

White, W. (2009). Advocacy for medication-assisted recovery: An interview with Walter Ginter. Posted at www.facesandvoicesofrecovery

Advocacy for Medication-Assisted Recovery: An Interview with Walter Ginter

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There are many pathways to recovery, and all are cause for celebration. That proposition is a founding principle of the new recovery advocacy movement and of the Faces and Voices of Recovery organization. In June of 2009, I interviewed Walter Ginter about the work he and others have done in advocating the legitimacy and effectiveness of medication-assisted recovery. Walter is one of the most skilled recovery advocates in the United States. I have learned much from him and am sure that you will also as you reflect on his story and the service work that has been such an important part of his life.

Bill White: Walter, you are one of the most visible advocates of medication-assisted recovery in the United States. Could you describe how you came to this role?

Walter Ginter: To do that, I will have to talk about my addiction history, which is something I really don't like to do a lot. I prefer talking about my recovery. I started using heroin when I was in the service in 1970. When I got out of the service, I continued using, and eventually I got into methadone treatment. Treatment went very well for me until my business partner at the time said to me, "Walter, you're so smart. You don't really want to be on this junkie drug. Why don't you get off of it, and I will make you Midwest Sales Manager?" I thought this was a great opportunity and went into a 28-day detox to end my methadone treatment. I relapsed after about three or four months and then returned to methadone treatment for several years, again doing well during this period. Eventually, my counselor started pressuring me. "Walter, you have your own business; you're making a good living. You make more money than anybody else in this program. Why do you want to be on this drug?" I said, "Ok. That makes sense." I tapered and relapsed again before returning to methadone treatment.

Several years later, I tried to taper again with the pressure coming from myself at that point. I had all the possible supports in the world. I had seen a psychologist in therapy and acquired considerable self-understanding, and I had lots of support. I really thought it was time to taper, which I did and relapsed again. Now I'm starting to feel pretty lousy about myself. "Why is it that I can't taper off this medication? Don't I have the courage or the guts? Other people are capable of doing it." What I didn't realize then was what I would teach others later: "It doesn't matter how smart you are or how much money you make or what kind of supports you have. There's more to recovering from addiction than that. This really is a disease. "

As for my advocacy career, I got into treatment again at the clinic on 125th Street and, as sometimes happens in methadone clinics, the counselor treated me very poorly. At this time (1999), I was very active in my own business and had learned a lot about the Internet. So I decided as more or less for revenge to set up a website where people could complain about treatment. I set up a website called "Bitchandgripe.com." It was geared to most of the patients involved in the 19 methadone clinics at Beth Israel at the time. It was a humorous take on the clinic experience, but it was all true. The website came to the attention of someone at the state agency who was active in advocacy and the next thing I know, the National Alliance of Methadone Advocates invites me to get involved in advocacy work. My first response was, "Are you crazy? I have a business to run. I'm doing this on the side." But they worked on me and convinced me to become editor of the NAMA newsletter.

I started learning about addiction from my associate, Joyce Woods, who has a graduate degree in neuroscience. I started to understand what was going on inside my brain. I started to understand the fact that I wasn't capable of being medication-free had very little to do with how gutsy I was or how strong I was, but more what kind of addiction-related damage had occurred within my brain. I learned about Dr. Dole's metabolic theory of addiction and the real nature of methadone treatment, and I started feeling better about myself.

In 2001, I attended my first American Association for the Treatment of Opioid Dependence (AATOD) conference and also was inspired by the St. Paul Recovery Summit. I caught fire between those two meetings. I felt like somebody robbed 20 years out of my life by not telling me the truth about my condition and what was needed to manage it. I had been going through these endless cycles of detox and relapse and feeling tremendously bad about myself, not realizing that I was stopping the very thing that was

working for me. I didn't want others to go through what I had gone through, so, like every advocate, I decided I would change the world. I started getting very active in advocacy.

In 2002, Joyce Woods and I attended a NIDA constituents meeting and discussed the need to train and certify methadone advocates. Following through on that idea, NAMA became the authority for certifying people. We did our first training in 2003 and have since trained over 500 advocates, mostly at the AATOD conferences. The training led to applying for and being awarded a CSAT Recovery Community Services Program (RCSP) grant and that grant led to involvement with Faces and Voices of Recovery and so on. It has been a long journey, and I think what really got me involved in it was concern for my fellow patients.

