

Advancing Recovery Grant, Maine Community Education

One Face and Voice of Recovery presentations, April 2008

Background Information

As a partner on the Advancing Recovery Grant awarded to Maine Office of Substance Abuse (OSA) by Robert Wood Johnson, Maine Alliance for Addiction Recovery (MAAR) Coordinator Debbie Dettor worked to obtain input from Maine's recovery communities. 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. As one of its goals with this grant, OSA had chosen to expand the use of medication assisted treatment (MAT) in Maine. In accordance with this, one goal of this information-seeking process was to identify barriers to medication assisted treatment and recovery, then to strategize targeted educational sessions to address some of these barriers.

One outcome of this informational process was the report 'Barriers to Medication Assisted Recovery in Maine', completed 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 are also current treatment participants. Of this total sample, 128 had responded to a survey conducted with people in recovery throughout Maine; 81 attended focus groups conducted at their outpatient treatment sites or as members of one community-based peer support group; and another 24 participated in focus group discussions within methadone clinics. A total number of 14 focus groups were conducted throughout Maine between February and July 2007.

Original Training Project: structure and plan

Upon completion of this effort, Deb Dettor contacted national recovery advocate Lisa Mojer-Torres, JD, who is a practicing civil rights attorney, to review the outcome of the surveys and focus groups. An outline was developed for 2 targeted '*One Face and Voice of Recovery*' presentations to be delivered by Ms. Mojer-Torres to address a number of the treatment & recovery barriers identified. Lisa is an experienced addiction literacy educator who has represented consumers in treatment and recovery on three distinct study Committees of the Institute of Medicine of the National Academies. Ms. Mojer-Torres is a nationally recognized expert regarding stigma and discrimination in addiction treatment and recovery. She speaks from her experience as a methadone advocate who is also in long-term recovery from heroin addiction. We were very pleased she was available to travel from New Jersey to speak to Maine audiences.

The target audience invited were people in recovery, families, friends and significant others. Education was provided to address the following five **barriers to medication assisted recovery** identified through Deb's survey and focus group process:

1) **Stigma**: People in recovery have biases based on misinformation or lack of information regarding the benefits of medications to assist the recovery process; this includes those who use medications as part of their treatment. Stigma was reported to be the primary recovery barrier throughout the survey and focus

group information-seeking process. Feedback also indicated that individuals engaged in MAT, particularly through the methadone clinics, experience additional layers of prejudice and discrimination within recovery communities as well as in mainstream society.

2) Education for families: When defining recovery support needs, many participants identified family members and significant others as being 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 MAT as well as their own support to understand this treatment modality. They reported that because these close contacts can't access this help, they in turn are unable to get support within these relationships. Women and men in early recovery do not have credibility with their family and friends due to relationship break-downs that occurred as part of their active addiction. Like the general community, their close contacts don't understand 'how drugs will help a drug addict get better'.

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 recovery goal. Maine's 12 Step communities have been unwelcoming toward those using medications to assist recovery, which leads to an experience of alienation for recovering people engaged in MAT. These negative views also discourage those who might benefit from medication from considering its use. Clear and accurate information about medication is lacking within recovery communities, including their effects, benefits and risks.

4) Positive MAT recovery role model: Participants in focus groups expressed their perceptions that the majority of people don't make it (ie. aren't successful) in MAT recovery. When asked if they could identify anyone who is doing well in medication assisted recovery, the consensus from group to group was a resounding 'no'. This poses problems because when positive recovery role models are lacking, it is difficult to imagine that anyone can succeed. People who are identified as being in long-term recovery in traditional recovery circles often state the importance of witnessing recovery success in others to reflect the possibility of recovery and to offer them hope and encouragement. It is important to note that there are no media or cultural portrayals of women or men who live successful lives in long-term recovery that includes methadone or suboxone.

5) Self empowerment as recovering person: Within focus group discussions, the level of disempowerment that women and men feel while in treatment and early recovery was very clear. When coupled with the lack of community support available for MAT participants and the lack of visible recovery role models, this leads to despair and inability to maintain recovery efforts over time.

These Forums were held during the evening to be more accessible to recovering individuals and support people. One was conducted in Portland and the other in Bangor, key population sites 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, in her role as a partner on the Advancing Recovery grant awarded to OSA. She also mentioned that these Forums were designed to address some of the recovery barriers reported by the 233 respondents involved with the grant survey and focus group process.

