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## Advocacy and Medication-assisted Recovery: An Interview with Lisa Mojer-Torres (2007)

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Inclusiveness is one of the distinctive core values of the new recovery advocacy movement. That value is predicated on the belief that there are multiple pathways and styles of long-term recovery and that the shared elements of those pathways and styles are more important than what distinguishes them. One of the most complex, conflict-ridden, and stigma-laden topics of discussion within recovery circles and the larger culture is that of medication-assisted recovery. In the following interview, I explore the life and life work of Lisa Mojer-Torres, one of the most committed and competent recovery advocates in the country.

**Bill White:** You have specialized in civil rights and health law, representing people who experience discrimination because of their past history of addiction or their recovery status. Could you describe how you came to this role?

**Lisa Mojer-Torres:** My commitment to legal advocacy on behalf of people in recovery has its origin in my personal struggle with active addiction. In building my own “bridge” to recovery, I became an advocate for medication-assisted treatment. However, it was the impact of my experience as a victim of discrimination while pursuing sustained recovery that ultimately shaped my career as a civil rights attorney.

I was introduced to heroin in my early teens. I now recognize my drug experimentation as a quest to self-medicate a teenager’s frustration, insecurity, discomfort, fear, and raging hormones. While most of the drugs I used were recreational distractions, heroin “completed me.” I was addicted in no time and within a few months I transitioned from snorting to injecting heroin in order to maximize its effect. This was the mid-70’s before the AIDS epidemic. My (middle class) parents were absolutely horrified about my drug use. They were particularly frustrated with the professionals they had turned to for help. I had been through several facilities, multiple modalities and even a relocation to

Puerto Rico, all of which resulted in a resumption of my heroin use.

Finally, in my late teens, I was admitted into methadone maintenance treatment. Methadone maintenance was the only modality that allowed me to stop using heroin so I could focus my energies on the rest of my life, which by then was in shambles. After a few years of heroin-free stability as a methadone patient (I excelled in college and was admitted to law school at NYU), I came to believe I had overcome my heroin addiction; that it was a thing of the past. And so I left methadone treatment, only to be stupefied and disgusted when a year later, at law school back in New York, I relapsed.

I didn't understand the chronic nature of the disease of opiate addiction. I had no knowledge about the pharmacology of methadone, and I wasn't able to appreciate the crucial distinction between methadone as a medication and methadone as an over-regulated, consumer-unfriendly treatment system. And so, when I reentered methadone maintenance treatment, I was ashamed of my failure to manage my heroin addiction and disgusted that I would be subjecting myself to the clinic's control. I knew I didn't have the energy or other resources to maintain active addiction and AIDS was becoming an increasingly ugly reality, but I resented having to go to a methadone clinic day after day; I felt it was demeaning and beneath me.

I despised myself for letting my heroin use get to a point where I didn't have a choice and for the next several years, methadone became the "scapegoat" for all that was wrong with my life. So, I carefully devised a plan that would provide the best possible chance of resuming a drug-free life. I chose one of the finest drug treatment programs money could buy and within a few months, I was weaned off of methadone and introduced to the 12 Steps. My discharge plan, which was pretty much the standard at that time, integrated weekly psychiatric care

with daily attendance at Narcotics Anonymous meetings.

At that time, sustaining my recovery was my daily objective and sole function. I was without external pressures or distractions; I had the support of both a wonderful, loving husband and family; and I had never in my life been more committed, more motivated or more determined to succeed. Despite having everything I was told I needed to live "drug-free" (and then some), despite all of the careful planning and coordination of resources, and most of all, despite my best most focused effort (I had never wanted anything more), I failed. I relapsed.

I was caught off guard, on my way to my therapist's office one morning just before my 60th day of sobriety, when I opened my car door, looked down and found illicit drugs there, in the snow. (I thought my "Higher Power" had actually put it there for me.) The experience; the relapse; the failure; the return to heroin broke my heart. Eventually, the weight of that failure also took away my will to live. I believed my addiction was beyond fixing. I was so disappointed in myself; so full of shame (I could not bring myself to share it with my family). I did not think I would ever be free of the hideous monster my heroin addiction had become. I did not want to live consumed with fear, lying to the people who loved and believed in me. I couldn't see the point of continuing to struggle with something I had no control over especially in light of the personal devastation and toll it was taking on all that had ever mattered to me. I just could not imagine continuing to live a life where, at any given moment in time my entire thought process was vulnerable to hijack. And I knew it was only a matter of time before those (drug) thoughts coincided with an opportunity to get high. Not knowing what else to do until I could plan my life's end, I returned to a methadone program.

Something different happened to me during my final episode of methadone maintenance treatment. It began with an increasing appreciation for my own ignorance about

methadone. I developed a thirst for factual information and eventually (it was a process), I acquired a thorough understanding of how methadone functioned to manage specific elements of opiate addiction. I came to understand my heroin addiction “monster” as a brain disease; the cravings and compulsions as the manifestation of that disease; and methadone as a medication that could neutralize the symptoms. That understanding helped me to reclaim my self-respect and dignity and made it possible for me to thrive in methadone treatment. It allowed me to work with my doctor to find the effective dose of methadone that could silence the monster (without invoking arbitrary limits on how long I could continue taking it). It allowed me to “forgive” myself for the failure I thought I had become. In finally learning about some of the consequences of a structurally and functionally damaged brain, I was able to appreciate the limits of my own efforts in trying so hard to manage my obsession to use. I realized that my damaged brain was at the heart of the heroin addiction “monster.”

