

## **The Maine Experience: A Strategy to Minimize Barriers to Recovery**

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### **Collecting data about the barriers to medication assisted recovery within recovery communities**

As one of its goals with this AR grant, Maine Office of Substance Abuse had chosen to expand the use of medication assisted treatment (MAT) in Maine. In accordance with this, grant partner Deb Dettor, Coordinator of Maine Alliance for Addiction Recovery (MAAR) worked to seek information within Maine recovery communities to identify barriers to medication assisted treatment and recovery.

A survey was developed by the grant team that asked questions about 1) beliefs and attitudes regarding the use of medications to support addiction recovery 2) recovery barriers that challenge MAT participants 3) experiences people have had trying to access treatment and recovery supports.

A total of 233 recovering women & men provided their input:

- 128 responded to a survey conducted throughout Maine through Survey Monkey online and mail-back requests
- 81 attended 14 focus groups conducted at their outpatient treatment sites or as members of one community-based peer support group
- 24 participated in focus group discussions within methadone clinics

The report 'Barriers to Medication Assisted Recovery in Maine' was completed and distributed by Deb Dettor in November 2007. This synopsis outlined specific feedback regarding 17 treatment and recovery barriers collected from 233 recovering people, the majority of whom were also current treatment participants.

### **The top five identified recovery barriers to be addressed through community education**

1) *Stigma*: Stigma was reported to be the number one recovery barrier throughout the survey and focus group information-seeking process. Within the recovery communities, people from all recovery paths have various biases based on misinformation or lack of information regarding the benefits of medications to assist recovery. Recovery culture tends to be rooted in traditional 12 Step models that promote abstinence. As a result, MAT treatment participants typically do not use these support models since they feel excluded – or report they use them cautiously with minimal benefit.

Recovering individuals who use medication assisted treatment reported they experience additional layers of prejudice and discrimination within recovery communities as well as in treatment arenas

and mainstream society. It was noted that addiction professionals still don't understand the benefits of MAT and that treatment participants face negative attitudes from them. Maine lacks adequate treatment resources and intense NIMBY issues when MAT clinics plan to open in most communities. The police, employers & medical healthcare systems lack information and respond in prejudicial ways to people in MAT. Many respondents also explained that their own stigma about their illness and available treatment get in their way of recovery and that there is not enough treatment or community based support to overcome this.

Respondents explained that they are still seen as being 'drug addicted' due to MAT and that this recovery pathway lacks credibility. Their own families and close relationships continue to label them as 'drug addicts' as do both the general and recovery communities.

**2) Education for families:** When defining their recovery support needs, many participants identified that family members and significant others were key supporters for their recovery maintenance. Focus group participants engaged in MAT stressed the need for these allies to have access to accurate information regarding medication use as well as their own support networks to understand this treatment modality. But in Maine these networks and educational resources are lacking, leaving these key people with no understanding about the recovery /healing process. In addition, because their loved one had been sick in the past, frequently lying to or manipulating them, they had problems trusting what they had to say even when in recovery.

Along with this, recovering people reported that because these close contacts can't get help, they are then unable to provide support to them. Like the general community, their close contacts don't understand 'how drugs will help a drug addict get better'. This resulting lack of support from key relationships can be a significant recovery barrier for many people engaged in MAT.

**3) Education about benefits of medication:** A great deal of discrimination toward MAT participants exists within other recovery groups in which abstinence has been the stated recovery goal. Maine's 12 Step communities have been considered to be unwelcoming toward those using medications to assist recovery, which leads to an experience of alienation for MAT recovering people. These negative views also discourage others in these networks that might benefit from medication from considering its use. In Maine, there are no other established mutual recovery support models outside of traditional 12 Step programs available.

Clear and accurate information about medication is lacking within recovery communities, including their effects, benefits and risks. It is strategically difficult to outreach to these traditional recovery support networks to extend this information; and this combined with strongly held beliefs create barriers for those struggling to maintain medication assisted recovery efforts when they leave the doors of their treatment facility.