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 initiated by the recovery advocacy movement that highlights the telling of personal recovery stories. One 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. While the problems related to addiction are being made more visible in our media and within our service delivery system, recovery is not getting the same exposure. In fact, because recovery tends to become invisible as people achieve long-term recovery and reintegrate into society, members of our communities do not realize that lives are being restored all around them and that people can recover from addiction. This leads to a sense of hopelessness about addictive illnesses, which creates another barrier to recovery. In addition, this unbalanced view fosters more shame and societal stigma for those afflicted by this condition. The goal of sharing recovery stories is to lessen the stigma and discrimination associated with addiction.

Goals and Outcomes for Initial Project

We had projected that attendance would run as high as 100 in each of the two Recovery Forums. MAAR has learned from experience that it is very challenging to draw members of traditional recovery communities out to participate in recovery-focused activities. We surmised we'd face even bigger challenges with engaging the MAT recovering individuals since they face even more stigma and don't tend to associate themselves with community groups. To date, Maine's community recovery activities have also not been focused around issues specific to medication assisted recovery. This number was a conservative estimate given the number of people who are engaged in MAT throughout our state.

We did not draw the numbers we hoped for in either Recovery Forum. There were 30 registrants for Portland and 62 for Bangor and fewer attendees at each.

Recovering people were encouraged to attend along with families, friends and close relationships as the lens for these workshops would be the experience of living through medication assisted treatment and recovery. In addition, particular attention was paid to discussions regarding the types of concerns that these key support people have in relationship to medication assisted recovery.

This worked out very well; we noted parents in attendance with their children who are in treatment and recovering parents with adolescent and older children in tow. In both Forums, many questions were asked of Lisa by the parents who were making efforts to understand and support what their children are going through.

We expected that MAT participants would derive inspiration from the chance to listen to a nationally respected and successful woman who is in long-term recovery from heroin addiction, who could talk about her own experiences with medication assisted treatment. We also anticipated that individuals engaged on other recovery pathways might become more open-minded about the use of MAT as they heard Lisa speak. Ms. Mojer-Torres serves as a positive recovery role model through her courageous efforts to counter stigma and discrimination by openly telling her addiction and recovery story. We were hopeful that recovering workshop attendees would be empowered by learning what is possible in recovery.

Feedback written on the post-surveys indicate that these expectations were met on all counts. (See feedback in the 'Survey Responses' section of this report)

Barriers to this project

At every step of this larger project, there had been difficulty getting cooperation from some of Maine's methadone providers. Deb Dettor had first attended the ATOD meeting at OSA to provide an overview of the Advancing Recovery grant process and to request access to conduct focus groups with treatment participants at each site. Upon follow up, three programs were responsive to organizing group times when these discussions could take place, while the others were not.

When promoting the '*One Face and Voice of Recovery*' training events, OSA was asked to help with advertising and promotion as co-sponsors, and to particularly encourage the MAT providers. In addition, Deb contacted program directors at every MAT site to talk about the events, and sent them flyers and media coverage about them. MAAR also has key members and allies within several sites who were asked to help promote these workshops among clients and staff. Also contacted were suboxone prescribers and providers. It is not clear how many of them may have followed through with promotion for these Forums.

MAT participants struggle to fit into the traditional community based recovery culture and the recovery paradigm hasn't always been used in MAT programs that classify MAT as a 'harm reduction model'. When I met with MAT participants in focus groups, a number of them told me they knew they were not in recovery because they were taking medication. Their perception was that they would need to be medication-free to be 'in recovery'. They reported that others in 12 Step meetings hold this view. If this is a widespread belief, it may have been a causative factor for why people in MAT didn't attend a recovery forum.

The newer national recovery advocacy movement has been talking about the different recovery pathways and how they can work together to promote recovery. However, these are starting steps and reports from national recovery advocates also reflect tensions related to this growing process. It should be noted that women and men engaged in MAT expect to be stigmatized and ostracized in society as well as in traditional recovery circles, because of their direct experiences. Here in Maine, our chapter of Advocates for Recovery through Medicine (ARM) helped MAAR to publicize this event and encourage attendance among people in medication assisted recovery. Their two key leaders express that they face similar challenges to MAAR when it comes to engaging people in recovery events. Medication assisted recovery has no cohesive movement yet in Maine and participants have no real way of joining community.