Methadone provided me with stability and, for the first time I experienced freedom from the disease’s burdens. After what I’d been through, I felt tremendous gratitude about having access to a medication that is both safe and effective in quieting my cravings. If my drug of choice had been alcohol or cocaine, I wouldn’t be in the same situation. Not having to live my life burdened by the limits of active opiate addiction or the dread and fear of relapse has provided me with a bridge to recovery. It has allowed me the capacity to look outside and beyond myself, onto others, especially those who are suffering. The experience has motivated me to share my story and the feedback I receive fuels me with enough courage to continue to do so.

I decided that I would become an advocate and try to help others learn about the disease of addiction with the hope that, as has been my own experience, the information might help them discern

between the part of their disease that is physiological and that which is behavioral. I hope the information will help people to forgive what they really cannot control; and take responsibility for that which they can, including the making of better, more informed choices about treatment and recovery.

Having found a bridge to stability and peace in recovery, I was able to finish law school and pass NY and NJ bar exams. I was in the process of being admitted to the NJ bar association when I became a victim of discrimination. That profound experience would shape the course of my career and impact the path of my own recovery.

I confronted every conceivable type of misinformation and ignorance about methadone maintenance treatment during the “character review” process for admission into the New Jersey State Bar Association. My particular case was subject to committee hearing because I had (naively) answered the (illegal) inquiry about whether I had any history of drug or alcohol abuse truthfully. I had to appear before a committee of six attorneys who would assess the fitness of my character as a potential member of the bar and issue a final ruling. At the time, I was thriving as a stabilized methadone patient for and provided years of clinical records documenting regular random urinalysis (to substantiate abstinence from illicit substances).

My case was not complicated by a criminal record either, which often weighs people down in their recovery. Nevertheless, the committee decided that my admission should be subject to multiple conditions the most offensive of which involved my having to use a legal preceptor to supervise my handling of any clients’ funds. I was shocked at these conditions; pained to have been so misjudged and frustrated that the committee wasn’t able to process the facts we’d provided. Ultimately my legal efforts to challenge the conditional admission as discriminatory prevailed (and I’m admitted unconditionally in both NJ and NY) but at

great cost to my family and myself. The experience was a wake up call for me; it also changed my sense of priority and the direction of my advocacy efforts. I decided to use my legal skills to help combat discrimination—especially discrimination related to methadone and other medications used in the treatment of addiction. I became somewhat of an expert and began to specialize because quite frankly, nobody else was interested and willing to make the commitment. I had nowhere else to refer people who called me for help.

**Bill:** What do you feel are some of the most significant areas of discrimination facing people seeking or in addiction recovery today?

**Lisa:** People in recovery face discrimination in a broad spectrum of areas, from employment to housing, from denial of access to public services to denial of such basics as medical care and insurance to cover treatment. Those with criminal backgrounds face even greater obstacles as they negotiate the recovery process/their recovery paths.

In terms of the most common discrimination towards people in or pursuing recovery, the area of discrimination that has the greatest impact on the most people is definitely insurance; the inability to secure coverage for those services, including treatment and recovery, which are necessary to overcome active addiction and attain sustained recovery. In terms of what impacts the greatest number of people who are in recovery, it'd have to be employment discrimination: not being able to get or seek jobs, including professional work. The medical profession is probably one of the worst offenders. For people in recovery who have criminal backgrounds, the obstacles which derive from stigma and discrimination are that much more impossible.

But, given everything I've had an opportunity to experience and learn, the people in or seeking recovery who are most commonly the victims of discrimination would have to

be, hands down, methadone maintenance patients. There are people who are in critical roles of responsibility and influence (specifically, judges and law enforcement personnel, family court personnel, social workers, clinicians, physicians, and employers) who don't have the requisite medical education and haven't received any training as to the pharmacology of methadone who nevertheless routinely impose prescriptive terms as to whether opiate addicts can enter or remain in methadone treatment. Whether or for how long a patient should continue in methadone maintenance treatment/recovery is first and foremost a medical decision for the patient and his or her treating physician and the prescription by anyone but a trained medical doctor amounts to the practice of medicine without a license. You wouldn't believe the amount of arrogance, ignorance, and self-righteousness expressed in opposition to methadone maintenance.

And since you asked, government-sanctioned discrimination is perhaps the most significantly offensive because our tax dollars are paying salaries and financing services and programs that actively discriminate against those in methadone maintenance treatment by refusing to admit or accommodate them or by refusing to even offer medication-assisted treatment as a valid treatment option or referral.

**Bill:** Do you represent people spanning the whole spectrum of discrimination cases?

**Lisa:** I have developed a specialty in representing methadone patients, but there are specialties within the practice of law and I regularly refer clients to housing specialists, criminal attorneys or others. One of the problems facing recovery communities is the need for local referral networks of attorneys who can pursue discrimination claims. There is also a need to establish a referral of "recovery supportive" attorneys across the specialty areas as an important and much needed recovery support service/resource.