**4) Positive MAT recovery role model:** Participants in focus groups expressed their perceptions that the majority of people don't make it – or aren't successful – using medication assisted recovery. When asked if they could identify anyone who is doing well on this pathway, the consensus from group to group was a resounding 'no'. A number of barriers coincide with this

belief: when treatment participants lack hope and belief in their ability to succeed, it is very difficult to maintain recovery efforts over time.

Both the recovery advocacy and treatment fields have long recognized that hope arises when individuals in early recovery witness the successes of others who have been maintained recovery over time. This visibility of someone who can serve as a positive recovery role model is frequently a key support for many recovering people. Instead within our general culture, more frequently we hear about treatment failures related to the use of medications in recovery.

Within community based recovery networks, positive role models are not openly witnessed since MAT participants report they do not often use 12 Step programs due to the stigma or prejudice there. There are no established recovery networks for medication assisted recovery where someone can go to see long-term success or to be inspired. Visible MAT recovering role models are reported to be lacking in Maine.

**5) *Self empowerment as recovering person:*** Within the focus group discussions, the level of disempowerment that women and men feel while in treatment and early recovery was very clear. It is important to note that addictive illnesses lead the afflicted to feel a loss of self-control and disempowerment before people even get through the treatment door. Self empowerment and appropriate personal responsibility are key facilitators of the recovery and healing experience.

So many participants reflected that they lacked financial resources or adequate insurance to seek quality treatment; that quality treatment cannot be found in Maine and that the publicly funded system is problematic or virtually impossible to access for a number of reasons. These experiences also led to further discouragement and an externalized locus of control: 'I cannot do this because I cannot get the help I need'.

When this is coupled with the lack of community support available for MAT participants and the lack of visible recovery role models, participants reported they felt despair as about their situations well as unable to maintain recovery efforts over time.

**Once data was collected, an educational plan was developed to target these barriers**

Upon completion of this effort, Deb Dettor contacted national MAT recovery advocate Lisa Mojer-Torres, JD, who is a practicing civil rights attorney, to review the outcome of the surveys and focus groups. Four specific *'One Face and Voice of Recovery'* presentations were developed that would be delivered by Ms. Mojer-Torres to address the treatment & recovery barriers previously identified. As a speaker, Lisa uses her personal recovery story from heroin addiction as part of her teaching; she also made time in each forum for a question and answer interchange. The invited target audiences included people in recovery, families, friends and significant others; in addition to medical professionals and key community members and treatment providers.

Forums for recovering people and supporters were held during the evening to be more accessible. In total, two were conducted in Portland and the other two in Bangor, key population centers for Maine. At the start of each, Debbie Dettor talked briefly about her work gathering feedback from people in addiction treatment and recovery to learn about the barriers they face, as part of the AR grant process. She also mentioned that the Forums were designed to address some of the recovery barriers reported by the 233 respondents.

As each Recovery Forum was introduced, participants were asked to complete a pre and post survey conducted by MAAR to report if and how these presentations were beneficial to them. The 'pre' survey was designed to capture attitudes and beliefs of participants regarding medication use in recovery prior to hearing Ms. Mojer-Torres speak, as well as their reason for attending. The 'post' asked respondents to record what they had learned from the workshop and whether the information provided impacted their thinking about the issues.

The Forum title '*One Face and Voice of Recovery*' reflects the growing tradition within the recovery advocacy movement that highlights the telling of personal recovery stories. The purpose of this is to demonstrate that addiction cuts across every age, race, socioeconomic status, educational background, etc. Those who take the risk to be public with their stories believe that this process will teach that addiction is a legitimate illness but more importantly that recovery is a reality.

Such story-telling sessions are needed because the problems related to addiction are highly visible in our media and within our service delivery system, whereas recovery does not get the same public exposure. In fact, since recovery becomes invisible when people achieve long-term recovery and reintegrate into society, members of our communities do not realize that people can recover from addiction. This unbalanced view intensifies shame and societal stigma for those with addictive illnesses; and one primary goal of sharing recovery stories is to lessen stigma and discrimination.

