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Advocacy for Medication-assisted Addiction Recovery An Interview with Joycelyn Woods

William L. White

Introduction

One of the least known stories in the modern history of addiction treatment and recovery is the story of the efforts of methadone maintenance patients to change public, professional, and political perceptions of methadone, methadone maintenance treatment (MMT), and MMT patients. One of the people central to this story is Joycelyn Woods, whose advocacy efforts span the Committee of Concerned Methadone Patients (CCMP) in the 1970s, founding of the Association of ex-Drug Addicts for Prevention and Treatment (ADAPT) in 1979 and her present role as Executive Director and Spokesperson for the National Association of Medication-assisted Recovery (NAMA-R). She also serves as the Project Coordinator of MARS (Medicated Assisted Recovery Services) in New York City. I recently (December 2014) had the opportunity to interview Joycelyn Woods about her advocacy career. Please join us in this conversation.

Personal Background

Bill White: Joycelyn, I thought we might start with the personal story that led to your sustained advocacy for medication-assisted treatment and recovery.

Joycelyn Woods: I was born into an upper middle class family in Detroit—the only child of a physician and a nurse. My father died when I was five, so most of my developmental years were spent with my mother. As a teen, I owned a horse and won a number of horse show championships, and even tried out for the Olympics. I began drinking in my teenage years and using other drugs in the mid-1960s, beginning with pot when I was 18. I then tried heroin and felt like it was what had been missing from life. This led to dropping out of college and a ten year history of heroin addiction. I always believed that opiate addiction had some genetic component or that something predisposed some people to opiate addiction, in part because my father was a morphine addict.

I ended up at a city methadone clinic at New York Hospital and the Director of that program, who was also patient, told me in what I recall being 1975 that there was going to be a meeting at Rockefeller that might be of interest to me. It was the Committee of Concerned Methadone Patients (CCMP). I had no idea what it was at the time, but I went to see what it was about. It turned out to be led by the stabilized patients who had become research assistants (RAs) working with Drs. Vincent Dole and Marie Nyswander and who were organizing this patient advocacy group. It was there that I first met Herman Joseph and others who would be important to this advocacy effort.

I recall one speaker who was introduced as a lawyer and spoke about the new methadone “regs” who kept saying, “we have to do this,” and, “we have to do that”. I turned to the person

next to me and said that's really nice for a lawyer to think of us as equal to him. She said, "Whaddya mean, equal? He's a patient on my program." I thought, "Wow, if he can be a lawyer, maybe I can do something other than be a clerk with very bad skills" (I'm a terrible typist when I have to type fast). That started me thinking about going back to college, which I did and graduated in 1984 from Hunter College with a graduate degree in Biological Psychology and a focus on pharmacology and neuroscience (endorphin systems). I did my research at Rockefeller University and published one of the first papers mapping opiate receptors.

As for my advocacy work, I started to get very involved. I went to one meeting and then I went to another meeting and met a few people and we decided that we were going to organize a group to respond to questions that people asked about methadone. What prompted this were little local free newspapers popping up in each community of New York that were publishing these horrible stories about methadone programs. I became the Public Relations Secretary for the CCMP, and my advocacy work progressed from there.

Bill White: Let me ask about some of what you have referenced. Most of the literature about people in recovery working in early addiction treatment programs refer to recovering alcoholics working within the rising alcoholism treatment field or refer to the ex-addicts working in early therapeutic communities. It would seem that the presence of methadone patients hired to work in various roles in early methadone clinics is an untold story within the early history of modern addiction treatment. Was the majority of staff in the early clinics primarily former or current patients in recovery?

Joycelyn Woods: Yes, and they worked as counselors, some had special management positions like community liaison or court liaison and, in the clinic I was in, as the Director of the program. I would say about half of the staff were patients or former patients, and they understood treatment from the patient's perspective and went out of their way to help. I remember running in to one such counselor a block or two from the clinic because I lived in that area. When I asked how he was, he greeted me and said, "I've got to go over to the bank. I have a patient in the hospital who needs to pay his rent. So, I went and got a letter from him and went to the bank and got a check so I could go over and pay his rent for him." That kind of effort was common then. They don't do that today.