**Bill:** Where do we start to end such discrimination?

**Lisa:** First and foremost, we have to educate members of the recovery community that they have rights. Discrimination is happening all the time, but too many people don't recognize it. Many, many addicts believe that they deserve to be treated badly and that they (the addict) brought it on themselves by continuing to use drugs so they passively accept (mistreatment) by others. Most important, these feelings tend to outlive the active addiction and permeate recovery, often for years. Even when a person in stable recovery is mistreated, distorted perceptions about his/her own past drug use makes it hard to identify actionable discrimination. Too many people, including addicts, believe addiction is a personality disorder that can be fixed with resolve and determination.

Stigma and misinformation about how simple or easy it is to voluntarily stop using drugs contributes to intense shame and low self-esteem in addicts who fail to do just that, regardless of their personal efforts or desire to stop. This shame in combination with public and private condemnation in the form of discriminatory acts are often accepted as the price of indulging in drugs and tolerated as consideration for being an addict. Without correcting the fallacies upon which stigma flourishes and discrimination is enabled, the cycle is perpetuated. So education about how to recognize discrimination is only part of any meaningful effort to end it. Without a foundational understanding about the disease components of addiction and how they weigh in on the perpetuation of stigma and discrimination, it isn't likely to be challenged

As a civil rights attorney, I am often challenged to discern between the effects of stigma, which are horrendous, almost always rooted in ignorance (but not necessarily illegal), from discrimination which involves a violation of established law. Identifying discrimination is the simplest of my tasks. Even victims who know that

discrimination is unequivocally wrong and illegal, have reservations about whether or how to respond.

Ironically, in deciding to affirmatively challenge discrimination, the victim runs the additional risk of exposing her/himself (as a former addict) to even more people. Legal challenges can be incredibly expensive both in terms of time, energy and money to fight. Because the law isn't always clear or strong, the effort can involve much more risk than most can afford. Much depends upon where the discrimination occurs and the particular parties and facts involved. Victims with longer, more established recovery histories fare best, although documentation is the exception. Only the smallest fraction of these cases result in verdicts with damages for emotional pain and suffering and I have yet to know of any victim who wasn't absolutely devastated by having their hard-fought recovery interrupted with discriminatory acts. (It's hard enough to forge a path and build a life in recovery that doesn't revolve around drugs without the added obstacle of discrimination.) For these and other reasons, people in recovery from drugs and alcohol addiction who believe they may be victims of discrimination more often elect not to pursue legal challenges.

We must remember, though, that in addition to the victims of discrimination not pursuing their rights, many of the state and federal offices that are charged with enforcing the laws against discrimination do not prioritize discrimination against people recovering from addiction. The national recovery community, through Faces & Voices of Recovery, is taking a lead in making the fight against discrimination towards people in recovery a priority.

So, to respond directly to your question, we can begin to put an end to discrimination through a national educational initiative to inform people (including and especially those who are directly affected) about how addiction is a disease of the brain and how and why discrimination towards those who are in recovery is wrong and illegal.

However, this discrimination will only end when we stop remaining passive victims and work together to identify and challenge each and every instance of discrimination. Through a coordinated, nation-wide search for federal, state and local discrimination cases, we can identify the most promising fact patterns for establishing the most favorable legal precedence. The effort will result in a most powerful message not to screw with the recovery community.

**Bill:** Do you feel like we're making progress in ending these kinds of discrimination?

**Lisa:** I really do, but I'm "cautiously" optimistic, sometimes even hopeful, about the future. We're not anywhere near where we need to be, but the progress is significant. The scope and depth of the scientific understanding of addiction is growing exponentially. I am also hopeful that the huge gap between breakthroughs in the neuroscience of addiction and the public "cultural" understanding of addiction is finally closing. The recognition that addiction is a brain disease and that there are increasing numbers of options to effectively manage this disease in ways that allow people the ability to enjoy full and productive, normal lives—is a crucial principle to communicate to the public.

HBO's Addiction project is very promising. Other organizations including the Robert Wood Johnson Foundation, Faces & Voices of Recovery, Join Together, CADCA and local recovery community organizations are using the film, which showcases the latest science and clinical practices and the use of medications is up front and center. The show, I can tell you, is entertaining, riveting, potentially powerful and by far the most effective media product I've viewed to date in helping the public comprehend how addiction is a chronic, brain disease. While this film could and should have been more inclusive of the recovery process, as an advocate of medication-assisted treatment and recovery, I consider this film a gem. This film and coordinated events should provide an opportunity for dialogue on an issue that

touches as many of us as it does and impacts upon our culture and life quality.

**Bill:** What is your personal response to seeing this new science of addiction finally reach the public?

**Lisa:** The prospect of there being a vehicle to help inform the public about what we know to be true regarding substance addiction absolutely thrills me. That a major media entity would assign award winning filmmakers the task of creating an entertaining film on the subject is about as big a lottery win as the addiction advocacy field could imagine.

I've been telling and re-telling my story because it's the only way I know to help others appreciate the significance of the "science" of addiction. You know, I've participated in numerous stigma and discrimination study panels (on the addictions) that have each consistently recommended national marketing campaigns geared toward communicating the facts, including medical disease aspects, of substance addiction to the public. Faces & Voices of Recovery commissioned a study as to the "public's" receptivity to the "disease" issue and it turns out to be a complicated issue that hasn't yet been successfully communicated.

