**Barbara Demming Lurie talks about the development of minors' rights…**

One of the things that I was working on quite heavily was in the area of minors being hospitalized. We'd found that even though the law gave certain due process and other legal rights to people held involuntarily, teenagers could be put in the hospital by their parents and didn't really enjoy any rights in that regard. There was no due process. Sometimes, treatment was appropriate and sometimes, the kid was identified as a target, even though the whole family was dysfunctional. Or sometimes, the mother remarried and the kid didn't get along with the stepfather and the parents would send the kid away so as not to jeopardize the marriage. Or the parents couldn't abide by kids into sex, drugs, and rock and roll. Or the kid just had a big mouth, or for whatever reason [they decided], "Let's send Johnny to the psychiatric hospital."

And at the time, some psychiatric hospitals were really trying to woo and seduce parents to do just that. I mean, there were a lot of advertisements – "Is Johnny running around with the wrong crowd? Is he doing poorly in school? Send him to our psychiatric hospital. We'll shape him up for you." So, I tried writing some legislation, and I got legislative sponsorship. But now we had a couple powerful groups opposing – the hospitals, of course, doctors associations, and to some extent, the parents, who didn't want their authority usurped in any way. We weren't successful in getting those bills through, even though we could march out these little horror stories.

Anyway, the hospital, in response, decided, "Well, these bills are coming close to passing. Why don't we write a bill that seems to address the problem but is more congruent to what we want, one that will placate everybody." So, they authored a bill that essentially says, "Okay, the kid has a right to a hearing, but the hearing is going to be in front of a psychiatrist appointed by the hospital." Well, it's one of these things that has the window trapping of due process without really having much. But that law required that the minors had to be represented by a patients' rights advocate. So, after that bill was passed, we got involved with representing the kids at these hearings, called Roger S. hearings, after the legal decision that generated minors' rights in this area.

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**INTERVIEWEE**: Barbara Demming Lurie

**INTERVIEWER**: Troy Gabrielson

**DATE**: June 21, 2010

## I. Childhood; Education; DMH Research & Evaluation Division; Early Work in Patients' Rights; Doe vs. Galinot & 14-day Holds; Legislation; Roger S. Hearings; Riese Hearings

TG: Okay, today is June 21, 2010. This is Troy Gabrielson, and I'm here with Barbara Demming Lurie in her home. So, to start, can you tell me a little bit about your family and where you grew up and went to school?

BDL: That's a surprise question. I was born in Minneapolis, and I spent the first eight years there, until my father died. And then my mother plucked our whole family up and moved to Florida, where she knew not one soul, but wanted the warm weather. And there, she met her second husband, who happened to be from Cleveland. So, the family was then plucked up again and moved to Cleveland, where I went to junior high and high school. I have one sister. And my parents aren't around anymore. Anything else? I don't know what else you want to know.

TG: Sure. Do you want to tell me a little bit about your college experience and what you were interested in?

BDL: My mother gave me the choice of going to Ohio State or going to Ohio State. So, I chose Ohio State (TG laughs), and I went there. I majored in psychology. Then for grad school I got a scholarship to—to my regret, I turned down a few other scholarships at other schools – but I picked the University of Wisconsin because I thought they had a very good psychology program. I don't know if I was correct on that assumption.

So, I was in their Ph.D. program there. I left before I got my Ph.D. I do have a Master's degree in psychology from that school.

TG: What did you have in mind professionally as you were doing it? Did you have a field that you were interested in?

BDL: Well, it was one of these things that, when I look back, I think, what was I thinking? Even though I wanted to be a career person, I did not give much time or attention to, what I wanted to do as a career. And I [thought], well, psychology's interesting, so I'll just go along with that. I found out, in seeing clients, that my personality was not well-suited for sitting back, passively listening and beard-stroking. In fact, I didn't even have a beard. It wasn't a proclivity I had to be a therapist. The research part of it interested me more, and the legislative part of it interested me more, so that ended up [being] what I went into.

TG: And then you moved to L.A. at some point.

BDL: Yes, I did. In 1973, we moved to L.A.

TG: And you started working for DMH.

BDL: Yeah. So, I kind of cast around looking for jobs. I did well in college and graduate school. I thought the world was going to beat a path to my door. Little did I know the realities of life. But I interviewed for a job with the Mental Health Department. I figured, well, I'll take this until my real job comes along. So, I took it, and then all of a sudden, 24 years go by and I'm still with the Mental Health Department.

TG: And you were doing program evaluations at the beginning, is that right?

BDL: Yeah. I was hired by Sol Rochelle and Roger Rice to be in the Research and Evaluation Division. We were there to evaluate clinics and programs, write reviews, do some research about our findings. And then—well, I don't know if you want me to go through the whole chronology.

TG: Yeah, if you'd like to start, yeah.

BDL: Well in 1977, regulations were written in response to the fact that without any kind of enforcement mechanism, the rights that mental health clients were statutorily given were just paper rights. The regulations ensured that there were some means of overseeing and enforcing these rights. A new position of "patients rights advocate" was created and Dr. Roger Shock took responsibility for that role. He tapped me to head up this nascent advocacy program, and that's when it all started.

TG: Yeah. So, at that point when he said, "Okay, come on board and do patients' rights," what did you see as the state of—I mean, I know you said they were paper rights and that was about it—what else did you see going on in terms of patients' rights or the sort of marked lack thereof?

BDL: Well, one of the reasons that Roger appointed me was that when I was in Research and Evaluation, I did a little study about 72-hour [involuntary, psychiatric] holds. And I was finding that people were remaining, like, six and seven days in some of these hospitals on 72-hour holds, and I'm thinking, wait, what's wrong with that math? Either their reports are in error or people are being held illegally. And so, we launched into an investigation of that, and we found people were, in fact, being held illegally in some cases. I mean, hospitals were not paying sufficient attention to the legal standards of how long patients could be legally held.

And so, it kind of got me interested in this whole area. So, when I started in patients' rights, I found that—and, in fact, 24 years later, (chuckling) I can still say the same thing – everybody subscribes to rights theoretically. They're equivalent to mother and apple pie. But the more you then translate them, or operationalize them, into activities and requirements, the less people like them, the less copacetic the rights are with everybody. So, it was a matter of acclimating hospitals to the idea that there were certain rules and regulations that they needed to follow or there would be some kind of repercussion. We tried to work with the hospitals, training the staff about the legal process and the rights and to monitoring their adherence to statues and regulations. The problem still was that repercussions were hard to come by. The only trigger that we could pull was to take away the hospital's LPS designation, which means that they could not take involuntary patients anymore. [LPS, the 1969 Lanterman-Petris-Short Act, stipulates the conditions under which a person or facility may place someone on an involuntary psychiatric hold.]

To be honest, the Department was loathe to ever do that, so the [hospitals] sensed that there was not real teeth behind these rules and regulations – just rubber ones – which was always frustrating for us. I've heard from my successors that things are better now under the present leadership.

[Before the LPS Act was passed, there were hazy, indefinite standards about who could be held involuntarily in mental institutions and for how long. The elastic criteria it used invited abuse, and there was a lot of it. The Act, in setting definite standards for commitment criteria and length, attempted to integrate three separate interests that don't often coincide and sometimes inevitably collide: treatment needs, public safety requirements and civil liberty imperatives. No constituent was totally please with this new law – but that's probably the hallmark of a good compromise. Some people think the pendulum has swung too far in the direction of patients' rights, but the clients themselves, of course, think it hasn't swung far enough.]

TG: Sure. And when you were appointed patients' rights advocate for the county, that was just after the statute passed that said, "There has to be a patients' rights advocate for each county," right? And so, it sounds like there was definitely an adjustment period for, not just the hospitals, but for this whole system in understanding that someone will be asserting these rights for clients.

BDL: Right. And I'll be honest with you, imbedding the patients' rights job in the mental health department itself was, and still remains, to some extent, problematic because a certain kind of independence is needed.

TG: Right.

BDL: Otherwise, you are literally—not literally, but quite figuratively, biting the hand that feeds you sometimes.

TG: Sure.

BDL: And it puts you, as a patients' rights advocate, sometimes in an untenable situation where you have conflict of interest. In fact, I reported to one person who really ascribed to the medical model and basically didn't care for patients' rights at all – and that's my boss. And I once told him that reporting to him was like the NAACP [National Association for the Advancement of Colored People] reporting to Governor Wallace. [George Wallace, 1919-1998, was first elected governor of Alabama in 1962 on a platform of racial segregation. Wallace had been supported by the NAACP during his unsuccessful, 1958 run for governor, before he endorsed segregation.]