Bill White: Now, could you elaborate on your decision to go back to school? Was that, in part, a result of your early advocacy interests?

Joycelyn Woods: It goes back to that lawyer Pat Benedetto talking at the early CCMP meeting. Realizing he was a patient raised the way I thought about my own possibilities. But when I first went back to school, I did not have any specific goal but like everybody else around me I had some aspirations of becoming a counselor. Within a year, I realized I didn't want to be a counselor; I wanted to be an advocate. Then, I decided that I would rather be an administrator because I would have more control over things. And right around that time the discovery of endorphins was announced. That's when I really started thinking about going into research. So my last year in a bachelors' program, I totally switched everything and stayed for another year to study anatomy and physiology and to shift my specialty to physiological psychology. I then continued at the City University of New York (Hunter College) to complete a Master's program

in what Hunter College then called Biological Psychology. I completed by B.A. in 1981 and my M.A. in 1984.

Early Work at Rockefeller and NDRI

Bill White: Could you kind of describe the evolution of the roles you filled once you began working in the research and advocacy fields?

Joycelyn Woods: Well, I started out at Rockefeller University because you had to pick a mentor as you get into a graduate program and I chose one from there. I had a clinical psychology neuroscience and then a straight research neuroscience program and the head of the Department at Hunter College at that time recommended a person at Rockefeller as a mentor. So, I called Sarah Leibowitz who studied feeding behavior. She wanted someone to do studies on endorphins and feeding behavior. She had discovered that norepinephrine initiated feeding. I started working at her lab to earn some money, which was my first job. I did meet Drs. Dole and Nyswander during my time at the lab. I was leaving the lab one day and as I was walking down the main driveway who do I see but Ghinny Orraca walking up the driveway towards me. Ghinny was the 3rd patient in treatment and worked with Drs. Dole and Nyswander. As we were talking, a car pulled up to park and Ghinny said, “Wait a minute. There’s somebody here I want you to meet.” It was Dr. Nyswander. She was like Loretta Young she had a Pendleton plaid skirt and sweater on and did a kind of twirl as she got out of the car. While I was in the lab, Dr. Liebowitz asked me if I would go to Dr. Dole’s office to borrow a book that contained a chapter that he had written on opiate receptors. I remember being very nervous because I had not met him before then. It wasn’t until the 1990s that I really talked to him a good deal as part of my early work with NAMA.

Bill White: If I remember correctly, you went from Rockefeller to the National Development and Research Institutes (NDRI) as part of the International Work Group on AIDS and IV Drug Use.

Joycelyn Woods: Yes, that was in 1988. At the time, the AIDS epidemic was really raging. People were getting sick and dying and nobody could figure out what was wrong with them. I know now they had AIDS. I was very fortunate to be hired by NDRI as a project director working under Dr. Don Des Jarlais. I also played a role in helping prepare the innumerable published papers that came out of that project. That work was extended in my role as Senior Research Associate for the Chemical Dependency Research Working Group. This latter work was designed to respond to rapidly evolving drug trends in New York City, particularly the surging of crack cocaine use. We prepared papers on a wide variety of issues and hosted training symposia for front line treatment providers and allied health professionals.

NAMA-R

Bill White: Two of the roles that you are most known for are your leadership in NAMA and your work with the MARS project. Could we begin with how the former began?