So this HBO film, which I believe does such a magnificent job of communicating this very tricky issue in a way that is far more entertaining and at least as effective as my sharing my story, is incredibly welcome and appreciated. For the very first time, this film allows me to sit down and catch my breath for 90 minutes or so, until it's over and we can begin to take advantage of the dialogue it's no doubt provoked and then to plan and figure out how to best use it as the heart of an educational initiative for special populations, including our state's legislature.

When I first had to return to methadone treatment, after believing I had overcome my heroin addiction once and for all, I was annoyed and ashamed. I "tolerated"

methadone as a temporary solution to my drug addiction. When I last returned to methadone, after my best chance for an abstinent recovery (in terms of treatment resources, recovery support and personal motivation) failed, I was absolutely broken. The experience took away my desire to live because it became painfully clear that, the best of my inner strength and determination was not good enough. I did not believe there was anything left with which to fight my addiction.

It wasn't until I came to understand that there are actual sections of my brain that are structurally and functionally different from a "normal, healthy" brain that I was able to appreciate how my determination could never be a match for something that isn't working; it'd be like trying really hard and then expecting to walk on a broken leg. I stopped hating myself for what I believed were defects of character and began to take comfort in the logic that a medication could be helpful in the management of my disease. And I came to understand that an effective dose of methadone could silence the horrific, monster cravings for heroin and the obsessive thinking about getting and being high. That same dose neutralized the overwhelming emptiness and void I used to dread, without heroin. I can't begin to express how absolutely life altering this realization has been for me. This is why I am so passionate about educating others, including and especially those suffering from addiction.

**Bill:** Lisa, what do you think are some of the most pervasive misconceptions about methadone that continue, not only among the public, but also the treatment communities and the recovery communities?

**Lisa:** The most pervasive misconceptions about methadone center around the images of the methadone patient as the same or similar to that of a mentally deranged, homeless, unemployed, semi-dangerous, person in an obvious state of intoxication, (nodding off here and there), eager to share

barely coherent stories about the worthlessness of methadone. In its zeal to "entertain" the media have irresponsibly perpetuated this inflammatory image as the product of "methadone". That image fails to communicate accurately, the complete picture of the person's circumstances because quite frankly, it's more depressing than entertaining. The true facts about the people whose images are published are that they are almost without exception: indigent, either homeless or in transitional housing, unemployed, unskilled/uneducated, poly-addicted and under the influence of some other substance (most likely benzodiazepine) and, more likely than not, suffering from a psychiatric disorder (more likely than not, undiagnosed and/or untreated).

The most visible of the stereotypical methadone patients are people in government-subsidized methadone maintenance treatment programs in larger urban areas. These have evolved into a sort of "harm reduction" net, catching chronic opiate addicts who are mentally ill, poly-chemically addicted; and without resources, family/community integration or prospects (i.e., their addictions having burnt the bridges to a normal, healthy, independent, addiction-free life). Their use of methadone has been identified as the primary "cause" of their failure to thrive.

Methadone is specific to treatment for a single class of drugs: the opiates (note, it is also used as analgesia to treat pain). It makes absolutely no sense to heap such high expectations upon a single medication (can you imagine expecting insulin to cure overeating?). The fact that patients suffer from active poly addictions or psychiatric disorders while in methadone treatment is not due to any defects in the medication/methadone hydrochloride. Methadone has limited scope and purpose; it is not, nor was it ever intended to be "a magic bullet" to cure all addiction, or even to cure all of the various behavioral elements of opiate addiction.

Although methadone's efficacy centers on ending addiction to opiates, terminating patients from methadone (maintenance) treatment wouldn't be indicated for patients who do not abstain from abusing other substances because. At a very minimum people who are receiving methadone treatment with poly addictions (often with co-occurring disorders) are subject to observation by professional staff at the very least, once daily, preserving the possibility for effective interventions.

Without referral to mental health and/or poly substance treatment services, most patients with co-occurring diagnosis who are also poly addicted linger for years in the early or intensive phases of methadone maintenance treatment. Adding to the problem is the fact that in the course of their lingering, many of these patients require detoxification from alcohol, benzodiazepine, etc. However, many facilities will not accept or accommodate methadone-maintained patients. Many long-term residential treatment facilities and halfway houses are notorious for refusing to admit patients who take methadone to manage their opiate addiction.

In addition to a lack of access to treatment in long term facilities, access to acute care such as in-patient detoxification services for methadone-maintained patients from benzodiazepine, alcohol, cocaine, etc. is also limited. Mental health facilities that will diagnose, admit or treat methadone-maintained patients are also rare. Some of these limitations are due to a lack of resources including funding but more often than not, stigma and discrimination are involved. Unfortunately, the patients who are most in need of these services are also those most visible to the public and least likely to refuse a media interview where the negative image is perpetuated.

What you never see associated with methadone is the countless numbers of professionals, such as lawyers, doctors, business people, celebrities, artists, athletes and others who have been and continue to

be sustained on methadone for years. They are the stigma-silenced voices of methadone in the United States.

**Bill:** Do you see methadone clinics developing more recovery-oriented philosophies in service practices?

**Lisa:** Only to the extent that there is funding to cover/reimburse for these services. We're beginning to see an interest in expansion, but without incentives/funding and technical assistance to assure system-wide compliance, we are not likely to begin seeing a serious expansion of these services soon enough.