TG: I understand what you're saying, yeah. And I remember seeing in one of the patients' rights handbooks—I mean, the one I've seen is from 1986, I think, but it says at the beginning, "You have the right to an advocate who [has no direct or indirect clinical or administrative responsibility for your mental health treatment]." So, I could see that as someone within DMH, you're very close to the treatment end of it.

BDL: Right, right, although in the last ten years that I was there, there was another law passed – it was a federal law that established the Protection and Advocacy Organization, which was an external rights protection organization that was intended to counterbalance the quote/unquote "internal advocacy system." The thing is that in some counties, the more the advocate played along with the Mental Health Department, the better they were accepted by the Mental Health Department. In mine, I was quite, I think, vigorous in doing advocacy, or at least I tried to be. And that was sometimes problematic for me.

TG: Right.

BDL: In most other jobs, the better that you do, the more accolades you garner, the better you're received. Here, the better I did at my job, often, (chuckling) the more hostility I would generate. But anyway, that was the life of an advocate.

TG: Sure. And it sounds like if you were less fierce on the advocacy front and you were sort of more warmly welcomed into the department, then the position would lose some of its meaning, some of what it was intended to be.

BDL: That's right, exactly. It would be compromised. And I really tried never to compromise that position.

TG: Yeah. So, you became head of this program.

BDL: Right. Well, I was the head of me for a while because when I first came, it was me. I mean, that was it.

TG: You were the advocate.

BDL: I was the advocate. And, I mean, I could barely log in all of the complaints. Our phone number – [the number of] the patients' rights office – was posted in every facility because the law required it. And patients were invited to call with their complaints. Well, I was inundated. I could barely log them in, let alone handle them, and it was getting to be silly. I mean, I was just paralyzed. And so, there was actually a lawsuit. It was a friendly lawsuit, at least to me. Art Torres, who was an assemblyman, and some other groups – including the ACLU [American Civil Liberties Union] – sued the department and said, "You have laws to enforce – patients' rights. You can't really do it with one person, not [in a place] the size of Los Angeles County, so you're going to have to hire more people." So, as quick as you could say "lawsuit," bam! It was settled out of court, and I got 13 bodies, which really helped for a while – until we got other responsibilities. I don't know if you want me to give you the whole chronology of how we grew?

TG: Yeah, do.

BDL: Well, we were rolling along there, and our major responsibility was to empower the clients, to resolve their complaints, and to try and keep the clinics responsible in terms of patients' rights regulations. So, when I got a staff, we also started actually making site visits to the hospitals, especially, to see if our rights sign was posted, and how they were doing in terms of seclusion and restraints, and patients rights compliance overall. We'd interview clients there, we'd examine charts' and we would look around to see if everything was kosher. And we would write evaluation reports and give them to the clinics. I keep on saying "clinics," but they were hospitals most of the time. And these on-site visits weren't really fashioned as "Gotcha!" kinds of reviews where we were there to be punitive. We were there to say, "Here are your deficiencies. This is what you need to work on. We'll be back again to see if you were able to improve."

And so, that went on for a while and we meantime handled all kinds of client complaints.

And we worked with Licensing. Licensing was a little tooth that we borrowed, as far as having some enforcement power, because they were interested in the facilities following all the rules and regulations too. So, if we had a real problem and we did need some enforcement capability, we had a very, very good working relationship with Licensing, and they could and did cite clinics and hospitals.

So, that went along until—well, 1983. It all started in a parking lot in Santa Monica, where this guy with the pseudonym John Doe left his car in the driveway of the parking lot. So, people couldn't get in and people couldn't get out, and people were getting very upset at Mr. Doe. And finally, the police were called, and this police officer, Gary Galinot, comes and ascertains that Mr. Doe is mentally unstable and decides to put him on [an involuntary] 72-hour hold and take him to the hospital, little realizing that in doing so, his name would later be infamous as the Doe vs. Galinot decision. But anyway, Mr. Doe later got out, and he went to Federal Court, maintaining that his confinement was unconstitutional because he did not have any automatic right to review. He argued, "Why is it that rapists and your murderers, who've done horrible things, get an automatic arraignment hearing to see if the system has enough reason to hold them, [whereas] I, who have committed no crime, don't get any kind of review? And that door is just as locked in the hospital as it is in jail."

So, this went all the way up the court system, and finally, the court system agreed with Mr. Doe, and ruled that person detained beyond 72 hours (after 72 hours, there's a 14-day period of detainment if the person still meets the legal commitment criteria) has a right to an automatic hearing within four days of the subsequent 14-day hold. And so, my staff was tasked with representing the patients at these hearings. The hearings were held before a person appointed by the court, not someone affiliated with the hospital. So, all of a sudden we had an influx of thousands of hearings, and I, again, had insufficient staff to do it. I was just recruiting loaned bodies until such time as I could hire full-time positions because when the law became effective we had to abide by it

But eventually, I got to hire more people to represent the patients at these hearings and we were running about 14,000 hearings a year. That's a lot of hearings. And since the hearings have to be at the hospital where the patient is being held, that's a lot of traveling around by my staff too. And because all the hearings had to be coordinated with the court – every day we'd have a schedule of maybe 75 to a hundred hearings, and coordinate them all with the court – it was really, at first, a logistical nightmare, but that got all, I think, smoothed over, and they eventually were running well.

Representing our clients entailed meeting ahead of time with them, going through their side of the story, examining their chart, and then putting on a case on their behalf. In order to be held, the finding had to be that they were dangerous to themselves or others or what's called "gravely disabled," which means they were unable to provide for their food, clothing or shelter. And there had to be one or more of those three things because of a mental disorder. If the hearing officer did not find that they met the criteria, they were released from involuntary commitment then and there. They could not be held further unless it was on a voluntary basis. In the majority of the cases, the referees concurred with the hospital. We kept tabs on the referees' decisions. Different referees had very different statistics; some were more confinement-leaning than others, for sure.

So, we were also doing site reviews. And the department tied our reviews to whether the hospitals' LPS designation should continue. That gives them the authority to hold people against their will. So, the hospital's ability to hold involuntary patients was contingent upon passing the reviews. We enforced the patients' rights, we conducted LPS reviews, we participated in the hearings, and we handled the myriad different complaints. We also got involved with different aspects of the department in terms of policies and procedures. People would run things by us to see if what they were doing was compatible with patients' rights, and they wanted our input, which was good.

Meantime, my position moved from—eventually from Roger Schock's office to the Medical Director. And from there it moved to the Director. So, I reported directly to the Director, which was meant to bypass at least some of the conflict of interest.

And so, life went on like that until—oh, I should also mention that I was also working on legislation a lot, and in fact, [on] the legislation that was passed in response to Galinot. Some sentences in the statutes are mine. In fact, one time I was at a hearing and the hearing officer was debating a point in the law with me and they cited a section I wrote. I said that I had a different interpretation and could speak to legislative intent, since I wrote it.

TG: Right, sure.

BDL: So, that was kind of fun because we would go fly to Sacramento and meet with legislators and sometimes testify. Roberti [David Roberti, former State Assemblymember and Senator] was very responsive, and Polanco [Richard Polanco, State Assemblymember 1986-1994, State Senator 1994-2002] was very helpful and got some of the bills that I helped author passed. By the time they got passed, though, I was lucky to have a few "and's" and "the's" left in the bill from its original form. Most bills ended up pretty eviscerated. But that was a very heady time.

I remember the first time – this is a digression – I went to Sacramento to work with a Senator to get a bill that I'd asked him to sponsor passed. You know, like Barbara goes to Washington, but in this case, Sacramento. My first time, and I'm all excited. I'm in the Capitol and I asked him, "What I should do?." He replies, "Well, the bill's being voted on at one o'clock. Go find Senator [name withheld] and tell him that I want him there for the vote. I need his vote." I said, "Okay." I said, "Do you happen to know his office number?" And he says, "Oh, no, no, no. He's going to be in a bar." (TG laughs) And he names, like, three or four bars surrounding the State Capitol and hands me a picture of the guy. And I spent the first couple hours in Sacramento going from bar to bar looking for this guy.

TG: That was your first legislative experience.