An added factor is that this MAT-specific workshop presented by a national MAT recovery advocate is a first time event in Maine and it is easy to understand why people may be cautious. MAAR has no official connection with MAT community other than Deb's work with ARM. These dynamics are likely factors in the

low turn out for Recovery Forums.

Expanded Project: Additional Presentations Recovery Barriers and goals

In addition to the two original '*One Face and Voice of Recovery*' forums planned as part of this grant, two additional presentations were sponsored by community allies. Kelley Bowden, Perinatal Outreach Education Coordinator, and Lisa Mojer-Torres planned a training to address specific issues related to pregnant women who are actively addicted or in MAT. This event was hosted at the Portland-based Maine Medical Center and affiliated healthcare organizations were invited to send their staff. The intended targeted audience was nurses, physicians, and healthcare staff.

With regard to **recovery barriers**, other primary barriers identified by focus group participants were the stigma and discrimination they face during encounters with the healthcare system. Individuals reported numerous problematic situations during focus group discussions and several also confided that they do not tell their physicians about their methadone treatment due to bad experiences in the past. Pregnant women who are actively addicted or engaged in MAT also continue to report similar problems with their healthcare.

On the flip side, Kelley Bowden and other healthcare providers had talked with me about the lack of education and understanding within the healthcare field regarding addiction and medication assisted treatment and recovery. They also confirmed that prejudicial beliefs and negative attitudes prevail as a result, and that this can translate into inadequate care or discrimination. They had reminded me that healthcare professionals see people at their greatest times of stress or sickness and don't have the experience seeing the fruits of the recovery or healing process. A lot of interest was expressed in having this training provided to these healthcare professionals during several Portland task force meetings that I attended.

Some **goals** of this training at Maine Medical Center were to:

- 1) help participants understand the benefits of medication in supporting recovery
- 2) to demonstrate that addiction can affect any one in any circumstances
- 3) to demonstrate the benefits of recovery & what a restored lifestyle can look like
- 4) to educate about the experience of the addicted person and what it is like to face stigma & discrimination while also grappling with addiction, recovery and birth experiences

The fourth presentation was slated for the Bangor City Hall Council Chambers. This was co-sponsored by City of Bangor Health and Community Services, St. Joseph Healthcare, Community Health and Counseling Services, and Penquis CAP, with assistance from MAAR. These organizations stepped forth to support this education within a community in which tensions reverberate due to the growing number of methadone treatment slots which currently stands at 1700, or nearly 40% of Maine's overall treatment capacity. Community agencies, members and leaders are concerned with how to provide other services to the growing number of individuals in medication assisted treatment, about the increasing drain on social services and their fears about increased drug trafficking and crime. In addition, more of these MAT service recipients seek out community-based recovery support at 12 Step meetings and report they aren't

welcomed there. Education is greatly needed regarding MAT within greater Bangor and surrounding areas.

Reflecting on the previous summary highlighting **recovery barriers**, focus group respondents talked about the stigma and discrimination they experience within their communities in general. Employment was of particular concern for a number of those served at the methadone clinics who reflected their difficulty with meeting the required daily timetables of clinic and work, and who explained that there were 'only so many excuses they could come up with for why they were late'. They also noted that they are frequently followed by police officers when they leave methadone clinics and that it is their perception that the police are trying to bust them. MAT participants experience a significant lack of social support, including the arenas where those on traditional recovery pathways seek help.

The specific training format was developed in a meeting between these collaborative partners and the **learning objectives** defined as:

- 1) participants will learn new ways of thinking about medication assisted recovery and its benefits
- 2) participants will learn about the barriers faced by recovering people, especially when engaged in MAT
- 3) participants will learn steps that can be taken to reduce barriers and to support recovery maintenance
- 4) participants will learn how community members can support recovery and what can be expected as benefits from this

The target audience for this session was treatment, healthcare and service providers, law enforcement and corrections staff, employers and interested community members. The intention was to offer this community- based forum to various affected community groups who would benefit, in addition to providers who are often steeped in problems related to addiction.

One goal of all of these forums was to demonstrate that recovery from drug addiction can be achieved when using medication as an adjunct. The national recovery advocacy movement typically refers to people in long-term recovery as 'living proof that recovery works' and this is what Lisa intended to demonstrate through the use of her recovery story. Lisa's story highlights experiences with MAT – both problematic and positive – and reflects the elements that assisted her to achieve long-term recovery maintenance.