Bill: What was it like for you to move from this early work to work that brought you into contact with people from all pathways of recovery?

Walter: My first experience with people from what I think of as the mainstream recovery community was when I represented NAMA as a planning partner at meetings for National Alcohol and Drug Addiction Recovery Month. At one of the meetings, someone said to me, "You're not a recovery advocate; you're a methadone advocate." I was kind of appalled by that and by the fact that he was serious. From his perspective, I wasn't in recovery. I can also remember at one of the early RCSP meetings surprise being expressed by other project directors that a methadone project had been funded. Other than myself, only one person expressed visible support for the project. Over time, things really started to change rapidly. More and more people expressed support for multiple pathways of recovery—particularly through the influence of Faces and Voices of Recovery. We actually reached a point on the national recovery scene when no one dared stand up and say anything negative about medication. What people think in their heart of hearts, who knows, but I've had many people who once made negative comments about medication come up to me and say they were wrong.

Bill: To what do you attribute such a rapid change in attitude?

Walter: I think education has made the difference—particularly the work of Lisa Torres, who deserves a crown. People have a perception of what a methadone patient is, and even methadone patients have that perspective. To have somebody, like Lisa, who's a bright attorney, stand and say "I am a methadone patient" and tell her story over and over has made a big

difference. The fact that she was the first chair of the board of Faces and Voices of Recovery helped a tremendous amount.

Bill: Maybe we could shift to what some of those misunderstandings about methadone have been.

Walter: The biggest misunderstanding concerning methadone is really about opiate addiction and the failure to recognize it as a medical condition and to recognize methadone as a medication. When somebody breaks a leg, we don't ask them, "Hey, were you skiing dangerously? Because if you were skiing dangerously and going too fast, we're not going to treat you." When we deal with methadone, we deal with the perception of addiction as a self-inflicted condition and that such conditions do not deserve the best possible medical care. Opiate addiction has both medical and behavioral components. All chronic diseases have a behavioral component, and that's what you're dealing with—a chronic disease. The problem with the methadone community is we have too many people who think methadone is a magic bullet for that disease—that recovery involves nothing more than taking methadone.

This view is reinforced by people who, with the best of intentions, proclaim, "Methadone is recovery." Methadone is not recovery. Recovery is recovery. Methadone is a pathway, a road, a tool. Recovery is a life and a particular way of living your life. Saying that methadone is recovery let's people think that, "Hey, you go up to the counter there, and you drink a cup of medication, and that's it. You're in recovery." And of course, that's nonsense. Too many people in the methadone field learn that opiate dependence is a brain disorder, and they think that that's all there is to it. But just like any other chronic medical condition, it has a behavioral component that involves how you live your life and the daily decisions you make.

Perhaps the biggest misunderstanding about methadone involves the word "substitution." Extensive damage has resulted from using the word "substitution" in reference to methadone treatment. That one phrase completely blurs the distinction between treatment and active addiction. If methadone is just a substitute, then there's no difference or little difference between treatment and active addiction.

Bill: What do you think were some of the early sources of stigma related to methadone treatment?

Walter: When methadone was first introduced by Dr. Dole and Dr. Nyswander, it was extremely effective. We were in the middle of a heroin epidemic around this country, and there were other treatment modalities, particularly the therapeutic communities (TCs), that competed with methadone treatment for professional status and financial resources. The TCs looked at methadone treatment as the antithesis of everything they were doing. They started the mantra, “Methadone is not recovery; it’s just a substitute,” and a lot of that attitude had to do with financial competition. It was a financial thing rather than what would work best for which person.

One of my problems in treatment is that sometimes people get treatment based on what door they end up walking through. Somehow, we have to figure out a way to stop that. What we’re trying to do now in New York is do away with these silos of treatment and move toward a system in which the treatment you get is based on what you personally need. If I come into treatment, and I need to go into a TC, well that’s where I should be. If I need Suboxone, well that’s where I should be. If I need methadone, well that’s where I should be. If I need a psychologist, that’s where I should be. All of those possibilities should be available, not dictated by whether I happen to stumble into a methadone program or I happen to stumble into a TC.