BDL: Yeah, my first legislative experience. But I never did find him. And then I kind of learned the whole deal – there's a whole art to negotiations up in Sacramento about working with the other side and getting amendments to your bill and support for it. For example, one time, the California Psychiatric Association opposed my bill, so I sat down with their lobbyist and asked if we can meet somewhere. And she said, "Well, you're going to have to take this and this and this out if we're going to support the bill." And though it virtually crippled my bill, I figured, well, it would be important to enlist their support, so I said, "Okay I'll do that." And she says, "Okay," and we agreed on it.

So, I take everything out she objected to, the amendments go through, and it gets to the hearing. But she stands up and says, “We oppose it.” And now my bill has been totally gutted, and her continued opposition was a total surprise to me. Later, I reminded her that she assured me if I took out what she objected to, her organization would support the bill. And she says, “Well, I went back to my membership and they didn’t go for it.” So here, I’m now stuck with these amendments and they still opposed. So, you kind of learn some lessons after getting kicked around in the legislative process.

But anyway, that was all kind of tangential to some of the other things that I did. I was working in a lot of different arenas, like confidentiality policy, seclusion and restraint policies, and so on. We also did a lot of training. I made about, oh, 75 to 85 presentations a year to various groups or hospitals, mostly explaining the law. And the department, at one point required their staff to attend an all-day training I conducted and then pass a subsequent multiple-choice test based on my lecture and their studying in order to be designated to initiate 72 hour holds. So, these presentations were mandatory for people wishing to be designated. And obviously they weren’t very excited to have to be there, but they suffered through my talks anyway.

One of the things that I was working on quite heavily was in the area of minors being hospitalized. We’d found that even though the law gave certain due process and other legal rights to people held involuntarily, teenagers could be put in the hospital by their parents and didn’t really enjoy any rights in that regard. There was no due process. Sometimes, treatment was appropriate and sometimes, the kid was identified as a target, even though the whole family was dysfunctional. Or sometimes, the mother remarried and the kid didn’t get along with the stepfather and the parents would send the kid away so as not to jeopardize the marriage.” Or, the parents couldn’t abide by kids into sex, drugs, and rock and roll. Or the kid just had a big mouth, or for whatever reason [they decided], “Let’s send Johnny to the psychiatric hospital.”

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So, our hearing load got expanded. We were becoming hearing-impaired. We were participating in involuntary hold hearings, we were participating in Roger S hearings. And then came another kind of hearing named Riese hearing, after Eleanor Riese, an involuntary patient at St. Mary’s Hospital in San Francisco. She told her doctor she was willing to take other medications but not Mellaril because she had very bad side effects with it. [Mellaril is an antipsychotic medication used to treatment symptoms of schizophrenia and bipolar disorder].” So, the doctor weighs that input very carefully and gives her Mellaril, which she is forced to take because in those days, involuntary detention equated with forced medication. And sure enough, Eleanor suffered some serious physical consequences that she attributed to the Mellaril. So, she turned around and sued, saying that the Lanterman-Petris-Short Act, LPS, presumes that a person, even a person involuntarily detained, is competent unless there’s adjudication otherwise. She argued that “Well, given the assumption that I’m competent, then why can’t I make decisions about my medication?”

And so, this went up the courts again, and the court ultimately upheld the ruling that even involuntary patients have a right to refuse medication, absent an emergency, if they have the capacity to make that decision. If it’s an emergency, the hospital can still forcibly medicate. Otherwise, if the hospital wants to medicate, there’s going to have to be a hearing wherein it is shown that that person cannot make an informed choice about the medication. The person can be very impaired in other areas, but the showing has to be that they can’t give a rational reason for their medication refusal. Capacity is narrowly defined. For example, if they can say, ”I’ve got three angels tap dancing on my shoulder, but I don’t want to take this medication because it makes me drowsy, my mouth dry, and it didn’t help me last time” – if they can say that, then chances are they would be found to have the right to refuse.

So, this spawned another series of hearings called the Riese hearings. So, my staff then represented patients at Riese hearings. So, we’d have now Roger S. hearings, the LPS involuntary detention hearings, and the Riese hearings. We continued to do the LPS on-site reviews at all the hospitals and we handled hundreds of complaints a month. And these complaints could involve anything from just giving the person some information to long, drawn-out investigations and negotiations. There were a few that come to mind. Since you’re allowing me to ramble, I’ll ramble.

I remember—well, first let me preface this by saying that [with] a 14-day hold, the hold itself has to be signed by two specified people, one of whom has to have personally evaluated the person and attested to the fact that they met the criteria. Well, one day I got a call from a Deep Throat who said he had a stack of pre-signed 14-day holds – pre-signed by two doctors – that the facility just kept on hand because the doctors didn’t want to have to come in to do the evaluations.

So, I arrange to meet this guy on some street corner in Westwood because he didn’t want to come to the office. This is all very deep throaty. So, I’m there, standing on the street corner, and he walks by and hands me the papers – very cloak and dagger – and there they all were, all the pre-signed holds.

I later convened a meeting with the hospital and invited Licensing in. At the meeting, I asked if they ever had occasion to pre-sign 14 day holds. By the way, the two doctors who signed the ones I had were there in the room. They, of course, replied that no, they never would do that. And I said, “You understand that would be illegal?” “Oh, yes,” they said. I then asked (TG laughs), “Well then, how do you suppose these came about?” “Are these your signatures?” “Well, yes.” And I said, “Well, how did they get there?” One of the doctors said he didn’t know. The way he put it, it was as if the signature just jumped out of his pen when he wasn’t looking (TG laughs). I did not go to the newspaper, but this all ended up on the *L.A. Times* front page, and heads rolled over it.

And then there was another Deep Throat. You know, some of this—it was very exciting sometimes.

TG: Yeah, it sounds like it.

BDL: I get a letter in the mail addressed to me, saying that at another hospital, a guy came in – in his thirties – very out of control on an involuntary hold. He was too out of control for the hospital to do any kind of physical exam. But the hospital gave him five different medications to calm him down, which may not have been the best approach because they didn't know what medications he was already on. They don't know anything about this guy other than he was brought in out of control. He's placed in restraints, and if a person's in restraints, they're supposed to be checked every 15 minutes –,by regulation. Well, the next morning somebody checks on the guy, and rigor mortis had already set in, indicating he'd been dead for awhile. Obviously, they weren't checking every 15 minutes, or they weren't checking well.

Nobody had investigated the case because the doctor signed the death certificate. The patient was in a hospital, the doctor signed it, and the coroner's happy when that happens, since they then don't have to do any kind of autopsy or investigation. So then I go to investigate, but by the time I got this letter, the guy had already been cremated, so we could not even figure out the cause of death. We'll never know. And so it turned out what the letter said was true, and the hospital was cited. Again, this made the newspaper, but it wasn't me who called them.

But this case culminated in me working with the coroner's office, getting them to agree that they wouldn't just sign off on somebody who died in restraints. A death in restraints would be cause for investigation automatically. The doctor couldn't just sign off on the death certificate. In this case, the doctor wrote that the guy died of cardiac arrest. Well, everybody dies of cardiac arrest. That means your heart stops. That's all it means. It means he died because he died.

Anyway, so that was another interesting case. I had a lot, a lot of interesting cases. You want to hear about more cases?

TG: Well, I was going to say it sounds like as the office grew – I mean, it started from [having] just the sole patient advocate to a much bigger staff with different kinds of hearings, getting involved in legislation and cases – it sounds like it became pretty prominent and powerful.

BDL: I like to think so. I mean, it sounds kind of self-congratulatory, but I think it became somewhat prominent. Yeah, it grew, certainly.

I'm trying to think of some other interesting cases. One gratifying case was when these people called me and they asked if I could find their mother who had schizophrenia. The caller, apparently, was very successful, lived in West Virginia, and hadn't talked to or seen his mother in 10 years, and he wanted to find her. He told me, "She's somewhere in the mental health system in Los Angeles." It took me two seconds to find her because she was in the system. But I could not give them that information.

So, I called the mom, and I said, "You know, your son is looking for you, and he really wants to speak to you. Would you mind if I gave him your contact? Would that be okay?" And she said, "Oh, all right, you can do it." So, I called them back with the information, and then the next day, they called me and they were so appreciative they got to talk to their mother for the first time. They sent me flowers, and they were just beyond grateful. But then when I talked to the mom again, she said, "I thought it was something important." (laughing) "You said that they needed to talk to me, and they didn't have anything important to say." So, she wasn't that thrilled with the whole thing. But the family was very thrilled.

Anyway, there were just a million stories. It was a very colorful job. There was just always something going on that was interesting. And we also saw a lot of celebrities, which I can't ever mention. I always admonished my staff that there could be no gossiping at all, even among ourselves, because we needed to respect the clients' confidentiality rights.