Discussion and Lessons Learned

This training project surpassed both Lisa's and my initial plan to provide crucial community education regarding medication assisted treatment and recovery. We hoped to address recovery barriers with the goal of increasing public understanding and changing attitudes within 2 recovery-specific forums. It was very encouraging that other Maine community partners valued the concept of this recovery-specific presentation enough to step forward and sponsor two additional '*One Face and Voice of Recovery*' talks in Bangor and Portland. These opportunities also surpassed what we initially thought could be accomplished by Lisa's visit to Maine. Given the volume of positive feedback received from survey respondents, it seems clear that this training format was highly effective to increase understanding about the benefits of MAT, to be a catalyst for different thinking and positive attitudinal shifts. 98% of survey respondents indicated that this event was beneficial to them and 100% of them noted beliefs in the post-survey that medication can be a helpful adjunct to support recovery. One half also mentioned that their views had been changed for the better regarding medication use. In addition, comparisons of survey groups reflect that these talks worked equally well for the 3 different venues instituted through this project: recovering people, families, friends;

healthcare professionals; and mixed community audience.

As previously noted, recovery advocates from traditional recovery pathways across the country have been speaking publicly to act as change agents in similar ways. We expected that Lisa's use of her addiction & recovery story would positively impact audiences in Maine and based on this feedback, we can see this was an effective strategy in Maine. When families, friends, providers and community members are able to witness MAT recovery success, they can believe that it is possible. This experience certainly counters everything else in the public realm that we are seeing and hearing when it comes to addiction. Through these recovery-focused presentations, the dialogue can shift to a positive focus and expectations can become more hopeful as well as realistic. When people grapple with these illnesses, they often fear they have been given a death sentence due the nature of addiction. Unfortunately, the professional community typically highlights the research based on disease and pathology which does not reflect recovery outcomes. The description of addiction as a 'chronic, relapsing disease' is heard much more frequently than 'recovery is possible' throughout one's treatment engagement. Addiction is certainly a daunting condition for everybody affected and diligent efforts are needed to get well and stay well. But along with this, it is crucial that people continually be inspired by visible recovery role models and accurate portrayals of the growing recovery presence in communities nation-wide.

Are recovery barriers reduced when people gain more understanding about the personal experience of the addiction and recovery processes? Parents who were present told us Lisa's presentation brought new information and clarity they didn't have before; and that her personal story gave her credibility. Since these talks, I have continued to receive phone calls from parents about treatment barriers faced by their children. They have spoken about the new hope and inspiration they got by attending Lisa's presentations and also about the recognition of the need to support and stand up for their family members.

We were reminded that there is much work to be done to lower barriers to recovery. As our current recovery advocacy movement develops, we need to continue conversations to find common ground, not only with those in medication assisted recovery but with those on other recovery pathways too. MAT providers are needed as allies in this process; many first need to develop a better understanding of the recovery experience and paradigm. Recovery-focused community education by these allies will facilitate understanding and the lessening of roadblocks for those in recovery. Maine service delivery systems need to take steps to move toward becoming a recovery oriented system of care. Recovering people must be empowered to understand the central value they have as change agents in the creation of this progressive system model, as well as teaching about the value of recovery for individuals, families and communities.

Other Details

Total number of participants in 4 forums	176
Total number of returned pre-surveys	132
Total number of returned post-surveys	108

Coordination with other Maine AR Grant partners

Strategic conversations were held with Linda Frazier, Grant Coordinator for Maine OSA, during the planning stages for these forums. OSA served as co-sponsor with MAAR and was asked for their help in promoting this event through their contacts. The Maine Association of Substance Abuse Programs assisted through help of their Executive Director and Office Coordinator in managing certain tasks. The MASAP member providers were encouraged to attend these events and were asked for their help in promoting these workshops to staff and clients; many are also grant partners. All grant partners were kept advised of the planning process and media announcements while they were in process. In addition, the AR Coaches for Maine were kept apprised of the progress of these Recovery Forums.