I believe there is a clear distinction between patients who are in the earlier phases of methadone treatment from patients who have achieved pharmacologic stability and are in sustained recovery, no longer using illicit substances, etc. At this point, the medication's functions change from one of "treatment" for primary active opiate addiction to that of supporting and sustaining recovery and relapse prevention. I believe that as the field of substance addiction treatment begins to shift in orientation from acute care to one which is consistent with our knowledge of substance addiction as a chronic disease, the shift in services will follow. Again, though, the incentives, technical assistance and accountability for outcomes, etc. will have to be in place to assure more than a superficial transformation. Token compliance with ill-defined concepts such as "client-centeredness", "recovery", and "recovery-oriented services", "recovery support services", etc. won't do the job.

There also needs to be a respect for and deference to the organized recovery community to determine the process and deliver the particular services for each client, allowing him or her to identify their individualized paths to recovery. Otherwise, as with the rest of the treatment field, recovery-oriented philosophies and services will be limited and referred to the current

universe of established volunteer, peer-to-peer 12 step recovery meetings.

It is time that we nested methadone within a vibrant recovery culture and made sure that an array of comprehensive services are available for every patient who crosses the bridge from treatment into recovery through the nation's methadone clinics.

**Bill:** Do you think pilots of peer-based recovery support services in methadone clinics is a sign of changing attitudes towards medication-assisted recovery?

**Lisa:** I think these pilots are signs of changing attitudes, but it's the actual behavior I'm more concerned about. When addicts who responsibly take prescribed medications are no longer subject to rejection, singled out for special treatment or given conditional privileges, when they are treated as equals and not distinguished due simply to the fact that they take a medication, then I'll begin to relax. Why shouldn't someone who takes Suboxone or methadone for chronic opiate addiction who has achieved and sustained abstinence receive equivalent respect for their courage and wisdom, for their individual treatment experiences? As an advocate for diversity in recovery, I wonder why can't they celebrate and be celebrated for their unique recovery paths? When this happens, then I'll believe the underlying "attitudes" may be changing.

I believe these "pilots" are actually evidence that these attitudes aren't changing fast enough. If the doors to all peer-based recovery support services were truly open to methadone-maintained patients, the methadone patients would not need funds to develop parallel tracks of "segregated" services or participation in those services would be optional, rather than, the only option.

**Bill:** What do you see as the future of medication-assisted recovery?

**Lisa:** Quite simply, I believe the future is in the development of medications that

respond to the changes and deficiencies in the brain structure and function associated with addiction. The pharmacotherapeutic benefits of methadone and Buprenorphine for opiate addiction include cessation of opiate cravings (among others). I believe we'll see the introduction of medications to provide similar benefits for alcohol, cocaine and methamphetamine in the future. There are very promising medications to look forward to which help alleviate cravings for alcohol, methamphetamine and cocaine. Also, given that a specific addiction-related gene has been isolated, a vaccine to prevent addiction onset isn't outside the realm of possibilities and, according to the neuroscientists at the Picower Institute, a vaccine is certainly possible within our lifetime.

We're learning new things about the brain all of the time. I recently read an article where stroke victims who had brain damage at very distinct parts of the brain actually "forgot" that they smoked cigarettes and the implications for other substances of abuse/addiction are fascinating. I am very confident in science; it's what the rest of us do or don't do with it that matters. If we can't put a serious dent in the stigma, misinformation and myths about addiction, the cycle of active addiction, blaming the addict, criminalizing addiction and the endless costs of the war on drugs will continue to spiral out of control (and the chasm that exists between science and reality/practice will continue to deepen).

We are an "anti-medication" culture in that the use of medication (including how much and for how long) is subject to judgment and often perceived as a "crutch" to the human will. The ability to refuse medications (even those known to be safe and effective) is always applauded and "no medications" (i.e., women who refuse epidurals during labor are heralded as heroes) are always preferred as the ideal.

My hope, and that of my colleagues, is that with the introduction of new safe medications which are incredibly effective in eliminating

cravings for alcohol, medications will begin to become more and more widely used and accepted. With their increased use, acceptance of medications as a legitimate component of treatment, recovery and prevention of addiction to substances will evolve to become a norm. I am hopeful that in combination with public understanding and acceptance of addiction to substances as a disease, the anti-medication era in the treatment of addictions will begin to fade out along with the myths, misinformation and, ignorance. I have confidence that in addressing ignorance and bias with education and eventual de-criminalization, stigma and discrimination associated with methadone will no longer function as an obstacle to people's recoveries.

I continually scream at the top of my lungs, "Medications are not a magic bullet for addiction!" Medications offer different benefits to different people at different times of their life and at different stages of their diseases in order to manage different components or symptoms. Addiction is a chronic disease for which, at this point in time, there is no cure (but look out for vaccines within our lifetimes). Medications are important management tools just as they are with other chronic diseases (compare the development of medications and other aids to ease the withdrawal of nicotine addiction). Whether a medication is something to be used briefly or for a lifetime is not a question for political debate but a very personal decision that is most appropriately left to a patient and his or her doctor.