So, go ahead, ask me some more questions.

TG: So, I'm curious – as the program grew, and as we're talking about [its becoming] more prominent and really involved, do you have a sense of how the way people received the program changed? I mean, I know you're working in a lot of different contexts. But, for instance, in the courts, you said you could tell that some judges were inclined to decide in a certain direction. As time passed, and it sounds like the office got sort of more and more credibility and more experience, [do you have a sense of] how the way it was received changed; or how the idea of patients' rights was received changed? Does that make sense?

BDL: Well, I have seen mental health providers really embrace patients' rights. They sometimes would call and tell me about different infractions or different problems. But there was still resistance in many quarters. I think that patients' rights, at least at the very worst, was viewed like death and taxes by some. I mean, patients' rights were seen as something that you're just going to have to deal with; it's inevitable. And you're just going to have to play the game.

TG: This is on the part of providers?

BDL: On the part of providers, yeah. Again, some of them were more accepting, and some of them were just, "Well, all right. It's something I have to do. You know, I have to go through this audit. I have to pay my taxes. Okay. Let's do it."

TG: Right.

BDL: And now you see—there's a whole, what's called the recovery movement.

TG: Sure.

BDL: I think there was a greater appreciation that you're going to get a lot farther doing something *with* the clients than you are doing something *to* the clients. And it's very important to enlist their cooperation whenever you can, as much as you can, and to try and meet them where they're at. And to try and enlist their motivation by finding out what *they* want, and if it's at all reasonable, to try and work around their goals. So, the patients' rights movement was part of this whole recognition of the autonomy of clients. And I think that's now come to greater fruition, so to say. I don't know if that answers your question.

TG: It does, yeah. And I'm glad you mentioned recovery because I actually wanted to ask you – I mean, you started working in this right around the time that Judi Chamberlain's book [*On Our Own: Patient-Controlled Alternatives to the Mental Health System*, 1978, a seminal book in the recovery movement] came out and as the recovery movement really started gaining momentum – '70's and '80's – and I wonder, if you can say, how you saw that impacting this arena you were working in and also if it had any kind of influence on the work that you were doing.

BDL: Well, again, as I mentioned, I think there was starting to be growing appreciation of—

TG: Yeah, I see.

BDL: —autonomy and enlisting clients' cooperation in their treatment and trying to hone their self-management skills, because I think providers saw that they could do what they wanted to do in the 72 hours or 14 days of involuntary treatment, but eventually, that person's going to leave. And unless that person has been convinced that something is right or given the skills to cope or the motivation to do something, things are going to be right back, probably, to where they were before.

TG: Sure.

BDL: So, I think I saw a softening of the Doctor Knows Best mode. But I think much of the recovery movement got traction after I left. I don't think there's a cause and effect there (TG and BDL laugh). But, I mean, in the last, maybe, decade or so, it's been a more vigorous movement than it was in the '80's or '90's.

TG: Uh-huh. I mean, it sounds like at the time that you were there and just in the immediate aftermath of the implementation of LPS, you were really kind of at the vanguard of this kind of thinking and this small, nascent movement.

BDL: Uh-huh, yeah.

TG: At least as a way of thinking about—movement or just a way, like you're saying, of just thinking about patients' rights and autonomy and all of that.

BDL: No, it's true. It's true. So, I'm glad to have been a part, whatever part I played in that movement.

TG: Yeah. And so, that was 24 or 26 years that you were there, correct?

BDL: Let's see. Seventy-four to—well, my official retirement was '98, so 24 years.

## II. Entertainment Industry Council; *The Soloist* & *A Beautiful Mind*; On Stigma & Media

TG: Yeah. And so you left DMH, and where did you go from there?

BDL: Well, my odyssey reminds me of the story of Oedipus, where he tried to escape his fate, but in doing so, he just sealed it (TG laughs). What I did was I figured, okay, 24 years of mental health – actually, it's been more because I was in mental health before that – it's enough. I'd like to just turn the page and explore other areas. So, I got a job heading the research and evaluation program for the Entertainment Industry Council. What I was working mostly on was violence in the media, especially gun violence. And that was kind of fun because I was housed at Disney Studios and I was working with different TV shows and movies.

But then the Surgeon General of the United States at the time – David Satcher – asked the organization I was working with, the Entertainment Industry Council, if they would put on training for the entertainment community around mental health and stigma. By the way, stigma was an area I got into, as well. But anyway, I was the logical one for them to approach to do this. So, I became involved in mental health, then, with the entertainment industry. And that kind of became my little niche there, so I thought, (chuckling) God, I can't escape it.

TG: I'm glad to see you still have both of your eyes, though.

BDL: Both of my eyes?

TG: Unlike Oedipus.

BDL: Oh, unlike Oedipus, right. A funny story, as an aside, was when the Surgeon General was coming to L.A.—the Surgeon General's people wanted to be at this big conference we were putting on with the entertainment industry. His staff kind of micromanaged – what color the flyers were going to be on and what side of the packet things were going to be on and so on. But anyway they wanted a clip shown of the Josh character on *The West Wing* getting therapy. Just about every day they'd call and ask if I'd gotten it. So, I call The *West Wing* and they'd say yes, they would send it,. But they didn't send it. And so days would go by and they'd call again from Washington – "Did you get the clip?" "No." Then I'd call *The West Wing*: and they'd again promise to send it. But anyway, this went on and on until the Surgeon General was coming in. The day there were coming, I had to pick them up from the airport, and all of a sudden, that very day, the doorbell rings, and there's a messenger at my house with the video tape. I watched a few minutes to make sure it was right, and there's this guy getting therapy, and so I thought, "Great, I finally got it." It was fifteen minutes before I'm supposed to go to the airport.

So, I go to the airport to pick them up, and who should be standing there but Bradley Whitford, the actor who plays Josh on *The West Wing*, who I just saw fifteen minutes ago on the video. I wouldn't have even recognized the guy, but I *just* saw him.

TG: Right.

BDL: And I said, "You know, I'm here to pick up the Surgeon General. (TG laughs) And his staff really wants you. They've been telling me about your role in *The West Wing*. Would you mind coming to greet them?" And I guess he's a real hard-nosed Democrat, because he said—it was at the time we were just transitioning between Clinton and Bush—he said, "Which Surgeon General? Who appointed him?" And I said, "Clinton." So, he said, "Okay, I'll go, I'll go." So, the guys get off the plane, and we're both standing there, and I greeted them by saying, "So you wanted Josh from '*The West Wing?* (TG laughs) Here, here's Josh from *The West Wing*." And their mouths drop open, and they were grinning, and they thought, boy, I could move heaven and earth.

TG: Yeah, right.

BDL: But of all the coincidences in the world.

TG: That's great.

BDL: So, I did that for a couple years. It was fun. I had a good time. Then Wallis Annenberg, who funds a lot of charitable organizations and has given lots of bucks to the Annenberg School for Communications at USC [University of Southern California], gave a grant to them and to the Annenberg School at the University of Pennsylvania to work on mental health issues with the media. And so, I was asked by them to head it.

So, I kind of reluctantly left my job with the Entertainment Industry Council. I mean, I really did like my job at the EIC, but this was a good opportunity, and I was heading my own program. We called it the Mental Health Media Partnership, and I was essentially doing the same thing, only under different rubric. I would work with different TV shows and films when they needed some guidance. [When] they had a character with a mental health problem, they would contact me.

For example, the TV show *Cold Case* actually had a love interest for one of their central characters who was schizophrenic. And the writers didn't know how to write schizophrenic. So, I actually got some people with schizophrenia to meet with them and be interviewed. Same with *Without a Trace*. I got Rod Shaner [Medical Director of LAC-DMH] to come and meet the writers and executive producer, along with a couple of people who had schizophrenia, because they were doing an episode on that. I knew a bunch of experts that I could call on depending on what the producers and writers wanted.

A major network, for example, was going to put on another show about somebody with Asperger's, and they had a whole bunch of questions. And I said, "Well, I'll get you an expert on Asperger's." In that case, they said, "No," they didn't want to vet the script with anybody in the community. They kind of trusted me. So, they just wanted me. So, I had to bone up on Asperger's, which I wasn't that familiar with, to give them advice.

And I went on sets a lot, and I dealt with a lot of celebrities. And I put on different kinds of [trainings] and programs for the Writer's Guild. For one, we got Art Buchwald [a well-known writer and humorist]. Remember him?

TG: Sure.