Community Education Provided

Four *'One Face and Voice of Recovery'* presentations were conducted by Lisa Mojer-Torres:

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

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

Additional community education was provided through these presentations & media:

- **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**

Pre and Post Training Survey Results **Summary of Pre-workshop surveys (132 returned)**

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)

- mental health professional
- I think more of the public needs to be educated
- working towards building a recovery program in my area
- I work with many people who are in recovery
- work in a treatment facility that uses suboxone
- I work in NICU with methadone babies
- I work with moms at birth
- want up to date info to help my patients
- we have seen an increase in this type of patient population and we need as much information as possible
- RN who provides care to post partum women
- our unit cares for patients who are in recovery
- RN who works with patients on medications in OB
- I want to have a better understanding of addiction & how to care for & help my patients
- RN working with patients on meds to assist recovery
- nursing student
- student nurse in pediatric rotation @ UNE on BBCH
- to help me with my studies in understanding how to care for mother & baby
- work in NICU
- colleagues & I are conducting research with mothers
- involved with study of women in recovery
- I work with pregnant/p.p. women with drug use/addiction & on methadone Rx
- Work @ OTP
- it's my job
- I care for patients in recovery
- I'm a LADC too
- I work with patients in the birth center, prenatal & family center
- Work with clients in recovery
- Biology teacher
- Homecare nurse
- Work-related
- Work with families using meds for recovery

- Part of community advisory group for methadone treatment
- Work at methadone clinic
- Work with patients on methadone
- Work at Acadia
- Practicing nurse
- Nursing student
- City staff
- Education for current job as DV advocate, I hope this will help my ability to work with & advocate for people struggling with addiction
- I work as a DV advocate with women & men who are in recovery or thinking about recovery

Discussion

It was interesting to note that of 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. This may have been a factor in that reporting. In addition, only 12% of that group indicated a close relationship with someone in recovery, which was the lowest percentage amidst the 4 presentations. The predominant interest in this 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% of all attendees. Two contributing variables may have been the ongoing community discomfort regarding the growing number of MAT slots and the increased media coverage for these Forums obtained through news releases and promotional phone calls.

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 difficulties reported with the recovering groups' acceptance of a medication assisted recovery pathway. It is assumed that there was some degree of openness for learning by the recovering attendees who did not report the use of 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.

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 indicated ambivalence or a lack of support, with the overall average of 6%, indicating a general acceptance of local community –based treatment among attendees.

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 (*see appendix for complete list of responses to this question*)

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.

Summary of Post-workshop Surveys (108 returned)

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

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

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.

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*

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
- 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.

5) Any other feedback?

- Thank you so much, this was very helpful!
- Worthwhile!
- Great presentation
- Lisa was very interesting & very education based
- Interesting presentation that encourages and challenges the role of the consumer
- Great presentation!
- I am on suboxone & it has saved my life. If it weren't for Acadia Hospital I would be dead. I have been sober for a year.
- I like the seminar. I believe that replacement therapy can help people a lot in recovery. Replacement therapy is a good thing.
- 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!

- Thank you
- Great to hear Lisa's story – wonderful presentation. How can we develop client recovery advocacy
- Information about suboxone not true
- Mrs. Torres was very interesting
- Lisa has an excellent story which I can relate to
- Thank you to all who work to help others with their recoveries & put on this presentation
- Good speaker
- 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!
- 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.
- Presentation was unfocused slightly, talked too long, some jargon
- 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.
- Would like to help in advocating for recovering addicts
- Keep up the good work!
- 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
- Are there any long-term side effects from being on methadone?
- Good presentation
- Excellent
- 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.

Report Completed by,

Debbie Dettor, M.S.

Coordinator, Maine Alliance for Addiction Recovery

Appendix

'Pre Survey'

4) Do you have any concerns about the use of prescribed medication to support recovery?
If so, please describe your two biggest concerns