The key for me as a "consumer advocate" is to make sure competent consumers have accurate information in order to make informed decisions about whether or not a particular medication, treatment service, regimen, modality or facility might be something that could be of benefit to them. A primary component of that information is education about addiction as a medical disease with behavioral components.

**Bill:** You have served on the National Advisory Council for the Center for Substance Abuse Treatment (CSAT). Describe what you tried to bring as a recovery advocate to that role.

**Lisa:** Each Council is different and you serve primarily as an advisory resource for the Director. CSAT's Advisory Council provides an invaluable opportunity to impact on the future of the national treatment (and recovery) field. As a Council member, I considered my primary role as a representative of "consumers" (of addiction treatment and recovery support services) with always a special interest in medication-assisted treatment and recovery. The weight of a unified Advisory Council is a very powerful tool in helping to direct future policy, funding and other Center initiatives. I am most proud of the impact we had on assuring that the "authentic" voice of recovery was represented throughout the Recovery Community Support Program (RCSP) grant application and award process. Subsequent generations of RCSP funding assured that the local recovery advocacy organizations had a vehicle through which to become active. Those organizations provided a structural foundation for the vibrant and wildly successful national recovery organization, Faces & Voices of Recovery.

**Bill:** The RCSP program in its early renditions helped spark a lot of the recovery advocacy activities around the country and then shifted its philosophy away from advocacy and toward peer-based recovery support services. A lot of people are concerned that this will result in a lost focus on advocacy among local groups. Do you share that concern?

**Lisa:** Absolutely. The earliest RCSP grants provided an enormously important source of foundational support which helped to launch the national recovery advocacy movement, represented today through Faces & Voices of Recovery. However, as the organizational grants run out, many of these advocacy organizations aren't able to secure funding to continue operations. People in recovery

who identify themselves “publicly” are vulnerable to stigma and discrimination and unfortunately this same stigma and discrimination functions as the very obstacles that prevent people in recovery from becoming active advocates. In addition to the negative consequences from the public exposure, the national and local recovery advocacy organizations ask for contributions of time, money or other specific resources. Studies show that the vast majority of people who overcome addiction do so without resort to traditional professional treatment or peer-based recovery support services, so the sense of “external” gratitude is rare.

Recruitment into the recovery advocacy movement is definitely a high art form that we are working to perfect. It will be some time before local recovery advocacy groups can transform themselves into self-sustaining organizations. And, of course, the local recovery organizations are the foundation of the larger, national recovery advocacy movement, so the shift of funds from organizations to services impacts us all. Until addiction is de-criminalized and the public changes its image and understanding of addiction to substances as a primary medical disease of the brain, we need every single penny we can borrow, beg or steal to help support the cause. Until people’s fears are alleviated, we will need help.

**Bill:** The National Alliance of Methadone Advocates (NAMA) received their first RCSP funding, which I think is the first RCSP funding of a methadone-related organization. How important do you see the issue of linking recovery support services to methadone clinics and other medication-assisted programs?

**Lisa:** I think the link-up of recovery support services to methadone programs is crucial for both stigma reduction and for retention in methadone. The extension of the chronic disease model into methadone means the acknowledgement that methadone maintenance can and, if the continuum of care is followed, should function as a

resource of recovery support. That having been said, the introduction of supplemental recovery support services tailored especially for methadone maintenance patients is a logical progression.

In a perfect world, long-term stabilized patients in methadone maintenance wouldn’t need support services any different from anyone else in long-term recovery. However, until we eradicate stigma and discrimination towards methadone, these services will be invaluable in establishing a supportive recovery environment in which patients can thrive. With recovery support services, more stabilized patients are likely to continue taking methadone and from this population come future leaders. Likewise, the pool of potential recovery support peer/mentors deepens.

I am thrilled that the National Alliance of Methadone Advocates (NAMA) aligned with Albert Einstein Hospital to receive an RCSP grant. I look forward to this project’s legacy, which should be a host of replicable models of recovery support services for methadone-maintained patients.

The methadone advocacy field also needs consumers who can lead the way toward a greater integration of medication-assisted treatment and recovery models with 12-Step and other recovery models (many half-way houses and residential treatment are intolerant of methadone maintenance as a legitimate treatment for addiction). The stigma attached to methadone makes it difficult to recruit such potential leaders and they are unlikely to voluntarily step forward into such positions of visibility. The RCSP program of support services for methadone maintenance patients should provide a very rich environment from which to recruit advocates and mentor new leaders. We need an affirmative plan to actively recruit and promote such leaders from the hidden world of those who are thriving methadone maintenance.

**Bill:** Describe that hidden world.

**Lisa:** I once spoke at a reception at a medical maintenance program in New York City that had some 200 “elite” methadone patients. I spoke about the legitimacy and effectiveness of methadone and the misguided stigma and discrimination attached to it, as I always do, but I also spoke about how we were victims of the stigma and discrimination and how it was incumbent upon us to change that. It was an incredible experience. There were enough lawyers in the room for our own Bar Association and at least five or six doctors. There were artists and celebrities all over the place and highly successful business people offering money to support the cause. It was a wonderful, hopeful day. I left with lots of names, phone numbers and email addresses and many commitments to help. We were all going to join committees, pool resources and work on action plans.