BDL: And William Styron, the author, to speak about their coping with depression in their lifetime.

And we had about 450 people, and we held it at the Writer's Guild auditorium. And when movies had a mental health theme, I would partner with them to have premiers and debuts of the film – like *Sylvia.* I invited people from the Mental Health Department and the entertainment community. S*ylvia* was about [writer] Sylvia Platt, who had bipolar disorder.

I compiled some clips of TV and film depictions that treat mental health problems in a non-stigmatizing way. I would show them in presentations. I wrote an article in the Writer's Guild magazine about mental health portrayals. I fashioned my job not as a censor at all – because if you do that, they'll head for the hills – but rather as somebody that they could trust, somebody that's willing to work with them, somebody that wouldn't be judgmental or point fingers or say, "No, you have to do it this way or that way." You can make more inroads that way, I think.

And so, I did that for a couple years. The job was part of a two-year grant, which I did not know when I was hired. They told me it was a four-year grant when they hired me. The day *after* they hired me, the dean called me in and said, "I am so, so sorry. I am so sorry, but it's just two years. I just found out."

So, it lasted two years. But then I landed on my feet again. My life has kind of become a little cork bobbing in the water – I just kind of go wherever the stream takes me. Somebody taps me on the shoulder and says, "Can you do this?" And I say, "Okay, I'll do it."

So, just then, somebody tapped me on the shoulder, and it was Mary Rainwater, who said she's starting this project for the California Endowment [a private organization that advocates and funds health projects], and wanted me to help her with it. So, I said, "Okay". The project became the IBHP – the Integrated Behavioral Health Project.

TG: Yeah, I think I'm going to interrupt you quickly right there. There are a few more things I want to ask you about the work with the entertainment, and so I'll ask you those—

BDL: Go ahead.

TG: —and we can go more into the IBHP. I wanted to ask you specifically about the movies *A Beautiful Mind* [released in 2001, directed by Ron Howard] and *The Soloist* [released in 2009, directed by Joe Wright], if you've seen them.

BDL: Yeah, both.

TG: Okay. And I ask you about those because a lot of people we've talked to have mentioned those specifically, probably because they're two very prominent, recent portrayals of mental illness in film. And I've heard people say different things about them – whether they worked or not and how accurate or not they were – and I'm curious what you thought of them given the work that you've done, and just as someone familiar with mental illness.

BDL: Well, I mean, *A Beautiful Mind* took a lot of liberties with the truth.

TG: Sure.

BDL: But then, Ron Howard didn't claim to actually be making a documentary, a really accurate film. And what I think people liked about that film was that, not withstanding the fact that the protagonist had schizophrenia, he still managed to win a Nobel Prize.

TG: Right, yeah.

BDL: And he still managed to function so well in his area and to cope and to triumph. So, it was an uplifting message for many, even though some people in mental health circles said, "Well, they gave too much credit to the medication when, in fact, he wasn't on it at the time." All this stuff about, again, what really happened. You know, I saw Ron Howard before the film came out—I just ran into him. He was an exceptionally nice guy, and said that he hoped that his film would be embraced by the mental health community because, though he didn't fashion it as something to de-stigmatize mental illness, he was hoping that that would be the effect. And, in fact, I think, to some extent, it was.

I had the film's screenwriter, Akiva Goldsman, speak at a Writers Guild Conference about the film. I remember him saying that we have a tendency to look at those with mental illness as others, as outside ourselves, and they're not. They are us. And the day we forget that is the day we cease to be compassionate.

With *The Soloist*, I went to a private screening before it was out. I arranged to have the head of NBC Standards and Dick Van Horn [former director of Mental Health America of Los Angeles and a prominent mental health advocate] also attend the screening. Again, it hopefully raised people's awareness that under the disheveled clothing and appearance of these people on the street lies real character, real talent, real intelligence. Despite what problems they may be coping with, they're people too. On the other hand, some of the depictions, I thought, of Lamp [Community, a homeless service center in downtown Los Angeles] and Skid Row were akin to bedlam. I think they were a little bit overdrawn. But all in all, it was a decent film.

TG: I've heard the comment made that a scene – I actually still haven't seen *The Soloist* – but a scene where, I guess, Nathaniel Ayers, in the film—I'm not sure if he gets violent, but he at least gets sort of aggressive towards Steve Lopez.

BDL: Yeah, that's true.

TG: Did that actually happen?

BDL: Yes, it did in the film.

TG: Because the criticism that I heard was that they had—the idea is that they had to include it, otherwise people wouldn't believe it [the depiction of schizophrenia in the film].

BDL: It's funny that you mention that because immediately afterwards, I was—I didn't mention it, but I was kind of upset that they had to include that. But they're looking for drama.

TG: Right.

BDL: And the thinking is that it can't be all peace and love and [still] be dramatic. That's why I worry sometimes with the depictions of people with mental illness on the screen, that the drama's going to be them getting into some kind of trouble. In my Writers Guild article, I likened the traditional depiction of mental illness to the proverbial gun on the mantel; if it's shown in the first act, it's bound to go off by the third act and probably kill someone. Although, I have to say that there's been at least eight different shows that I've been involved with where the person with the mental disorder was erroneously thought of as the perpetrator. Throughout the film, you think it's that person, and then it turns out either they were an innocent victim or just a bystander, or actually, in some cases, they played some kind of heroic role.

In the Writer's Guild article I wrote, I said that the gun-wielding, crazed killer, and the "crazy scientist," quote/unquote – are such clichés. Some shows have moved beyond this moth-balled depiction. And then I gave some of these as examples. And I deliberately took this approach because the writers sometimes don't care about stigmatization. Well, I can't say they don't care, but if you say, "Oh, this is stigmatizing and hurtful," they'll just run to their first amendments rights and tell you that they, can say what they want. But if you say, "Hey, this is hackneyed. This is clichéd already"—

TG: I see.

BDL: —that gets their attention. That's anathema to them.. So, I would say, "This crazed killer thing – that's just been so overdone." And that resonated with them. And so, I think a lot of these films – again, there's at least eight of them that I know of – took the cliché and then turned it on its head at the end.

TG: I wonder if you see film and TV moving more in one direction than another. For instance, two [that] I think of off the top of my head are *Shutter Island* and a movie called [*The*] *Crazies,* which I haven't seen, but I saw the preview and I cringed a little bit. There are more favorable depictions going on and then there are, obviously, others still out there.

BDL: Oh, yeah. I mean, you're not going to rule the world.

TG: Sure.

BDL: But one of the things that I do now with my job – I haven't even gotten to telling you about current projects, like the one with SAMHSA [Substance Abuse & Mental Health Services Administration] – but we recognize the entertainment industry's contribution to mental health understanding through positive depictions. We actually awards for favorable—I can't say "favorable," but at least empathetic and accurate portrayals on the screen.

So, that's one of the ways to encourage a positive focus of the media. I think that many producers and writers are more cognizant of the fact that they should not be offensive to different groups. They very much, I think, embrace the idea that say they shouldn't be offensive to certain minorities, like Blacks, or hell would be raised. But at the same time, they were using terms like "nut case" in their scripts. They wouldn't use the corresponding vernacular for Blacks, generally.

TG: Sure, sure.

BDL: But I think many of them now have an awareness that they need to be sensitive to all different kinds of groups, not just ethnicities. I can't say everybody does. But I think it's improved greatly since the '70's, '80's. I think the industry is more likely to depict people with mental disorders as having problems rather than causing them.

TG: Yeah, and it sounds like people you worked with were very receptive in a lot of ways.

BDL: Yes. Well, the ones that called me were very receptive (laughing).

TG: Sure.

BDL: And the ones that didn't call me were the ones I had to worry about.

TG: Sure.

BDL: But yeah, right.

TG: Since we're kind of talking about it and you also mentioned stigma, let's talk about it. Besides what we've been talking about right now, why do you think stigma persists? How do you see it persisting? What forces do you see behind it?

BDL: Well, one of the problems is you can have 20 shows that are empathetic and sensitive, and you can have one headline – "Mentally Ill Person Kills Three at Bus Stop" – and that one headline will overshadow the 20 shows in people's minds. Because it's fear, it's a kind of a guttural fear. And so, it's hard to eradicate because there are going to be people with mental disorder who do commit crimes, though most aren't violent at all. The pejorative linkage of mental illness and violence unfortunately, is what's played up in the media, and that's what resonates in people's minds. So, stigma is a very difficult thing to surmount.