Joycelyn Woods: My work with what is now known the National Alliance for Medication Assisted (NAMA) Recovery began in 1988. I got a call from Ghinny Orraca, who was the patient representative at Beth Israel and President of CCMP. Bob Newman and Nina Peyser, in response to the AIDS epidemic, had begun asking the RAs that were around at that time to meet with them. They decided that addicts needed an advocate. I was talking to Ghinny and he said, “By the way, they’re having a meeting you’d probably be interested in it. Why don’t you come by?” And so that was how I walked into NAMA. At that time, they were just figuring out the name of it. They were making everybody come to the meetings at first and the minute that Nina Peyser said that nobody had to come, only two people showed up: Stan Novick and me. There we were with Nina Peyser, sitting at this big board table at Beth Israel with me at one end, Stan at the other end, and Nina’s in the middle. We’re all sitting there trying to figure out what to do – at this point I realized it could be the end of the idea of an advocacy group or we could give it a try. So finally I said, “Stan, if you’ll be President, I’ll do the work.” So, he agreed to that, and that’s how NAMA began its work. We never dreamed it would be a national organization. Someone sent us money wanting to be a member. We never thought of having members so we sent the money back. I remember doing that several times. I saw NAMA as a small group of patients and professionals in New York working on policy. But once we starting going to conferences and professionals brought out materials back to patients – and it only took a few times mind you – we got letters about membership and patients wanting to start a chapter. What! Oh my word we never ever imagined that. We would also get letters from patients all over the U.S. and in fact other countries too. John Mordaunt, who started Frontliners in the UK was the first methadone patient to go on UK television with AIDS. Many of the letters were written by hand and some of the patients could barely write – they were just not use to writing letters but they thought it was important to tell us how much NAMA was needed. We decided that we – well I should write back to everyone and I did for several years. I still have those letters and they are so touching.

Bill White: What do you think have been NAMA Recovery’s most important accomplishments?

Joycelyn Woods:

When NAMA started in 1988 the average dose was below 35 mgs, one-third of the programs would not tell patients what dose they were one because they thought that patients would compete. It was called Blind Dosing and the dumbest thing – well one of the dumbest things that was done. What responsible adult would take a narcotic and not know their dose? Programs continually infantilized patients. When I went to the first methadone conference in the role of NAMA, I was told by a social worker that it probably was not a good idea for patients to be there. When I asked why she said, “Well you might see something”. Right, I and other patients might see what is supposed to be done that programs are not doing. NAMA brought up a lot of these issues and made professionals think about it. I recall a California program that had in its patient handbook that complaining about their treatment was a reason for discharge. I couldn’t believe it, so he sent the patient handbook. Now that is outrageous. If you are paying hundreds of dollars for treatment you have a right to complain if something is wrong.

Also, being part of the committee that wrote the new regulations was an important accomplishment. There was a big issue over patients being able to get a month’s medication and the other issue that I kept bringing up was that patients needed to have input into the policy of the program. When the regulations came out actually they were very smartly written with just

the bare minimum in the Federal Code and that included guidelines for take home with up to a month and also a means for patients to have input into program policy. Most programs have what are called Patient Advisory Committees. All the important stuff went into Best Practices so when issues change they can be adjusted and you don't have programs spending time on procedures that make no sense.

Bill White: And how did you get involved in the MARS project?

Joycelyn Woods: Well, Mark Perinno, President of AATOD (President American Association for the Treatment of Opioid Dependence) called me to say that CSAT [Center for Substance Abuse Treatment) was going to be awarding grants for recovery support services and that he felt NAMA was exceptionally qualified to do such work. The timelines did not allow us to respond at that time but we eventually applied for one of those grants and we were informed in October 2006 that we had been awarded funding. The project was called Medication Assisted Recovery Services (MARS, <http://marsproject.org/>). It was developed in collaboration with NAMA Recovery and with support from the Albert Einstein College of Medicine. Walter Ginter has served as the Project Director and I've been the Project Coordinator. My primary role has been to do design and deliver the core training. The primary function of MARS is to help medication-assisted treatment (MAT) programs develop a holistic approach that includes MAT education and a supportive peer community and to help traditional abstinence-based programs integrate medication-assisted treatment into their other services.

When we wrote the grant, we had no idea how important MARS would eventually be in helping elevate the quality of medication-assisted treatment. But NAMA-R had been in existence then almost 20 years and we knew what patients were hungry for – basic information about MAT. We have begun the process of changing how professionals see MAT patients and changing how MAT patients view themselves. And we have begun to change what has too often been an adversarial counselor-patient relationship in MAT.

The Evolution of Methadone Maintenance

Bill White: As a patient and an advocate, you've had an opportunity to experience and observe the evolution of methadone maintenance in the U.S. How would you describe this evolution?