A couple weeks later I started making calls and sending emails but I got almost no responses; it was frustrating and I was baffled. How unique and how valuable it was just to have a social network of new friends each with this common bond (never mind our combined potential to do something positive for ourselves). I hoped we would share experiences and work together on a vision for eliminating the stigma attached to methadone, but people weren’t returning my calls. I began to get angry and then it occurred to me that this “non-response” was actually a consequence of how deeply stigma and shame permeates the lives of people in methadone maintenance. While I am furious with the extent of the stigma, I really feel nothing but compassion for the victims, my fellow patients.

There is a large hidden universe of mainstream (and quite exceptional) people whose lives differ from that of anyone else’s in only one small respect: the daily task of consuming a specific medication to help sustain recovery from opiate addiction. But the effort in keeping that fact a secret is unbelievably costly in that it takes enormous effort to keep track of who knows what and how much. In social situations, rather than

relaxing, and sharing your thoughts and feelings with friends, family members, you’re dodging this question and avoiding that subject, all in an effort to protect that which you’re unwilling to share. And so it isn’t relaxing or even fun, but it becomes work to be in the company of others who don’t know some or all of the facts about who you are. And I know this because I also live it; believe it or not, in the course of my advocacy work and educational efforts. It is actually easier for me to share intimate details of my life with total strangers than it is for me to tell some of our friends I was ever an addict.

**Bill:** You’ve been involved in all of the major advocacy meetings at a national level in recent years. At a personal level, do you see a lessening of isolation of the medication-assisted recovery advocate from the larger recovery community and recovery advocacy community?

**Lisa:** I think that is changing; I hope it is lessening. People have come up to me after I’ve presented and told me that hearing me speak has affected their former hostility, skepticism or even their ignorance toward the role of medication in recovery. The best part of what I do is to hear this type of feedback, especially when it’s from someone who is directly affected. On a national level, in terms of the recovery community, I have noticed a definite trend in expressing more tolerant attitude toward medication-assisted treatment and recovery; no doubt. However, one word of caution is that the bias against methadone and other medications runs very deep and it’s just that it’s now become politically incorrect to express it publicly. Personally, I’m much more comfortable knowing who my adversaries are and what they’re thinking.

I believe it is critical that diversity and the inclusion of medication-assisted recovery were structured into the very founding principles of Faces & Voices of Recovery and that Faces & Voices has thoroughly absorbed this principle. Its leadership has reinforced. I volunteered to be among the first group of original board members to

rotate off of the board, my term expires this July. I will remain diligent, however in making sure other medication-assisted treatment and recovery advocates are authentically and consistently represented on the Faces & Voices board of directors.

**Bill:** What did it mean to you to receive one of the Johnson Institute's America Honors Recovery awards?

**Lisa:** I was very pleasantly surprised about the award. I was very proud, grateful and honored to have my work acknowledged. I'm an advocate for what remains a controversial "treatment" (medications) among the traditional field of addiction treatment providers, professionals/clinicians and people in recovery. The pleasant surprise came from realizing that my status as a very vocal (and not always diplomatic) advocate for a controversial treatment and recovery path didn't intimidate the Johnson Institute. I felt honored to have been chosen among so many others for this distinction (among a field of many heroes, there aren't many vehicles through which recognition is formalized). While I will always be extremely grateful for having survived the perils of heroin addiction and for forging a bridge to recovery with methadone, this particular award also helped silence my husband's criticisms that my efforts, and our mutual sacrifices, are not acknowledged or appreciated by my peers.

**Bill:** You were part of the planning committee for the first national summit of recovery advocates in Minnesota in 2001. What do you think that first summit experience did in terms of the larger recovery advocacy movement?

**Lisa:** Quite simply, that historical summit was the launching pad for the national recovery advocacy movement, what today is known as Faces & Voices of Recovery.

**Bill:** Following the summit, after Faces & Voices was incorporated, you served as the first chair of its board of directors. From that vantage point, how important do you think

Faces & Voices has been to the whole recovery advocacy movement?

**Lisa:** I think its influence has been central and phenomenal. Faces & Voices of Recovery is THE voice of a unified national recovery advocacy movement. With some very competent people in strategic leadership positions and a highly specialized, dedicated board, we've enjoyed several critical successes; moved to a membership organization and our future is bright with possibilities. We've certainly "arrived" as a permanent fixture in the landscape of stakeholders in the addictions field, and we are poised to play an integral role in the transformation to a more client-centered, recovery-oriented system of care for the addictions. It would have been impossible in 2001 to predict five years later, we'd have 40,000 people participating in more than 500 Recovery Month events. A lot of this we owe to Faces & Voices, the Johnson Institute's Recovery Ambassadors training, and the work of the local recovery advocacy organizations.

**Bill:** When you look at the larger movement, what do you see as the stakes involved in whether this movement succeeds or fails?

**Lisa:** If we, as recovering people, and our families, take on this issue of stigma and achieve some early successes, it will provide the momentum needed to begin what I often refer to as a "snowball effect"--attracting increasing numbers of people from the shadows of shame and secrecy to join this movement and become known as one of many who have taken full responsibility for the successful management of a chronic disease.