Bill: What do you think are some of the service philosophies or practices within the clinics themselves that may have inadvertently contributed to the stigma attached to methadone maintenance?

Walter: A huge problem is that the counselors who work in the clinics, especially here in New York, don’t really have any training on methadone and methadone counseling. In New York, our counselor certification body has no requirement for any training related to methadone and methadone maintenance treatment. To be certified as an addictions counselor and have no training in methadone treatment is terrible. In the TCs and other programs, we turn out people who want to later work in the field, and all too often hire people in methadone clinics who philosophically don’t believe in medication-assisted treatment. My own experience was “When are you going to get off of this, Walter? You’re making too much money to be on methadone.” We have too many people working within the modality who don’t fully understand and support it. In New York, we have initiatives through which we are finding methadone patients who are interested in working in the field and sending them off to school to become counselors.

Such projects create candidates for the workforce who do fully understand and support medication-assisted treatment.

When I first started in the project here, I can remember about every other day, someone would be knocking on the door, and one of my peer leaders outside would be doing an orientation. They would knock on the door, and they'd say, "Walter, tell this person you're a patient." And I would have to say, "I'm a patient." They would have to hear it, because since I wore a shirt and tie and was a project director, they could not imagine that I was a patient.

A counselor who I knew who was in treatment was working at a major medical center, and she used to tell the patients that she was on methadone. She felt that this was a good example that they could see that they could get their lives together too. A couple of the patients complained, "I want somebody better than me." And that's how they felt about methadone treatment. But the worst part about it is, instead of educating those patients, the program told her, "Don't tell anybody you're a patient." That's what we're up against.

We need such positive examples. Look at myself. For 20 years, where did my knowledge of methadone treatment get me? I was in treatment for 20 years. I came from the street and believed everything I got on the street. It was all complete nonsense, but that didn't change the fact that I thought I knew what I was talking about. One of the things that we do here at the MARS project that's different than any other RCSP project—and it's the only thing that we do that's different really—is we provide training in medications. We explain opiate addiction, opiate treatment, and recovery from opiate addiction because those are the three subjects that no matter how long people are in treatment, they know the least about.

Almost every patient I see comes in here initially and says, "Well, I'm only going to be in treatment for three or four months. Do you mind if I hang out here for now?" That's fine. I always tell people when they come in here that I'm not selling methadone treatment. I'm selling informed decisions. I want them to understand what's going on in their own brain, in their own body, and if they do want to taper, I'm going to give them all the support in the world. I know that only 30 percent of them are going to make it, but I'm hoping that with the support that I give them and the training that I give them, that maybe 40 percent will make it. It's tough.

Bill White: What kind of responses do you get, Walter, when you begin to challenge some of those misconceptions?

Walter Ginter: We do an intake training that Joyce and I alternate teaching that focuses on the basics of addiction, treatment, and recovery and what the project is. We talk about addiction and receptors and how the medication works and what else must happen in the recovery process. The patients are very receptive to this. It changes the way they see themselves. Methadone patients come into treatment on what feels like the worst day of their life. They look at entering treatment as “I’m such a failure. I couldn’t even make it as a junkie.” And that’s one of the myths—that methadone is a free high and that patients come in wanting the maximum possible dose. It’s a complete load of nonsense. The reality is patients don’t want a large dose. When they come into treatment, they’re already planning on leaving treatment. They usually end up with a dose that’s too small for them and not adequate for what they need, but they insist upon it because they’re already planning to get off of treatment.

Bill: What do you think would be the most effective strategies to challenge the misconceptions about opiate addiction and reduce the stigma related to medication-assisted treatment and recovery?

Walter: We have to get people out there to be seen. We need the Lisa Torreses. We need people to stand up and talk about it. I can remember doing these educational panels at various places and then telling the audience, “Some of us up here are methadone patients.” They always picked out the wrong person trying to guess the methadone patient. We were of course all methadone patients. We need people who wear a shirt and tie, dress well, and are articulate to stand up and say that they’re patients. The first strategy is that simple, which of course isn’t simple at all.