I was involved in some stigma research with Patrick Corrigan, who is very prominent in this field. He's a professor. Do you know him?

TG: Yeah. I saw him present recently, actually.

BDL: He and I were authors on a paper on stigma. He was first author, of course. (TG chuckles) I was second. It was about how kids perceive other kids with a mental disorder. But in his research, he isolated three approaches to address stigma. One is the "What you're doing is bad and it's hurtful, and shame on you ", that kind of guilt-tripping thing. Second is education: "This is what somebody with a mental health problem does, is," so forth. And the third is just having someone with a mental health problem speak directly to groups. And he found that the third approach, for sure, is the most favorable. He found that the more like you that speaker was, the more you would embrace the message. The first approach – "You shouldn't be doing this" – actually almost had a rebound effect. It almost went the other way.

And so, when I worked with the federal government on PSA's [Public Service Announcements] that they were doing, I encouraged them to look at the research. And so, with my input and others', they changed the PSA's. I'm kind of fast-forwarding to fairly recently. So, I think what's needed is more people with mental health problems who look [and] act like their audience to go out [and speak]. The very best scenario is for them to be co-workers.

But I don't know that stigma can ever be completely eradicated, though hopefully it can be significantly decreased.

One of the other issues around stigma is that there's a school of thought that says we should make it on the same plane as diabetes – as an illness that should be accepted like any other illness.

TG: Right.

BDL: And so, they try and take that [tactic]. The problem is that the research doesn't really support that approach. It differentiates people with mental health problems from those who may not have them – "They have an illness. You don't. They're sick. You're well." It's distancing. The two basic underpinnings of stigma are people's fear that the person is going to be violent and the fear that they're unpredictable. Those are the two things that buttress stigma. If people are seen as having an illness, they're also seen as not being able to control their actions, so therefore, they could be perceived as potentially violent and unpredictable. So, the disease model is not the best approach to address stigma. It may elicit sympathy, but it's not going to elicit more acceptance – more wanting to work with these people, to be with them, and so forth.

The better approach is [saying], "A lot of us are on the same continuum. We're in just different places on the same continuum, and, but for the grace of God, we could be moving down that continuum. And some people just have more problems coping than other people." That's a more unifying approach. So, I don't care for the medical model because the research doesn't support it.

TG: So, you're talking about the medical model approach and people make the comparison to diabetes, trying to just have people conceptualize mental illness as just another illness. But in doing so, they kind of inadvertently shoot themselves in the foot by focusing on the illness as opposed to the ways in which the person is just the same as you.

BDL: Right.

TG: "You," a coworker or "You—"

BDL: And, I mean, people aren't the sum total of their problem, their mental disorder. And that's why to reduce stigma, it's better to say "people with mental health problems " rather than "the mentally ill. Consumers don't even like the word "illness" for the reasons I just mentioned. I'm sure Ron Schraiber, whom you spoke with [a mental health activist] made this point. This is part of his rap: You don't say "the cancerous." It's not like you're collectively that. It's not like it defines you. It's just one thing that you are living with. And that's what, I think, the public needs to realize, and that's why *The Soloist* was good in portraying, yes, this guy was seriously impaired, but yes, he had some amazing talents [Nathaniel Ayers, the man on whom the film is based, is a cellist and attended The Juilliard School], and he's not the sum total of his impairment. He's far more complicated and intricate than that.

TG: Right. It's like an argument I first heard about in an article on schizophrenia [whose author] didn't like the use of the term "schizophrenic" – for various reasons, but one of which was [that] in doing that, you're only thinking of the person as the schizophrenia.

BDL: As that [mental health] problem. Yeah, that's right.

TG: Defining the person—

BDL: as the problem.

TG: Yeah.

BDL: Right. So, that's why they like what's called *people-first language*. "People *with* whatever."

TG: Making the "whatever" – the illness, whatever it is – a part of the whole person, which is what you want to focus on.

BDL: Exactly.

## III. Integrated Behavioral Health Project; On Recovery; Accomplishments; Disappointments; Vision for California Mental Health Care

TG: Yeah. Let's move to IBHP.

BDL: Okay, so, simultaneously with me being tapped on the shoulder and asked to work with IBHP, I was also tapped on the shoulder by the federal government to work on mental health and stigma, and so I'm doing both simultaneously. I have both of those jobs. And I'll run by both of them.

TG: Okay.

BDL: So, IBHP, the Integrated Behavioral Health Project, was an offshoot of the California Endowment and the Tides Center, another funder of health programs, to try to accelerate the integration of mental and physical health in California. What was happening was that people had to go to one system for their mental health problems and another entirely different system for their physical health problems, and never the twain shall meet, especially in this county. And so, integration has just been trying to reattach the head with the body, trying to rediscover the neck. And the impetus for this was, among other things, the fact that the physical health community was realizing that a lot of physical problems are inherently interconnected with mental health problems, whether by cause or effect. A lot of people with diabetes and heart disease have depression. Sometimes people with mental health problems somaticize and their behavioral difficulty manifests itself in physical problems. There's an inexorable link between the two.

On the mental health side, there was a research paper that shook up the mental health community a few years back, saying people with serious mental disorders actually die 25 years earlier than the general population. And most of the time, they're dying of the same causes. They're just dying earlier. And many of these causes are, to some extent, preventable. So, that got physical health on the mental health side's radar screen.

Our edict, our marching orders, were to try and get the two conjoined together. Our first approach was to try to foster more vigorous mental health programs within primary care. And so, we gave out grants to different primary care clinics to do that. We did some research to tease out what, exactly, worked and what didn't and what correlated with positive outcomes.

This past year, we have been trying to bring the two systems together – trying to bring the county mental health system and the primary care system into some kind of alliance – either an interaction of operations or the embedding of primary care services within mental health or vise versa. Recently, I was asked by my old Mental Health Department to be a consultant and draft an RFP [Request for proposals] for them – what they call an RFS – for this arrangement, which they're going to be funding with Innovations money [the 2005 Mental Health Services Act, which funds and maintains mandates for mental health services in California, funds innovative mental health programs]. My draft wasn't the final one, but I worked on it with them and kind of advised them.

IBHP was a four-year project – again, a time-limited project. And it's now sun-setting because we've given out all of our money and we've done all of our mission. Whatever we had to do, we pretty much did it. IBHP also worked a lot on policy. I put together a little tool kit – it was called the Tool Kit for County Mental Health Primary Care Collaboration. And I built a web site, which is kind of like a library that compiles all the different information needed for integrated care. It's at IBHP.org. I work with Mary Rainwater, and we have a research branch, headed by Gary Best, and some other people. I don't know if you need to know their names. And Mandy Johnson. It's been fun since I've gotten to go all over the state to visit our different grantees to see how they were doing or to decide which should be candidates to receive grants. And we helped put on a national conference last year, and I get to go to other national conferences. It's been a lot of fun, very interesting.

What I'm doing with SAMHSA indirectly is working on what's called the Voice Awards, which is what I earlier alluded to. It's a program to give recognition to the entertainment industry for positive depictions of people with mental health problems. And I also work with the entertainment industry still. They still call me with questions about different shows or advice or whatever.

So, that's what I'm doing now.

TG: With the IBHP, I'm curious how you see that philosophy of care and that approach, in practice, working with a mental health system that, right now, is based so much around the MHSA [Mental Health Services Act]. I mean, you mentioned Innovation funds being one way to do that. I don't know if that's specific enough or if that's a little bit too broad.

BDL: Yeah, can you hone that down for me a little?

TG: Sure. Well, maybe a better question is how you see this kind of approach being implemented? I mean, it sounds like you're sort of doing pilot projects to see how it goes and to see how people respond to that.

BDL: Right.

TG: If it were implemented on a broader scale, how do you see that happening when, at the same time, there are all these stipulations and programs from the MHSA, some of which are about the whole person, but I don't hear much in there about primary care. They're mostly on behavioral health.

BDL: Well, it's kind of interesting that, as you probably know, MHSA has rolled out in different pots [of money].

TG: Right.

BDL: And there are actually a few counties that took their basic pot – the seriously mental ill pot, the first one – and gave some to primary care to work with their seriously mentally disordered population. For example, Shasta County is a Full Service Partner now [Full Service Partnerships are one type of program funded by the MHSA]. Alameda [County] got also got funds for their primary care clinic to do it. In San Diego, the Mental Health Department approached a consortium of primary care clinics and said, "Okay, we want primary care clinics to implement what's called the Impact Program for Depression and we want them to treat serious mental [illness], and we'll give you the money and you can oversee the clinics doing it."