See our faces; hear our voices; feel our numbers! Studies have demonstrated that the more people see and hear us, the more they change their perceptions of addiction recovery. We are not the dangerous, selfish, irresponsible, pleasure-seeking deviants perpetuated by stereotype and an irresponsible media. In fact, as more of us begin to emerge and identify with recovery,

the public will realize that they've known us all along; they just didn't know that we also happened to be in recovery. Every reduction in stigma we make lowers the obstacles for others seeking recovery. Maybe I'm idealistic, but I truly believe with the combined momentum of increasing numbers and decreasing stigma, our influence over the public, the field of medicine generally, and the field of addiction treatment is potentially limitless.

Another important element in this "snowball" is that addicts are the population that stands to gain the most from education and information about the disease of addiction and the various services for treatment and recovery support. With an underlying educational foundation about the disease and the wealth of information as to particular services, the addict (and his/her family, and other supports) becomes empowered as a consumer. On the one hand, the information assists consumers to make better, more intelligent, informed decisions in accessing treatment and recovery support services. And the choices made by consumers helps to shape the market and future markets of available services.

I am extremely confident that with the eradication of ignorance and an increasing appreciation for the factual, scientific basis for the disease, the worst stereotypes associated with addiction will begin to fall away; making it more inviting and therefore more likely for people to "come out" and be counted as another face and voice of recovery. What is actually at stake here is not whether or when this snowball moves, because it's already rolling, but where it ought to be directed.

**Bill:** You played a policy advisement role as a Committee member on three Institute of Medicine committees, including the Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders. What has been your experience serving as an advocate at that level?

**Lisa:** "Crossing the Quality Chasm" was my third experience on an IOM Study Committee. The first Study (Federal Regulation of Methadone) was my initiation to the process. I was a bit awestruck with the credentials of my study colleagues, but I felt as though my perspective as the only consumer advocate was respected and valued. More important, that consumer perspective was very much incorporated into the final recommendations to deregulate methadone maintenance treatment and transition into accreditation, which were ultimately adopted. It's a bit ironic, but I now realize that I was advocating for a more client-centered, recovery-oriented system then, over ten years ago.

My second IOM experience was "Bridging the Gap" between research and practice. In the midst of some of the heaviest-hitting researchers, one of my themes was the advocacy for consumer access to the science. My hope is that by having access to the results of the various research studies, consumers will be able to make better informed decisions about treatment (and recovery) thereby impacting the market with an increased demand for more consumer-friendly services.

This last experience was by far the most challenging. The "Crossing the Quality Chasm" series for general healthcare had preceded us (behavioral healthcare) and 20 of the 24 members of our committee were from the mental health field. Much of my energy was consumed distinguishing substance use disorder issues from those of mental health and advocating for "consumers." For the first time in my IOM experience, I questioned my ability to adequately represent consumers of addiction services and I agonized over what issues were not being raised, analyzed thoroughly or included in the recommendations. Ultimately, I believe our recommendations encompassed some important principles, but the final product lacked incentives and direction as to how to even begin to implement the enormous systems-wide transformation. I was actually

quite surprised that the field “embraced” the study with the kind of enthusiasm it has. I realize now that the study is a valuable starting point from which to begin further planning. In this light, there are many more of us now working on the development of alliances, blueprints, instruments and other details to help assure a genuine client-centered services and extension into recovery. While it will take time and resources, I’m hopeful that logic will prevail and consumers will make informed decisions about treatment and recovery services that will impact and ultimately transform the system.

**Bill:** Let me ask you a final big question, and I think it’s a really important one because you’ve been the most public advocate on medication-assisted recovery. Who’s going to be following in your footsteps? Are you developing up-and-coming leaders behind you to help with that process?

**Lisa:** I don’t know that I’m the “most” public advocate for medication-assisted recovery but I can say that I have been around for awhile and personally know the other active national advocates for medication-assisted treatment. We’re a small community and I count each of them as a friend. I speak on behalf of that rather small community in expressing serious concerns about the future of advocacy on medication-assisted recovery. We’re always looking for help from others like us and we’re developing an understanding that each of us needs to begin to mentor promising protégés.

There are several important sources from which to encourage new leadership. First and foremost, the methadone advocacy certification courses have become a breeding ground for future advocates and leaders.

NAMA is using its RCSP grant to establish a recovery support center and services for a significant population of methadone patients in the Bronx, NY. That center will provide a nurturing environment from which to scope out, train, and recruit potential new national advocates. In addition, the New Jersey Access Initiative, under the federal government’s Access to Recovery grant, has trained over 500 mentors who represent an important potential peer-to-peer workforce and an additional potential pool of protégés.

The expansion of physician-prescribed Buprenorphine/Suboxone to treat opiate addiction offers a huge new population of mostly younger consumers who represent a rich source of future advocates. We need to be cautious that Buprenorphine isn’t promoted at the expense of methadone. An alliance for the sake of common advocacy interests is definitely a work in progress.

We need fresh new faces and voices for medication-assisted treatment and recovery to work in both paid and volunteer roles. We need to assure the integration and representation of genuine medication-assisted treatment and recovery advocates into the larger national recovery advocacy movement. We need ambassador-in-training programs for methadone patients who show a potential and have an interest in advocacy. We need to find a way past the obstacles created by the stigma and to appeal to the pool of hundreds of persons like myself to help push the snowball and to assure the visibility of the true faces and voices of medication-assisted recovery.