One of the problems is the government itself. We have CSAT and SAMHSA, bless them, who say that methadone patients can do pretty much anything anybody else can do. The data show that methadone patients drive as well as anybody else, but the federal Department of Transportation will not allow a methadone patient to get an interstate driver’s license. You don’t see SAMHSA saying, “Well this is outrageous; there’s no basis for it.” There are patients who work for SAMHSA who are also methadone patients who can’t stand and speak out for fear of hurting their careers. I know patients myself who work for the government, have good jobs, and who say, “Well, when I retire, I’ll come out.” But I understand that from my own career. I was in the personnel business for 30 years. At one point, one of my clients found out I was a methadone patient and didn’t want to work with me anymore. It’s a terrible stigma. The only way we’re going to combat it is to

have people stand up who everybody can look at and say, “Well, if that person’s a patient, methadone treatment can’t be that bad.”

For that to happen, we have to train and support the patients. The patients have to understand their own treatment. I can remember sitting down with an assemblyman in New York several years back and talking to him about treatment in Harlem. I was a patient in Harlem at the time. I was talking to him about treatment and how well everything was going, and I finally sold him on how this was a good thing, and we’re walking down the street by the methadone program. And he stops a patient and says, “Well, what do you think about your treatment,” and the patient says, “Well, methadone’s great. It saved my life, but I got to get off of it before it rots my bones.” We’re our own worst enemies. Until we train the patients to understand their addiction, to understand their disease, to understand how methadone works, it’s not going to change.

Bill: Could you elaborate on those patient beliefs?

Walter: The cycle of patients coming into treatment and back to the street with such nonsense is appalling. There are the stories of a Beth Israel patient whose bones were so rotten he completely disintegrated on the stairs and when autopsied, was orange inside. People believe this stuff, including the more ridiculous stuff—Dolophine being named after Hitler or the Nazis giving methadone to their fighter pilots so that they would keep flying. It goes on and on and on. People believe it because there is no one standing up to say that this is not true. When I talk to the patients here, they’re amazed. People who have been in treatment 20 years read TIP 43 like it is a novel because no one has told them about the nature of their condition and its treatment.

We really have to train the patients. We’ve tried a top-down approach for a long, long time where the idea is, “Well, we’re going to train the supervisors, and the supervisor will tell the counselors, and the counselors will tell the patients.” It never trickles down that far. It’s like one of those party games where you start off and you start talking around in a circle, and whatever you say comes back and it’s nothing like what you started with. That’s what happens with this trickle down approach. What we really need to do is exactly the opposite: train the patients. The funny thing is, when patients are educated and they go into the clinic and they say something, suddenly the counselors want to have that information. If the patient says, “Well, this is not true; this is not in the state regulations because I’ve seen

the state regulations,” well suddenly, I get a call from the counselor who wants a copy of the state regulations.

One of the big things in treatment—and it’s not that counselors are bad or evil—but people are trained by the person who came before them. So what happens is some guy 20 years ago said, “Well, the reason we don’t do that, it’s in the state regulations.” It was never in the state regulations, but that type of thing gets passed on from counselor to counselor to counselor. When they actually see the regulation, they understand. The counselors suddenly become more interested in understanding these things when the patients come to them and have a better understanding than they do. I’m a firm believer in the bottom-up approach. I think once the patients understand their addiction, understand how their medication works, and understand recovery, the system itself will change.

Bill: We have called for a vanguard of people in medication-assisted recovery to step forward and declare their presence and put a face and voice on this pathway of recovery, but the stigma such individuals could face has real consequences. What kind of advice would you give for people in medication-assisted recovery who are thinking of stepping forward and being part of this advocacy process?

Walter: The first thing is to caution people against taking this role too early in their recovery. Methadone is an agonist, and people get into treatment and go from feeling miserable to physically feeling much better. Suddenly, they think all their problems are over. We all know that addiction is more than just physiological stabilization; there are these huge behavioral components. But people tend to think, without ever addressing any of these behavioral issues: “I’ve been taking methadone. I feel great. I gotta tell the world.” It’s best not to put people into the strain of this situation until they have a better understanding of themselves and their treatment.