Joycelyn Woods: There have been many changes, both good and bad and many of the latter were unanticipated. In the beginning, it was a free-for-all. There was a new program opening in New York every month. There was methadone all over the place, and people were selling it in the streets. You didn't have to pick up medication daily during those earliest days because nearly everybody got take home medication. Restrictions on take-homes really didn't start happening until the regulations came in to place after it was recognized that deaths could occur during methadone induction, and the program needed to know that the patient was taking their medication. That may have been an area where Dr. Dole failed: he thought that if he provided the formula to guide doctors overseeing methadone maintenance that all would work well, but he underestimated the consequences of doctors not understanding opiate addiction and changing the protocol because of one patient doing something. Lacking was a formal training of physicians in the nuances involved in the clinical management of MMT. The medical schools are even more responsible and that continues to this day with physicians receive no training in addiction. It was

assumed that doctors could do this but the range of expertise was all over the place. And there were abuses, from doctors that charged exorbitant fees to those who expected sexual favors for medication. There was no control over that. That's in part why a system was created where doctors could be trained and attached to a clinic.

Bill White: Do you see the quality of methadone maintenance in the United States better today than during those early years?

Joycelyn Woods: I think that if you look at the whole system, the quality is better today, but it remains mixed. There are pockets of clinics that are horrible and there are clinics that are really good. The early years were guided a great deal by intuition, and Dole and Nyswander made some very good guesses, but other practices evolved as MMT spread that were very destructive. These included low dose clinics, arbitrary limits on the duration of MMT, blind dosing, and reducing methadone dose as a form of discipline. Fortunately, most of these practices have been abandoned, in part, under the influence of the federal regulations. Under dosing of patients was a problem for twenty years before the low dose versus high dose controversy was resolved. As for arbitrary limits on methadone maintenance, there were some clinics that actually encouraged patients to leave treatment as was encouraged by the early regulations that required written justification for MMT after two years. What happened was that Dole did this huge study following people who had left MMT and found out that most were either in jail, dead, or back in treatment, so they realized at that point that it was not a good idea to leave treatment. Poor clinical practices eventually gave way to improved clinical practice, but we still have a long way to go. For example, people in Johnson City, Tennessee have been trying to establish a treatment clinic there for twenty years and have finally gotten a lawyer who is using the ADA to overcome some of the past efforts to block opening the clinic. The local comments resisting the clinic are very depressing and this is in an area with a high opioid overdose rate. The places where clinics are needed the most are often the most resistant because of their misconceptions about medication and its potential role in supporting long-term recovery. It's the patients who have benefited from medication and the families who have lost someone to addiction that are finally organizing to counter such ignorance and resistance.

Methadone Myths

Bill White: You have played an important role in educating patients, professionals, policy makers and the public about methadone. What do you see as the myths that continue to be pervasive about methadone?

Joycelyn Woods: Well, there is still the perception that methadone is a narcotic drug used primarily to get high. There's still that perception that MMT patients get high on stabilized doses of methadone. I just read this crazy paper from this guy in Long Island who talks about "lurid euphoria" from methadone. When you take any psychotropic drug, you feel an effect, but that's not euphoria. If you think the effect of a daily methadone dose is euphoria, you've never experienced euphoria. A patient may experience sedation effects during induction, but that's not the same as euphoria. The stereotype of a methadone patient sitting around stoned and nodding off as an effect of MMT is ridiculous, but unfortunately that is the image.

Bill White: One of the other continued criticisms of MMT is that methadone just substitutes one drug for another. What is your response to this criticism?

Joycelyn Woods: Well, the pharmacological profile of methadone and heroin are quite different. Methadone is a long-acting legally prescribed medication, while heroin a short-acting illicit drug. To be sure methadone is a powerful narcotic, which you need it to block the effects of heroin, but it has very unique properties. When taken in a steady daily dose, it has a normalizing effect rather than an intoxicating effect that would interfere with physical and social functioning. If you asked most methadone patients what it feels like to be on methadone, most will say, “Normal.” Herman Joseph and I once did a chart comparing methadone and heroin to challenge this whole notion of “substitution.” When you call methadone a substitute for heroin, you totally blur these differences. The choice of the word, “substitution,” is probably one of the poorest choices in the history of methadone treatment. MMT providers in American have mostly abandoned it, but its use is still common in Europe. Even patients often see methadone as just a substitute in Europe, so of course they are unhappy because they have expectations.