#### **Four Maine MAT Recovery Forums took place**

*'One Face and Voice of Recovery'* presentations by Lisa Mojer-Torres, JD:

April 14, 2008 - Maine Medical Center, Portland, for healthcare professionals, 2- 4 pm

April 14, 2008 - Maine Medical Center, Portland, recovering people & allies, 6 – 8 pm

April 15, 2008 – Bangor City Hall Council Chambers, professional & community, 1–3:30 pm

April 15, 2008 – Husson College, Bangor, recovering people & allies, 6 – 8 pm

**Additional community education was provided**

- March 24, '08 – Bangor Daily News story by Meg Haskell
- April 8, '08 - Bangor Rotary Club presentation by Deb Dettor
- April 14, '08 - Maine Public Broadcasting Radio Interview with Susan Sharon, Portland
  - April 15, '08 – Channel 7 TV news, Bangor
- April 15, '08 – live public access cable TV from City Hall, Bangor
- April 16, '08 – Bangor Daily News story by Anna Ravana

**We collected feedback from Forum participants to identify the impact that education made on participants**

There were 176 participants in 4 forums

132 returned pre-surveys

108 returned post-surveys

**Summary of 132 pre-workshop surveys**

1) Why were you interested in attending this forum? (check any that apply)

28 (21%) I am in recovery

10 (8%) I have used medication to assist my recovery efforts  
Medications identified: suboxone (4), methadone (2), prozac, paxil, trileptal, naltrexone

38 (29%) I am close to another in recovery

82 (62%) I wanted to learn more about medication use in recovery

60 (45%) I support the use of medications to assist recovery

41 (31%) Other (please explain)

**Discussion**

It was interesting to note that within the 42 respondents from the professional medical group, not one person identified him/her self as being in recovery. According to statistical odds, this is an unusual finding. However, I've been told by recovering medical professionals that there is a great deal of fear related to licensure status and discrimination which prompts most to be silent about their recovery status in those settings. In addition, only 12% indicated a close relationship with someone in recovery, which was the lowest percentage amidst the 4 presentations. The predominant interest in this medical group appeared to be related to their work status. Nursing CEU's were made available to this audience.

Bangor Forums drew 117 of the 176 total participants, which was 66%. Two contributing variables may have been the ongoing community struggle regarding the growing number of MAT slots and the increased media coverage obtained through news releases and promotional phone calls.

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2) Do you believe that medications can help someone with their recovery from alcohol & drug addiction?

Yes 128 (97%) No 1 Sometimes 1 Not sure 2 (2%)

### Discussion

100% of the respondents in the professional medical training marked 'yes', possibly reflecting this group's comfort level with the use of medication to treat illness. 95% of respondents from the Bangor City Hall community-based Forum indicated their support of MAT. 96% of the audience in the Forums delivered to recovering people and close contacts also noted 'yes', which is higher than might be expected based on the prejudice reported by MAT participants. It is assumed that there was some degree of openness for learning for the recovering attendees who did not report they use medications. 45% of the participants in the evening recovery-specific forums reflected they were in recovery, 20% of those attendees reported their use of medications to support recovery.

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3) Do you think the option of medication should be available in your community for people who are in treatment for addiction?

Yes 124 (94%) No 2 (2%) Not sure 5 (4%) It is 1

- yes, with supervision at clinics or private docs
- yes, but it needs to be controlled environment with supervision

### Discussion

Each of the 4 groups had a very small response that indicated ambivalence or a lack of support, with the overall average of 6%, indicating a general acceptance of local MAT among attendees.

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4) Do you have any concerns about the use of prescribed medication to support recovery?