The most important thing is training. Patients have to be trained. I recommend that patients take the certified methadone advocate training course that we give and to get a mentor to guide them through their first disclosure experiences. When I started, Joyce Woods was my mentor, and I spent two hours a day on the phone with her. You need someone to help you along the way.

Bill: Do you see the methadone clinics in the United States developing more recovery-oriented philosophies in their service practices?

Walter: I wish I could say I did, but it's a yes and no. I've been to all the AATOD conferences since 2001 and there are clearly people who are developing more recovery-oriented programs, but there are 1200 methadone programs in the U.S. How many are represented at the AATOD? 40? So yes, some of the programs are developing more recovery-oriented services, but many are not.

I was amazed at the response from the Guide on recovery-oriented care that SAMHSA released at the AATOD conference. I didn't expect that to be the be-all and end-all of recovery for opioid treatment programs. We were hoping to just introduce the recovery concept and the response was exceptionally positive. I've received dozens of calls since the conference from people wanting more information, which suggests a real openness to greater recovery orientation. The major breakthrough is introducing patients to the idea that recovery is not something that begins when you stop using medication but something that can unfold with the assistance of medication. And to have that message coming from peers is very powerful. I don't think you can overemphasize the importance of this idea being modeled in the lives of one's peers in treatment. Patients entering treatment need to see and be coached by other people in recovery who are on medication.

Bill: You are now serving as the Director for the Medication Assisted Recovery Services (MARS) project in New York City. Could you describe this project?

Walter: Before describing the project, let me preface this with a bit of history. Funding through CSAT's Recovery Community Services Program (RCSP) used to be for more advocacy-oriented activities rather than recovery support services. And the truth of the matter is, if I would have had a choice when I applied for this grant, I would've said, "Oh yeah. I want to do advocacy." And you know what? It would have been a colossal mistake. The lessons that we've learned here couldn't have been learned doing only advocacy.

The project itself is like many other recovery community centers with the exception that our peer-based support services are designed for people in medication-assisted recovery and that we provide what we call our core training in addiction, medication, and recovery.

When we first got our funding, I feared I was going to sit here alone for four years—that methadone patients would not participate in the services we were offering. I also had this horrible thought of what it would be for me as a white person to carry our recovery message into places like the South

Bronx, which is 61 percent Hispanic and 27 percent African American. But what I discovered very quickly was that we all shared a special minority status—the status of being methadone patients—and that status transcends boundaries of race, ethnicity, and social class.

This project runs itself, and it runs itself because the peers know that I'm not the boss of this project, that they are. What they want is what we do. And they also know it's not lip service. We do off-campus events, like visiting museums or bowling, that allow people to socialize and have fun. We have to do something where people talk and laugh. The actual interventions we do are really unimportant. What's really important is the peer nature of the project. The peers themselves decide what they want to do, whether it's a book club or an activity in the community. For the first time in their lives, they're asked what they think and what they want to do with their lives, and what they want to do with their time. And you know what? They respond great. They take charge of their own recoveries. They've been around. They know what they need. They know better than I do.

Bill: What are the kinds of things that people who are involved in MARS get that you wouldn't see being received in a traditional methadone clinic?

Walter: One of the things about methadone, and a lot of this has to do with pressure from the communities, is that patients are encouraged to get their medication and leave. The patients call it “cop and go,” which is a shame. It's right from their addiction. So what happens is they never get the opportunity to socialize or to stay with other people who are successful patients. I'm going to shock you right here, but I want to say something. A methadone clinic is not a very recovery-oriented place. If you think about it, you have people who just came into the clinic, who've been on treatment for an hour, and they may be more interested in where the good crack house is than in recovery. So what's happened is you have people who are actually looking for recovery, they have one foot in the world of addiction and one foot in the world of recovery. As much as they might be looking for recovery and want it, the person standing next to them on line may not be. Maybe he's interested in selling sticks or something else. So it's very difficult for them. The people they associate with on the line in the clinic may not be interested in recovery and patients are told to leave as soon as possible because you can't loiter in the vicinity. But here, when they leave the clinic, they make a decision. They can make a left, get into the elevators, go upstairs, to 161st Street in the South Bronx, or they can make a right, and

come to the MARS center. They come to the project, and they can spend the entire day here; they can spend an hour here. Whatever part of the day they want. They get to associate with other patients and learn and be asked their opinion. They don't get that at a most methadone programs. One of the things I would really like to see methadone programs do is make space available for recovery-focused activities. Even if it was just one room somewhere for peer initiated 12-step groups or whatever the patients wanted to do.