Bill White: There has been great alarm about the increase in methadone-related deaths in the U.S. with many people assuming this is a consequence of the use of methadone in the treatment of heroin addiction.

Joycelyn Woods: MMT programs are sitting ducks for attacks following methadone-related deaths, but the truth is that most of these deaths are a consequence of prescriptions of methadone for pain. The deaths of MMT patients beyond the induction period are usually a consequence, not of methadone, but use of alcohol and/or illicit drugs in addition to methadone.

Some people believe that once on methadone you never get off. That’s silly people get off of methadone all the time, and for some it is easy and for some it is difficult. No it is not like tapering from heroin, and that is again because of their pharmacological profiles. Usually, if it is difficult it is because they are not being sensible about tapering and they do it too fast. Getting off is easy the hard part is staying off because 80% will relapse within two years and be back in treatment starting all over – that is if they survive the relapse. The goal of methadone treatment is not getting off; rather it is getting a life!

Another myth is that methadone makes you drink or use cocaine. Patients that think that way are just not taking responsibility for their actions. In fact I know of some so called persons in recovery that blame methadone for their behavior.

I have also learned that nearly every country has its own set of myths about methadone. In the U.S., it is that it gets in your bones, and in Europe it does things to your stomach. And that’s a people thing – we like to blame problems on something else rather than taking responsibility for it or trying to figure out what is going on.

Methadone and Recovery Status

Bill White: An interesting question arises among those working on a definition of addiction recovery. The question is: Are patients in MMT in recovery?

Joycelyn Woods: I happen to like SAMHSA’s definition of recovery, which says nothing about abstinence and defines recovery as “a process of change through which individuals improve their health and wellness, live self-directed lives, and strive to reach their full potential. Other

definitions are so complex; SAMHSA's is simple--perfect. Patients in MMT whose lives fit that description can be said to be in recovery. It's as simple as that. The recovery term was not used in the early years of MMT because it was associated with NA, and the grief MMT patients often encountered when they tried to participate in NA. The position of many NA groups was that you were not "in recovery" until you stopped MMT—again the equating of medication use and heroin use.

Bill White: Have you noticed any changes in the stance of local NA groups in terms of their willingness for MMT patients to claim clean time, speak in meeting, lead meetings, or be involved in service work?

Joycelyn Woods: I hear from people in certain areas that they're welcomed into an NA group, and I think buprenorphine has helped change that. But there's still a frequent stance that you can sweep the floors but you can't speak or hold a service position. It's pretty bizarre really. I mean you could be selling drugs out on the street and getting high, but as long as you have not taken anything in the past twenty-four hours, you can share at an NA meeting, but if you are an MMT patient who has not used anything for years other than your medication (as prescribed) and have worked and supported your family, pay your taxes and are considered an upstanding member of your community except that you cannot share at some NA meetings. That's crazy, but fortunately, is changing in a lot of groups. Such negative attitudes toward MMT effect how patients see themselves. When Lisa Mojer-Torres did her survey of MMT patients, what surprised me was how many of them thought of themselves as being in recovery but never verbalized it because of negative attitudes toward methadone. I was even one of the people that didn't want to add recovery to NAMA's name until Lisa told me that. She said, "You'd be really surprised how people think of themselves as in recovery but will not share that with others."

Duration of MMT

Bill White: We touched earlier on arbitrary limits on MMT duration. What have we learned about the optimum time for people to be on medication, and do we know anything about which people do well eventually tapering versus those who are best advised to sustain medication for a prolonged if not lifelong period?

