Universal Sheraton. Can you [do something] without insulting the Sisters of Providence who are honoring you and this other guy?" And I said, "I don't know, but I can't bypass saying something." I mean I was being introduced by the daughter, the beautiful young actress who is the daughter of the Hennings who did Beverly Hillbillies and Green Acres, and she knows some of my history. And then here comes this producer who was an MD from Harvard and clearly a bright young man with a top rated show and an Emmy. It's got [George] Clooney in it, but I had to think of something.

Meanwhile, I said, I'm also going to strike a blow against stigma. [I thought] David is going to be invited. I will dress him up. He's going to be sitting at the table. On one side of him will be his attorney brother, Steven, who is stronger than David. And then on the other side will be Beth, our daughter. So we go to this event, and we bring the two other children to keep David in the room. [I told them] "Don't let him go out all the time for his damn cigarettes and let's pay attention — especially when Daddy's up there. Don't let him walk out please." So they introduced Baer [Neal Baer, the producer of *ER*], who is a handsome young man, very articulate, and they honor him first.

### HP: This is the *ER* guy?

DW: The *ER* producer. And then I'm introduced by the Henning daughter, and the people applaud and as I'm walking by there I say to Baer, "You and I need to have a talk." I said, "I saw your show last night." And I go up on the stage not knowing what the hell I'm going to do. And I'm trying with all my heart to be appropriate because I was angry and shocked. So they gave me this nice award and I said, "You know, I'm very grateful to the people at St. Joseph's, not just for this award but for my even being here given what my own medical history has been [Weisburd had had several major surgeries at St. Josephs]. But I want to share this award with someone who is the only reason why I'm here — and that's my son, David who has been battling for a number of years now what is quite possibly the worst illness people can conceivably have: the loss of your mental faculties by having a severe mental illness. David, I want to salute you for your courage. And I want the rest of you folks to join me in that salute. To your courage Dave, would you please stand up?" And David stood up and everybody, seven hundred and fifty people [gave him a] standing ovation.

I walked back to my seat and that was the end of my tiny speech and Baer says to me, "[Your wife spoke to me and] I know all about what you want to say. I will have a writer at your house Monday morning and we will do a make-good episode. We'll tell the story your wife told me about when she went to the ER, and David was refusing medication and he was totally psychotic and on the streets. We will do an episode [based on that]."

And they did. A nice young writer came and worked hard. And one day she called me and said, "Dan, can you please bring David to the studio tomorrow? I want him to meet

the actor who is going to play him and then the director who is directing the episode." And I said, "I'm sorry I can't, Stacy. Do what you do for an undependable drunken actor who you've cast. Send a limo to where David's living, in his board and care home, and bring him in for lunch. You know, buy him a hamburger and he'll be honored and he will do his best to teach the actor how to smoke like he does and how to talk to voices like he does. And the director will talk to him about things. He will be honored to participate." "Will he behave himself?" she said. [I responded] "Well you know that's going to be on your hands. You know, will a drunken actor behave himself?

And David called me the next day and he said, "Best day in years Daddy. They treated me so nicely. I had so much fun." So, then comes through the mail a picture of the whole cast and they said, "You're great David." And they all signed their names. Neal Baer made me respect my industry more. I mean it was a top show. They could [have told me] "screw you" [but they didn't].

HP: I'm curious. You said it was a make good story. Tell me a little bit. What happened in this episode?

DW: Well, they truthfully represented something that happened between [hospital staff] and David. They didn't talk with me about it. I didn't want [them] to. I'm a writer. If I were to participate they would have to have a contract with me and pay me for some of the writing. It was strictly what happened, not stigmatizing David. He's an adult. He was much smarter than me when he was in college. He has gone through a severe illness and he knows every bit of it. If they treated him decently he would tell them his truth. His truth might not be my truth, but it didn't matter. If they represented it decently I would be satisfied.

It was on a number of weeks later and we recorded it and we sent them a little thank you note. Thanks, I mean it was there [sincere]. [Because in the episode that prompted us to speak up] there was a lack of dignity and respect for another human being. The [person playing the] psychiatrist [on the show] explained it to me. The psychiatrist was losing it: he himself was becoming ill or he wouldn't have spoken like that. But you know, we have long since gone way past that with things like *House*. I mean you've got all kinds of craziness being acted out — true, false, or just good dramatics, and perhaps with an effective actor. Whether it has any bearing on what is the true mental problem or physical problem. I don't know and I can't sit in judgment of it.