It's so important for patients to have contact with other people. In methadone clinics, we don't get that. Most of us in recovery get it from going to 12-step meetings, but methadone patients are often ostracized from 12-step meetings. We have Methadone Anonymous, but Methadone Anonymous really only exists in the methadone programs. At MARS, we have MARS Spiritual Recovery, and that's not because we're opposed to Methadone Anonymous as much as opposed to the name. Methadone Anonymous implies that you need to get off methadone. So we do our own. We have MARS Spiritual Recovery.

It's so important to patients to have a sense of community. In early treatment, methadone treatment had a feeling of community. If you were on the line and you were at the methadone program with Dr. Dole in those days, and somebody came in and said, "Hey, you know there's some really good dope on the corner," the other patients would take him to the side and say, "Hey, we don't do that here. This place saved our lives. We love it here. We just don't do that. If you want to do that, go someplace else." But with the expansion of treatment, and the rapid expansion, that sense of community was lost. Patients don't get it because they're told they have to take their medicine and leave the area. One has to see successful people to advance in recovery. If you don't give the patients the opportunity to see that at the program, they're not gonna get it anywhere else. It's the only place where methadone patients can see other methadone patients.

Bill: Walter, what do you think is the future of medication-assisted treatment and recovery?

Walter: Well, some of my colleagues are naysayers and there are some who think methadone is going to be completely gone and be replaced by Suboxone, which would be terrible because Suboxone doesn't work for everybody. What I see 10 to 20 years out—and I really have a positive feeling about this—is improved medications for the treatment of the whole spectrum of addictions. I think the treatment silos will disappear and

addiction treatment centers will provide a whole spectrum of services to address all patterns of addictions—where people will get what they personally need and not just what a particular site offers. The people who need methadone will get it, and the people who need Suboxone will get it.

The doctors will be better trained, and we won't have to worry about people dying during induction. There are things we could change overnight

I don't know any medical school that doesn't get public health service money. So if the public health service says, "Hey, we want a six-hour course on addiction," we'd have it.

Bill: Walter, you referenced the problem of silos, and I'm wondering if you would see a time when rather than being in competition with behavioral treatment, medications will actually dramatically enhance the effectiveness of behavioral treatments and vice versa?

Walter: Oh, I definitely see that. Methadone is not a magic bullet; the behavioral aspects of addiction treatment must be effectively addressed. Unfortunately, we have one side saying addiction is purely a behavioral problem and the other side saying addiction is a brain disease. It's both, and as the science gets better distributed, people are going to realize the importance of both. I think we need to work together to blend these treatments.

Bill: Walter, let me ask a final question. You've been part of a small cadre of very visible advocates of medication-assisted treatment and recovery. Do you see a new generation of advocates coming behind you? Are we working to prepare them?

Walter: The National Alliance for Medication Assisted Recovery (NAMA), who I work for, has been reaching out to the other medication advocates to create more of a unified front and to encourage a new generation of advocates. My priority right now is in the area of peer recovery support services for people in medication-assisted treatment. I think that I have somebody trained who could probably take over about 90 percent of my function. The interesting thing is, most of the people who work for me are people who never had a job before in their life. One of the young ladies working for me, she's had a couple of minor jobs in her life, but she just glows at this. She's just incredible. She has a talent for this. You have to spot them and bring them along. I'm helping her get a basic foundation. Here's somebody who's very bright and articulate, but she doesn't have a

GED. So now we have her going for a GED. As soon as she gets that, we're going to get her into college. There are people, not as many as we'd like, but I think that each of us who's doing this work has an obligation to find and train our successor. I'm 60 years old. How much more time do I have to do this? Nobody lives forever. I love my job, but still, I don't want what I've accomplished to go by the wayside when I'm no longer here. I want to be able to turn over what I do to somebody so it will continue into the future.