Yes 90 (60%) No 36 (27%) sometimes 4 (3%) need to learn more 1

If so, please describe your two biggest concerns

#### **Some of the primary recurring themes were :**

- Expressions related to negative perceptions of the medication dispensing treatment system: their lack of monitoring patient progress and prescription usage, possible lack of expertise and inappropriate dosing
- Concerns regarding perceived lack of state oversight – not enough clinics are being sited in areas where people live and seek treatment; there is a lack of monitoring of MAT providers; lack of assurance that participants are getting adequate treatment or support

- MAT participants are not getting enough counseling support
- Concerns related to ongoing drug diversion, misuse, & prescription use with other substances, all of which reflect ongoing active addiction and treatment failure on the part of treatment recipients
- Comments related to treatment recipients' lack of true recovery commitment; perceptions that they are simply substituting one addiction for another
- Medical staff expressed numerous concerns about MAT safety for mother and infant
- Concern that education for MAT providers is not adequate, and that other medical and service professionals lack training overall; patients are also not being given enough clear information
- Many questions were raised regarding the effectiveness of MAT; what is success rate and is MAT helping with addiction recovery?
- A great deal of stigma is attached to this treatment modality

### Discussion

There was a huge volume of feedback in response to this question within each Forum, with a vast array of stated concerns. The most unique collection of responses came from the medical professionals' group, reflecting the situations they come in contact with through their work. 60% of the respondents at these 4 *'One Face and Voice of Recovery'* Forums expressed they have concerns related to medication assisted treatment. We can surmise that this sample would be among the more open-minded community members given their commitment to attend these training workshops and to fill out these survey forms.

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### Summary of 108 post-workshop surveys

1) Did you find this presentation helpful? Yes 106 (98%) No 2 (2%)

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2) Please tell us 2 or 3 things you learned from your participation in this workshop:

### Discussion

There were volumes of feedback from workshop participants that indicated that attendees learned much and were reconsidering their previous beliefs and in some instances, behaviors. The very fact that 108 respondents had so much to say (see appendix) about what was learned makes these training workshops successful. These comments reflected some of what we hoped would be learned:

- You can recover with medication
- To advocate better for myself
- Remind myself that addiction is a disease

- Not to be ashamed
  - Not all treatment centers work
  - Not the drug methadone that is 'bad' – sometimes it is the method it is dispensed, etc
  - The importance of a community voice about the injustices in recovery treatment
  - The importance of empathy & open-mindedness within the recovery community
  - I will be more proactive in the future
  - Addiction crosses all socio-economic classes
  - How judgmental I have been towards my patients
  - How uneducated the healthcare system is
  - We need more education about this topic
  - Need to lessen stigma and judgmental attitudes
  - Stigma remains against addicts
  - There is advocacy for methadone treatment
  - That you can overcome addiction
  - Meds work as part of recovery
  - That Maine needs more recovery care
  - Need to change policy
  - Recovery-oriented treatment
  - First-hand perspective of a methadone consumer – never heard it before
  - I learned so much about how methadone can be instrumental in recovery
  - Encourage new moms to feel less guilty delivering addicted newborn
  - 'just because something is simple does not mean it is easy'
  - Like your risk-benefit framework
  - Simply, your story brought perspective
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3) Do you believe that medications can help someone with their recovery from alcohol & drugs? Yes 108 (100%) No \_\_\_\_\_

### Discussion

100% of the Post-survey respondents indicated that they think that medications can be of help in recovery. 97% indicated 'yes' before the workshop.

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4) Have your views changed based on what you learned through this presentation?