HP: OK, and how about some of the other work you have done regarding stigma and the way that individuals with mental illness are treated?

DW: I came up with the concept for what has become the MET Team and the SMART Team in LA. [the MET team is the Sheriff Department's Mental Health Evaluation Team, the SMART team is the Special Mobile Ambulatory Response Team – both programs help law enforcement deal appropriately with individuals with mental illness] Mark Ragins [psychiatrist at The Village in Long Beach] was one of the people along with me and a few other that developed the training for the MET Team. I found one, one person in the state assembly willing to carry a bill for a compassionate response team. It was a notion that I came up with. Compassionate Response Team called for an unarmed police officer — and either a nurse or a social worker — to be called when there was suspicion that a person acting out in public or in the community might be a mentally ill person. So [the idea was to have medically trained staff show up], instead of having a

law enforcement person, armed, showing up at the scene doing what you do when you have a suspect—which is draw your weapon and be loud, overpower them.

When I was looking for somebody to carry this Compassionate Response Team, the only person I could get was an ex-naval officer who was a right wing Republican. And I knew we'd be in trouble because the Democrats held the committee numbers. We could go down with nothing [being passed], especially if the legislators behaved like they behave in Congress now. But she was willing to carry it. And sure enough it died in the first committee and I thought, "Oh well, it was a good idea because you don't scream at people and point guns as if they were criminal suspects when they are in crisis in the community because they will react." David has reacted, like when he bit me.

Then I got a phone call [from the Sheriff's Office]. And I thought "oh boy." I mean I drive a fancy big Lexus now, but the car that I loved that I've held onto is that Beamer outside — that old shark model, the '89-635 CSI — because it flies. So I get a phone call and the voice on the other end is very formal. "Mr. Weisburd, this is Sergeant Perrou [Barry Perrou] of the Sheriff's Department." And I thought, "Oh boy. I've been spotted speeding again because that car will go a hundred and thirty miles an hour at a blink of an eye." And so I said, "Yes sir." And he said, "Did you have anything to do with [the Compassionate Response Team] bill?" And I said, "Yes, sir, I wrote it." And he said, "Well we're doing it and it works and the sheriff wants to meet with you." So, that was the beginning of the Mental Evaluation Team. I came in there and we staffed for training on it.

I got very deeply immersed because David had been arrested, at various times, and judges had sentenced him, and I had paid the fine. And here was the sheriff wanting to do this Mental Evaluation Team. How do we train them? One of the things I did was tell them that "you had better get used to knowing what life is like for a person with a serious mental illness, dependent on the bottom protective net," which is the kind of service the County Mental Health gives you. They don't give you medical care. They don't give you dental care. They don't have what The Village has in it. You don't go to the Department of Mental Health and get what we've got in the ISA. You don't. It just doesn't exist. And that is not their fault. They are going to be staffed to do what it is they do, and they do a lot of what they do very well.

So my point is that I wanted them to spend twenty-four hours in scruffy clothes in a locked facility. And I didn't want them to know that this was going to happen. They would stand in medication lines and they would be given some pills, but they were sugar pills. They were placebos. But at some time during each of their days the football players on the staff there [the burly psychiatric technicians] would take them against their will to a "Quiet Room," and put them in four point restraints, which means slamming them down on that mat and shackling them and then leaving them for twenty minutes — no more, no less — to feel the horror of what it feels like when you can't move, when you have to pee in your pants. So the men and women who were trained to be on that team said it was the worst experience they ever had. "This was the best training we've had about anything" [they said]. You know a woman said "this felt worse than a rape. This was — my God — you know some of these people aren't so crazy. They are very nice. Why are they subjected to..." It was opening the eyes of what it is like to be a person in there against their will. And it's worked out very well.

# VI. On How To Improve The Lives of Individuals With Mental Illness; The State of the Mental Health System Today; Concluding Thoughts

HP: So looking back on the experience that David and your family has had, what would you say still needs to be done to help improve the lives of individuals with mental illness?

DW: Well, the knowledge base hasn't changed that much. The jingoistic stuff continues to go on. In the "Decade of the Brain" — the '90s — there were supposed to be a lot of breakthroughs. [The Decade of the Brain was an initiative by President George H.W. Bush to support brain research and enhance public awareness] Well, the same answer that Herb Pardes gave us [that we know very little about the brain] is the answer I can get today from very reputable psychiatrists.