That was the first pot. Some primary care clinics got, then, part of the second pot of funding, for Prevention and Early Intervention [also called PEI, another category of MHSA-funded programs] because primary care is on the front lines of both health and mental health care. Most of the people go to their primary care doctor if they have a mental health problem. They just generally don't run into the mental health clinic with it. And now, at least in Los Angeles, some of the primary care clinics may be getting Innovations funding.

So, it just depends where the county is in its evolution of developing integrated services. Some counties are light-years ahead of others in doing this. Some counties have been doing it for years, even before the Mental Health Services Act. To other counties, it's just a whole new, unknown concept. I don't know if that answers your question.

TG: It does, yeah. It does. How do physicians and how do people in primary care settings respond to this idea, because I know it's not a secret that clinicians, even those in mental health, are not without stigma. And so, I wonder how people respond to that idea.

BDL: Well, it's interesting. IBHP just had a meeting of the CEO's of our grantee primary care clinics to gauge how well they were accepting it. There are some who are accepting it very well as an opportunity to expand their client load and services. Plus, to be honest and to be very pragmatic, the seriously mentally ill population is a rich source of Medi-Cal reimbursement, whereas in primary care, many of the medical clients are uninsured.

But some clinics see the situation as being drafted as a fix for a broken mental health system. They think that "The mental health system doesn't have the resources to deal with the seriously mentally ill population, so they're going to shift it over to us. They're going to shift the problem without shifting the resources, and we're going to be left holding this bag. And we don't want to do this."

TG: [Being] given this mandate without the funding.

BDL: Right, yeah. And one particularly outspoken primary care director, who's kind of leading this parade, foresees that with the coming health reform [the 2010 Affordable Health Care Act], there's going to be lots more people on Medi-Cal, generating a lot more competition from other provider sources. These clinics that have treated the indigent will now be more in competition with private practice practitioners. He's afraid the private practitioners will be more, shall we say, palatable, that his clinics will be at a disadvantage if they have seriously mental ill people in their waiting rooms. He thinks it may be off-putting to people who he's trying to attract to his clinics. So, that's stigma in action.

TG: Sure.

BDL: But he's looking to the bottom line, here. So, again, some of the primary care clinics – it just depends – are saying, "We're fine about integrating and becoming client-centered health homes." But some are saying, "We don't want the broken mental health system foisted on us." Some primary care clinics are saying, "We're happy to treat the people who are having difficulty coping, who are having maybe a temporary mental health problem, and that's what we're equipped for. We can do that. But when you get into seriously mentally ill folks, we're not equipped, and we don't have the know-how." Primary care doctors don't have the support system needed. Moreover, they're saying that they would need the ability to get these people psychiatric beds when indicated and most don't have that ability right now.

Many of them are exasperated at their county mental health programs because they have people who need psychiatric hospitalization and can't get it. They can't even get mental health's attention. And so, in some counties, primary care has become the mental health system by default, even though they feel it is out of their purview and their expertise. So, there's been distrust on both sides.

On the other hand, some mental health programs are saying to primary care, "We're happy to have you come and take care of the physical needs of our mental health clients, if we can oversee the program." That's their comfort level.

With this new—I don't know if you're familiar with the 1115 waiver.

TG: I've heard it.

BDL: Well, it's to kind of revamp the Medi-Cal system here, in California. It has to be, I think, finalized in August. But they're talking about medical homes; having one-stop shopping; having all the various services in one facility. Well, some people have expressed concerns about that, as well. As I mentioned, some on the primary care side are saying, "Well we don't want to inherit these seriously mentally ill people that we can't really properly treat, and we're not going to get any help from mental health." And the mental health side is worried that if it's going to be one-stop shopping, it isn't going to be in a mental health clinic because it would be very difficult to move a complete primary care facility into mental health with all the equipment and all the space that's needed. So, they're worried they may be kind of colored out of this thing.

So, there's all these politics, all these nuances going on. And in some counties things haven't been copacetic between the two systems. And so, you've got that to overcome as well. On the other hand, there have been strong relationships forged between the two systems in other counties.

TG: Right. I wonder if one form it could take is something like – you're talking about the one-stop shop – an Integrated Service Agency, like the Village [a mental health and social service center run by Mental Health America] in Long Beach. I don't remember if they have primary care.

BDL: Well, when I talked to Dick [Van Horn]—oh, a couple years ago, he was going to initiate a contact with a primary care entity to come in and provide services for their clients. So, we will see how this whole idea of this client-centered medical home shakes down by August. In fact, some people don't even like the term "medical" – they prefer "client-centered health home."

TG: Right, especially from people with an aversion to the medical model.

BDL: Yeah.

TG: Let's talk a little more about the MHSA and how you've seen it play out in L.A. County.

BDL: You know, I'm not the best one to talk about that because I've just been on the fringes of it. I only know about the different pots of money and the opportunities it presents for integrated behavioral health care. I haven't been on any of the umpteen gazillion meetings that they've had about it.

TG: Yeah, okay.

BDL: So, I wouldn't be the best person to respond to that.

TG: Let's go to recovery then, and [talk about] how you think of recovery; how you would define it; how you think of recovery for a person in a system in which behavioral and primary care are integrated – what that might look like.

BDL: Well, let me digress for a second. It's a tangential kind of a thing, but one of the models that I subscribe to is stepped care, and there's not enough of it done, I think, in mental health. Stepped care is, more or less, reassessing the clients all the time to determine their progress and see what else they need, see what level of care they need. What I see in mental health sometimes is that people just kind of sit on the same treatment for too long, and the person's not getting better and the staff just write it off as, "Well, the person can't get better," rather than taking a proactive approach: "Well, this doesn't seem to be working. Let's try this other approach. Let's move them over to this." So, I think actually, primary care does a better job at that than mental health. Mental health may be likely to simply say, "Okay, they're in group therapy, [on] medications; individual therapy, medications. That's it." Whereas primary care, I think, is more amenable to adapting different kinds of approaches if one isn't working out well.

So, I think that goes hand-in-hand with recovery – [the idea of] let's meet the person where they're at. And in primary care, the providers subscribe to what is unfortunately called the "chronic care model." This model – even though it's called "chronic," which kind of implies flat line – is very similar to the recovery model, which implies a grading up and the person getting better and better. Even though the two names don't mesh, the principles do. With the chronic care model, it's "Let's involve this person in their care.

Let’s train them and teach them the coping skills that they need, the self-management skills that they require to get better. Let’s see where they are and try and meet their goals as much as possible.” And again, that is part and parcel of the recovery model. Even though the two systems are different, I think those approaches greatly overlap.

TG: Yeah, and they’re not words I often hear go together. I mean, I remember hearing a client say—it was a guy who was diagnosed, I think, with schizoaffective disorder, who said that he really doesn’t like the phrase “severe and persistent mental illness” because he thinks—

BDL: Right, it’s forever.

TG: Right, that it can really shroud the potential you have.

BDL: The ability to get better.

TG: Yeah.

BDL: Yeah, right. I think, frankly – I’m not pointing fingers at any one mental health system or any person – but I think sometimes, the mental health professionals have a tendency to write the person off, especially those with schizophrenia or other severe problems – “Okay, we’re just going to be in maintenance mode.” [Whereas] I like to think of recovery as “What can we do to get this person better? Is there anything that we can do?” In some cases, maybe there isn’t anything. I’m not saying that every single person can march happily off into the sunset. But I do think there’s too much of this just, kind of, maintenance mentality, and hopefully, that’ll be shaken up now.

TG: It sounds like you can see that starting to shift, or you can see the potential for it to shift.

BDL: Yeah, and I think one thing that’s important – you had asked me a question about stigma earlier – there’s different kinds of stigma. There’s stigma that society has about people with mental disorders. But there’s self-stigma, too. And the self-stigma takes two forms: one is, “I’m embarrassed about this. I don’t want to get treatment because of the shame and what other people are going to think.” But the other is, “I have this thing. I’m not going to get better. I’m just kind of—I can’t seem to find the light at the end of the tunnel. It looks dark to me.” And that’s another reason to enlist people who have gotten through this, to have people who are functioning who have mental health problems assist in care and give presentations – not just for the general public, not just for the Elks Group and the PTA, but also to people who are now struggling, themselves. Then they can see, they can see with their own eyes that there’s people who have been where they are and now they’re much better and now they’re coping. It gives them hope. Hope is a very powerful medicine.

TG: Sure. So, that would be an important component of recovery too?