Yes 50 (46%) No 51 (47%) 6 – not completed 1- in between

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*If yes, please tell us how:*

- Really advocate for suboxone over methadone – now more open
- Made me more aware of what my role can be in my recovery & to share these things with the right people
- I know now that I CAN be successful!
- It made me more open minded towards it
- Already a supporter of methadone treatment
- That the 'climate' is changing re: recovery & treatment for addicts & possibly easier(?) medication treatment
- I believe these patients should be treated the same way any patient is treated – with dignity and respect – we need to be the role models for acceptance
- I believe in MMT
- I held the medication-assisted recovery view to begin with

- I will be more informed and more comfortable caring for moms with addiction
- Better understanding of the anguish the addicted patient goes through and the real need to offer help & not be judgmental
- More compassionate about addictions
- The desire for people to get through treatment is powerful and support is essential
- Better understanding of maintenance
- Better understanding of thoughts during active & early addiction
- To not be judgmental about someone until I know the situation they are in
- To see someone be successful is wonderful
- The down to earth discussion allowed me to understand why addicted patients are subjected to – allowing me to see them in a different light
- Reinforcing of thoughts/knowledge but always great to hear information – especially shared in such a personal way
- The presentation was a great reminder that addiction is not a choice
- It is less physically limiting to take methadone than I thought. It really normalizes the chemicals in the brain
- Being more supportive
- Help patients get the right treatment
- Methadone can be the treatment that will make these mothers a responsible mother
- Views about staying on medications to maintain sobriety. May need to stay on them indefinitely
- As a long-term person in recovery, I am slowly seeing that I have to start pushing back. As an RN I have always been afraid of being 'out'; due to many biases in the nursing profession
- Increase tolerance
- I feel much more invested in the importance of clinics in this area
- This has helped me understand the MANY issues & complications of addiction & recovery
- I guess I viewed the issue with a bit of polarity before – like it was this or it was that – I appreciated the viewpoint that there are a variety of ways that folks recover from addiction, and that what works for one person might not work for another. This was a broadening experience for me and one I appreciated.
- Dispelled myths
- I feel more hopeful
- Cemented more solidly the need for serious treatment reform
- I always supported MAAR – myself being one
- Simply reaffirmed my beliefs
- Am all for recovery no matter which way you obtain it- be it abstinence or MAT or any other way
- I have always believed in the benefits of methadone / suboxone treatment
- More encouraged
- Better understanding of reason for long-term medication because of personal story of success
- Positive of methadone
- I have attended AA for 19 years and had not really ever thought about how the program may be actually standing in the way of long term treatment options, vs short term and then expect people to just move on
- Respect for the process
- I learned the importance of recognizing the differences in early medication therapy and middle to stabilization phases of this treatment
- I feel like the medication is essential in recovery, but what helps those in recovery get off their medication
- More open to med. assisted treatment
- Thought there was an end expectation with methadone

- o Greater understanding

## Discussion

Roughly half of the respondents indicated that their views had been changed by these presentations. In the comment section, some noted they had already been MAT supporters.

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### 5) Any other feedback?

- o Thank you so much, this was very helpful!
- o Worthwhile!
- o Great presentation
- o Lisa was very interesting & very education based
- o Interesting presentation that encourages and challenges the role of the consumer
- o Great presentation!
- o I am on suboxone & it has saved my life. If it weren't for my treatment program I would be dead. I have been sober for a year.
- o I like the seminar. I believe that replacement therapy can help people a lot in recovery. Replacement therapy is a good thing.
- o I think this seminar or the speakers story should be put into a junior high school and high school setting so that the younger generations can understand what it is like to go through addiction and then how hard it is for a person to live their lives solely drug free and get anywhere in life after being truly addicted, so that kids are able to understand what happens if you don't die or end up in prison due to drug addiction. I think kids would be less likely to think drugs are okay risks they can take. If children saw what drugs would do to them if they didn't die or become imprisoned due to drug use, maybe they wouldn't be so quick to try drugs!
- o Thank you
- o Great to hear Lisa's story – wonderful presentation. How can we develop client recovery advocacy
- o Information about suboxone not true
- o Mrs. Torres was very interesting
- o Lisa has an excellent story which I can relate to
- o Thank you to all who work to help others with their recoveries & put on this presentation
- o Good speaker
- o We need to figure a way to let these addicts know if they are taking medications for recovery; other meds can not be mixed. I think people in this area are not educated enough; just given the drug and put off on their way. We are losing way too many people to this 'medication' that is supposed to be helping these kids!
- o Lisa might consider saying the 'Twelve Steps didn't work for her'. As in any authentic Way of Life, the Twelve Steps must be worked – they don't do the work for us. There is no magic in life; we are responsible for the work – with help – of course.
- o Presentation was unfocused slightly, talked too long, some jargon
- o Very good presentation, but not really helpful to people in the Mental Health System or the 'poorer population' of Maine. More drugs of this kind need to be made affordable for the uninsured.
- o Would like to help in advocating for recovering addicts
- o Keep up the good work!
- o It was wonderful to have you here, it is always inspiring for me to meet other women who are on methadone, successful, and doing what you do, it helps me remember what I can do, even though I am an addict
- o Are there any long-term side effects from being on methadone?
- o Good presentation
- o Excellent
- o More education, more education, more education