Joycelyn Woods: I don't think we know anything about that yet. It's very iffy. You don't know until you try it. I know people who tapered and did well for ten years and then, all of a sudden, relapsed in their early 50s. Because they did well for so long but now feel shame due to the relapse, they are then hesitant to come back into treatment. Many don't survive.

Bill White: The risks of tapering would seem to be enhanced by the lack of any systematic post-treatment check-ups for people leaving MMT. I'm a cancer survivor and will be assertively monitored for the rest of my life. I see no counterpart to that for people following MMT.

Joycelyn Woods: No, there is no such counterpart now. At one point, Beth Israel and this was an influence of Drs. Dole and Nyswander and the RAs because they cared for their patients so they would have patients who had tapered off methadone keep in contact and stop by the clinic once in a while, but there it was not formal and today there is no such routine follow-up care

following MMT. There are individual counselors that encourage continued contact, but there is no system of post-MMT recovery checkups.

Peer-based Recovery Support and Medication

Bill White: Of interest to me about the work you've done at MARS is the power of adding peer support to MMT. What's been your experience with this so far?

Joycelyn Woods: MARS grew out of the NAMA belief that we as patients need to take control of our own recovery and support each other in the recovery process. NAMA pushed for a MARS project that would allow patients to design and deliver the kinds of peer recovery supports they believed could be most helpful to people. For example, we've had everything from book clubs to advocacy training programs. We now have a group that's writing a recovery book based on their own personal recovery stories. I see this as an extension of what Drs. Dole and Nyswander did when they hired patients. They considered the patients the experts that they looked to for assistance. As methadone treatment became professionalized and many of the RAs retired, what happened was a system of book-learned professionals. Very often they didn't understand the culture that the patients came from or how patients feel when they come into treatment. MARS Projects with peers can take the place that the early RAs served.

Bill White: You know, there are a lot of books of recovery stories that have been a great boon to other people seeking recovery, but I can't think of a single book filled with the stories of people in medication-assisted recovery.

Joycelyn Woods: There are none. And that's a sad commentary after fifty years of methadone maintenance. We hope to change that.

Closing Reflections

Bill White: Joycelyn, you have been an advocate of medication-assisted recovery longer than anyone I know. What advice or guidance would you have for patients in MAT who have an interest in getting involved in advocacy work?

Joycelyn Woods: Well, I always start by telling people you can't do advocacy work alone, but there are lots of things that you can do from writing letters to politicians to just sharing your story. A lot of people think that advocacy is about exposing poor clinic practices and that can be part of it but it is much broader. NAMA-R is about getting at the larger attitudes, policies, and laws that shape treatment practices. There are always secret players in this game and our challenge is to reach and influence them, whether they are congressman, hospital administrators, journalists, or physicians. Some advocacy springs from anger. I remember one retired teacher's aide who went through the core training and who said, "I've been on methadone twenty years and I never knew all this stuff. Why didn't anybody tell me?" Well, she put together this little presentation based on what she had learned and started going around presenting it.

Bill White: Do you think one of the most powerful things that advocates are now doing is finally telling their stories of the role medication played in their recovery from addiction?

Joycelyn Woods: Yes, I do. And people are beginning to hear it, but we have a long way to go. The hardest thing is to tell your family. Most patients just don't have the knowledge and their family will say negative things about methadone. And very often a parent only knows what they read in the paper and they will say to their family member "Why don't you just stop?" That's the point, they can't, and even if they do for a time they usually relapse. Families like everyone also see it as just a behavior and a choice that you can stop. But if that were true then there would be no addicts because I have yet to meet someone that wants to be one.

Bill White: Let me ask a final question. Looking back over the years you have been involved in advocacy, what do you personally feel best about?

Joycelyn Woods: I think being part of the committee that rewrote the federal regulations governing MMT is a definite highlight because of the impact it had on the whole treatment system. It has been an honor to be part of efforts that have increased the quality of addiction treatment and to be involved with so many patients who have changed their lives with the support of treatment.

Bill White: Joycelyn, thank you for your willingness to share your personal story and all of your professional advocacy work with our readers.

Joycelyn Woods: Thank you for the opportunity to do so.

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