BDL: Yeah.

TG: A person recognizing their own—

BDL: Well, and that’s why there‘s been a growing appreciation of peer support. Not only can peers show these people the ropes of where to go to get benefits and how to navigate the system, but they also can say, “Hey, look at me. I was where you were. I got better.”

TG: Yeah. I want to go to some broader questions about your overall reflections on your experience. Up to this point, what do you consider your biggest accomplishment or something that you are most proud of having been involved in?

BDL: Oh, God. Well, the thing that seems to have the most lasting impact is legislation. It’s kind of interesting that sometimes you go to meeting after meeting after meeting after meeting, and what do you have to show for it? Just talk and talk. But when you work on legislation, you write a sentence, and that is the law of the land, and people are going to have to abide by what it says. When I write, “And within four days, there has to be a hearing and blah, blah, blah, blah, blah,” it becomes a requirement for everyone in the state. Legislation has had a huge impact on procedures and on rights protection. So, I mean, if I had to distill my contribution down to just one thing, it would be that, which seemed to be the most durable.

TG: Very immediate, tangible impact.

BDL: Yeah, immediate and tangible, yes. The other stuff is a little soft and fuzzy. But this is hard and fast.

TG: Sure. What about a disappointment or disappointments or things that you would like to have seen done but really haven’t happened, if there is anything?

BDL: Well, during my time as an advocate—now it has happened after I left, of course – but for years and years, it stuck in my craw that private, for-profit hospitals had these private Psychiatric Emergency Teams who would go out in the community and round up clients and then bring them back to the facility against their will for treatment, and the facility, then, would charge for their services. It’s kind of like the Revlon salesman smearing lipstick on your face and saying, “You *will* buy this make-up. Give me five dollars.” I mean, I saw it as a total conflict of interest. And in fact, we found a smoking gun once in one of the hospitals where their private PET Team [Psychiatric Emergency Team] had written in a memo that they could bring the hospital patients for six hundred and fifty dollars per patient.” I mean, it was bounty hunting. And I was constantly begging the department to address this issue, but they didn’t do it. I even had proposals. I drew up plans to how I wanted it done, and they just all fell by the wayside. That was a source of constant aggravation. Now, after I left, they finally changed the system.

The department didn’t really, when I was there, take much of an aggressive stand on patients’ rights, even though I tried to, myself. But the backing sometimes was lacking. So now, apparently, after I left – with Marv Southard [DMH Director since 1998] in the Director’s position—he was just coming in as I was leaving—things have been much better, I’m told.

Another source of constant [aggravation] – and I’ll just be up front about it – were components in the civil service system, which bred inefficiency, as far as I’m concerned. The situation was exacerbated when the Department went into a system that exempted certain people from accounting for their work time while others still had to. And so, not being held time-accountable culminated in people who didn’t have much to do or who weren’t inclined to do much, coming in for maybe an hour, if that, and getting paid for the full day. On the other hand, if you had a lot to do and were inclined to work hard, you would work overtime, but you wouldn't get any credit for it. So, it was the inverse of what should happen – people who weren't working were getting rewarded. They were rewarded because they could go to the beach or shopping during work hours. People who were working hard, working overtime, were punished because they had less time and they were just working more. It just is a strange system. And it was just about impossible to fire anybody.

And promotions often weren't—I mean, I just give you one example, even though this isn't what you want to hear about. But you said, "What's a disappointment?"

TG: Do, yeah.

BDL: I was the head of the Patients' Rights Office, and when I left, I wanted to be involved with who my successor would be because I had some ideas of who'd be good at it. But I was not allowed to say anything. They had a panel of people to make the decision and they couldn't be tainted by my input, and so the decision was made solely on how glib the candidate could be in a thirty-minute interview in front of a couple of people who don't really know them. Whereas I, who worked with some of these people for ten years or more, couldn't have any input at all. I mean what kind of a—it just made no sense whatsoever.

So, if promotions weren't contingent on good behavior and firing isn't contingent on bad behavior, then where's your motivation as an employee? That system used to just drive me to distraction.

TG: I remember reading in your piece [in the DMH 40th anniversary book]. You said there were a lot of great things, and it was also extremely frustrating at times.

BDL: Oh, God. Well, it was frustrating because of my job. That had inherent frustrations, but it was also frustrating with civil service.

TG: Yeah. That was just really not the way you wanted the transition to happen, especially after having been there for so long.

BDL: Well yeah. I just had—finally, I'd had enough. When I was leaving, I kept on thinking, "Oh, this is my baby. This is my program." It's like turning your baby that you've nursed along over to somebody else. But it was just getting so exasperating that I figured it's time to turn the page. You need more than one chapter in your career life. And I'm glad I did it.

TG: And so, the cork could continue to float down the river until you were picked out [again].

BDL: (chuckling) Yes, yes, yes.

TG: You mentioned, just in passing, field psychiatric teams, and I know that takes various forms. I mean, there [are those that] were called assertive outpatient treatment, now assisted outpatient treatment, and there are various teams that the department has now, and I wonder what your thoughts on those are.

BDL: You know, I don't even know that they were there when I was there.

TG: Okay.

BDL: The assisted outpatient—

TG: Yeah, I'm trying to remember the chronology. It may have been in the '80's that it started. I can't remember. I mean, there are a couple different teams now – law enforcement ones, and there are all kinds of different ones. But I mean, with the setup that you were talking about, that was clearly not something that you appreciated [given] the way that it was happening.

BDL: I'd have to know more about what you're asking.

TG: Sure.

BDL: I know at the time, some of the people wanted to have the compassion teams to join up with the police so it wouldn't be so frightening for people who were put on [involuntary psychiatric] holds. And they had social workers go along. That was sparked by a case where a mentally disabled person got shot and killed by the police. And I think anything you can do to make it less harrowing for the client is a step in the right direction.

TG: Yeah. In addition to integrating primary and behavioral health care, what's your vision for mental health care for—well, I should say mental health care or health care in California? Or another way of asking that is, if you were head of, say, mental health in California and you had sort of an unlimited budget, what would you do with that?

BDL: I'd do what, I think, hopefully, they're trying to do now, [which is] make it more community-based – look at jobs; look at housing; look at socialization; try and get these people acclimated into the community instead of spending more money on hospitalization. There's always going to be a need for hospitalization. I'm not that Pollyannaish to think that we're not going to be needing that. But I, again, would move more heavily into the community arena. I would integrate more physical health and mental health. I mean, that would really be a priority of mine because in four years of doing this, I see that there is a myriad of reasons to integrate the two. It's unfortunate that the two have traditionally not collaborated together. When you talk about integration, it's sometimes threatening for mental health, especially in Los Angeles County, because they used to be under the health department. [The County Department of Mental Health was merged with the County Department of Health Services from 1972 to 1978.]

TG: Right.

BDL: And in [1978], they finally got out from under the Health Department and established their own autonomy and entity, and so, when they hear "integration," they're worried that that's back to the old days where they were just subsumed by health. But that's not what, really we have in mind when we're talking about integration. We're talking about some arrangement between the two systems, some collaborative arrangement where the person can get whatever help they need when they need it, how they need it, rather than having to enter two separate systems that don't coordinate.

TG: Yeah. Much less dichotomized?

BDL: Yeah, right.

TG: Well, those are all the questions I have. Is there anything else, any other thoughts, any experiences, memories, anything you'd like to share that I didn't ask about?

BDL: Well, just to sum up – my years with patients' rights were very heady at times, very invigorating; always colorful, always interesting; sometimes very exasperating, frustrating, all those things; intellectually challenging sometimes, even when I'd have to work on policies or procedures or papers. And there were some people that were very dedicated in the Department. But there were others that were taking advantage of the leniency that the Department afforded. Let's put it that way and leave it that way.

It was a good run. I never expected to be there for over two decades. But it's been interesting, now, to see the transition. I kind of regret that the best time, I think, for patients' rights – the most welcoming environment – has been the last decade, when I haven't been doing it. I had some really tough years. I told you I reported to somebody who would just as soon as I'd go into a coma and stay there – I mean, me and the whole patients' rights movement. But all in all, it was fun, and I'm appreciative to several people at the Department who helped me – Roger Schock; Roger Rice; Mike Mochizuki; my old boss, Hal Maveritte; Roberto Quiroz, and many others. And I'm grateful to many of my staff who worked hard to ensure that patients' rights were upheld.

TG: That sounds like a good spot to stop.

BDL: Okay.

TG: Okay, great.

**END OF INTERVIEW**