We're learning, but we're learning the mechanics of the brain only up to the point where you say you have SSRIs [Selective Serotonin Reuptake Inhibitors — a type of medication for mental illness], and you're trying to go into the serotonin [system] and block the reuptake. [But] the brain is smarter than the people who are making chemical invasions of the brain. So the brain makes too much suddenly rather than accepting a block. You know no one has ever been cured of their serious mental illness of schizophrenia. There are rare remissions but it wasn't because Clozaril [a medication for schizophrenia] did it or whatever else. Symptoms are suppressed somewhat.

[It would be good if] people can begin to get a little bit of self pride and feel they are a little bit capable. I mean David does some cultivating. [One time], David snuck in to an a cappella course at UCLA, took the bus, came home. But they kicked him out of a cappella. He was doing nobody any harm, but he wasn't registered. He just went there and he was very social. Nobody filed any complaints about him. And I got a call from UCLA saying "Well, he told us your phone number and we want you to know it is nothing against him. He has a nice voice, he can read music better than most, and he behaved himself." See, *that's* what they should be doing for people like David.

KM: These kinds of activities?

DW: Yes, an integrated life, you know. He was able to go to UCLA. UCLA was nothing compared to the New England Conservatory of Music, but he felt safe and he felt a sense of belonging. And somehow if people with mental illness are allowed to feel that in this society, they would become less dependent and dragged down beings. You know, they don't need to beg, they don't need to be on a Skid Row. But they are excluded silently. It is like a gentleman's agreement.

The good people who are trying — whether they are in the L.A. County Department of Mental Health or an independent contractor or something — the majority of them are trying to use their skills to work with a very difficult population. The problem is that the concept of what these people need may not be the concept of what you are able to give them or what they want. It's a rounded life [that they want]. It's a real life. Sure, David will never have a child. But there is more to life than having a child, and a night of enjoyment in a theater somewhere or listening to a concert, are available. There isn't one of those places in the community if approached intelligently by — I mean Van Horn's son-in-law is in charge of education at a music center. He could do that easily — he'd probably want to do it! They could make available to people with mental illness, some

back row seats, and have an usher quiet them if any of them act out. But the odds are they won't. I mean David might bring sheet music so he could follow the score. But it would be a risk to invite them. They'd have to have some courage to.

So anyway, David cultivates certain areas and he's very proud of what he's done and how those flowers are blooming. It's just a question of what are human satisfiers? When his sister had her first born — who is now twenty and a junior at UCLA — we went to visit David at Metropolitan State Hospital. We took him out to lunch at Baker's Square because he liked the pie there. And Beth said, "David, would you like to hold Diana?" [Diana is Beth's daughter] Now this is a four month old baby and David could drop her. That went through my grandpa heart, thinking "Oh no." And David said, "Oh, I would like that." And David so gently took Diana in his arms and held her. And he turned to his mother — and if I cry it's not fake — he said, "I'll never have a child will I Mom?" And he handed Diana back to Beth. So, David knows his circumstance. He knows it all too well.

HP: So I guess one final question before I wrap up, just looking back. Let's say someone today was in the situation you were in when David got sick. Their son got sick when he was away at Harvard. How would things be different for them versus what it was like for you back then?

DW: Not a hell of a lot.

HP: Really?

DW: Yeah, I honestly think we have a few better drugs that are available that aren't as damaging, but essentially we have an industry of medication that is trying to sell their product off label to more people than to address what's on label [what the drugs were originally designed to treat]. The business wants numbers. And so there is random use [prescription of psychotropic drugs] especially with the younger and younger population. It is terribly dangerous, but certainly profitable.

HP: How about the non-medication side? What about the services people get?

DW: I don't think the services are organized to deal with individuals. And "treatment en masse" [treating large groups of individuals together] doesn't work. Their needs aren't met by "one size fits all" therapy.

HP: Is that still happening?

DW: Still. The Village model still makes sense to me but things need fine tuning with every individual. It's got to be respect for the individual. They are still leaning too heavily on medicating people. The dignity of an individual has to be respected a lot more than it is. Services that are available are often very underpaid, good people duck complicated diagnoses, and you are expected as a professional to produce dramatic results that take time. There are no quick fixes. And the politicians especially want quick fixes for less money. And that's a fantasy!

#### **END OF INTERVIEW**