- Thank you!
- So much more education and work to do – thank you for your part in the advocacy & education
- Thank you so much for sharing!!
- Come back here – also we need to promote larger attendance to educate more!
- Would like more education/training regarding working with opiate addicts including males
- Please put more in-services out on this subject – MD's need to be educated also
- Not sure what the reason is (probably political + \$ driven) that MMC doesn't have a methadone clinic on-site. If it was affiliated with the OB Clinic, the prenatal / intrapartum/postpartum, pain management issues could get addressed
- Would love to see training like this be mandatory program for all nursing and OB areas of hospital
- I think it would be beneficial to have a conference in how to interview and assess for drug use
- Should be open to the community, not just healthcare providers
- Presentation makes me realize how we still need to increase knowledge and support for addicted people; why haven't our justice system / government not developing more opportunities for addicts and recovering addicts / alcoholics

## Discussion

There was a lot of positive feedback expressed through these surveys and by participants in each workshop. Many stated a wish for more of these opportunities and for Lisa to return to speak again.

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## Conclusions

Feedback from these surveys demonstrate that these educational seminars were highly successful in teaching about the benefits of medication assisted treatment and recovery. As recorded here, participants expressed that they learned a great deal and that nearly half changed their views about MAT as a result of their attendance. It can be surmised that ongoing education presented by credible speakers who are in long-term MAT recovery will increase public understanding about medication assisted treatment and recovery, while lessening stigma and prejudice. Many recovery barriers can be lowered through this process.

There is a growing tradition of recovering people using their personal stories to teach what is possible, thus reducing stigma attached to addiction recovery. Studies are just beginning to be conducted by recovery researchers and will eventually provide guidance as to how these efforts can become increasingly effective.

It is critical that barriers to recovery be identified and reduced since they can be the basis for recovery success or failure over time. Community members witness what they label as successes or failures – for their loved ones or neighbors who are repeat offenders. It takes a community to support the recovery process and many lives will be enhanced when more women and men with addictions are able to sustain addiction recovery; which will in turn strengthen their families and neighborhoods.

In addition, when individuals with alcohol and drug problems relapse repeatedly, these experiences enhance their shame and beliefs they can only fail; which often becomes a self-fulfilling prophecy.

In reality it is the service delivery systems that have frequently failed their customers by advancing specific modalities like MAT, without also addressing the barriers that accompany them. No matter what research statistics reflect about MAT success, if the consensus in the recovery community is that MAT does not work, this will only create more barriers and more resultant failures for people who could benefit from MAT. Treatment participants spend many more hours in their homes and communities than they ever do in treatment settings.

Education, information and ongoing support for individuals and families– both treatment and community-based – are some solutions that will increase the effectiveness of MAT and medication assisted recovery. At this time, there is growing talk about the development of Recovery Oriented Systems of Care across our states. These models encourage partnership between treatment providers and recovering people to develop more extensive recovery support networks that will enhance sustained recovery. Such partnerships must be created as a key component of the solution that will lessen the Barriers to Medication Assisted Recovery.

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[www.masap.org](http://www.masap.org) 'recovery' link