- May seem too easy & won't be motivated to do inner work for long-term maintenance of recovery
- Except for the general public not being informed as to what it's really like & the misconceptions the public has
- It is replacing one addiction for another
- Long-term effects of medications
- For methadone: addictive?
- Doc's misdiagnosis – dual disorders?
- Inappropriate dose levels
- Inability to reduce doses to get off methadone
- Misuse
- Stigma attached
- My concern would be that are people replacing one addiction for another
- Cost (the high cost)
- Education is limited on medications
- How do they get off? Has to be a life change
- Over medication / abuse
- Clear/consistent protocols throughout medical arena
- Drugs being abused & sold
- I'm a little concerned about it being abused and sold to the public
- I'm not convinced the patients get appropriate help & support
- Prior drug use
- Active drug user
- Used solely for patient use & not shared with other
- Importance of continuing the med with supervision from clinics or private docs
- Providers not dosing correctly
- Patients not receiving social/psych support along or as part of recovery
- Physicians as well as pharmacy staff as well as nurses need some sort of policy in treatment of these patients
- We should all be on the same page in treating patients/families/newborns – there doesn't seem to be any consistency
- Some healthcare workers treat those in recovery with judgment and do not see their addiction as a disease process but rather a lifestyle choice – they need more education
- Misuse
- Safety of children born to methadone / subutex
- Polysubstance abuse
- Irresponsible use of the drug
- Providers of the drug not qualified or educated to dispense
- People claiming they are addicted when they are not and then getting addicted

- Never reaching recovery
- Further addiction
- Side effects
- Abuse of medication & crime associated with it
- More treatment time spent to withdraw person from prescribed medications
- What is the correct dosage to help with recovery?
- Are we ever looking to get someone totally off medication?
- How it affects mom
- How it affects the baby
- Further addiction
- Stigma
- The effects on Neonates
- Misuse
- Misuse
- No desire for 'true' rehabilitation
- Diversion
- Risk of accidental overdose
- Too many regulations for patients in OTPs. It makes treatment daunting and living a fully functioning life difficult
- As a nurse – care provider – I feel we all need more education in this area
- Lack of personal support for women in recovery
- Lack of guidance & information to make changes required for maintenance
- Safety for provider & patients
- The effect meds have on the fetus & newborn baby
- Is this a lifetime medication?
- Cost of medication & continued dependence on substitute
- Parental exposure
- Drug deviated for profit
- Overdosing
- Should be used for addicts who have failed other Tx's
- Dosages & eventually leading to getting off it
- Meds not used as prescribed and/or with illicit
- Lack of good level of ongoing assessment/counseling/support services to augment meds
- Does the medication work?
- Higher awareness/education to providers to understand
- Education with women re: drug affected baby law & reporting
- I am not sure whether some of the programs are as encouraging re: weaning as they could be
- I understand that for some people medication is needed for maintenance – how does one know?
- Conflict with medications use for pain relief on unit
- Overmedication vs sufficient medication
- Some follow up for patients after delivery to assist with recovery or encourage by options for addicted parents, ie. ? RN's with substance abuse certification on unit for our clients

- Current education for residents & healthcare
- Abuse of medication by the consumer
- Abuse & overdose
- Over or inappropriate prescribing by the practitioner
- Another addiction
- Those addicted & on methadone choose the dosage that they receive
- The time it takes for a person to recover from drugs by using other drugs
- Having to depend on drugs to recover worries me because if you have to go to a methadone clinic it makes it hard to have a life away, to be able to travel without being held down by needing to show up at a clinic and get a dose nearly every day!
- Too many prescribed
- Not enough discharged before new one prescribed
- Are they safe? Long term side effects?
- Substitutes one addiction for another
- Poor clinical support within medication assisted recovery
- Over prescribing/ dosing
- Lack of understanding by medical community about addictions
- Prescribing agencies that have no concept of recovery
- How to get treatment centers to have better discharge plan other than 'go to a meeting'
- People on methadone selling their medication
- Being discriminated against or being looked down upon for using methadone
- Getting off the prescribed medications
- Recipient still able to use
- Recipient able to mask use
- Can the recipient's addiction be greater than the assisting medication can handle
- Length of time on medications
- Long-term effects
- Abuse of meds leading to relapse
- That it works long-term
- Isn't methadone / suboxone merely a substitution for Heroin or whatever the drug of choice may be?
- Over medication
- Addiction
- Selling of drugs
- Is there a replacement or transfer syndrome that occurs with prescriptions in place of illicit drugs?
- Is behavioral change achieved with medication treatment?
- Overuse, overdose
- Treating with medication too soon in someone's recovery before they have had a chance to see issues resolve themselves with counseling and/or 12 step work, spirituality
- Abusing and not taking as prescribed
- Selling it to others
- Taking the medication too long

- Not learning any recovery skills
- What is the success rate?
- Will this prescribed medication just be a 'bandaid' and not solve the problem?
- Methadone where people get a high
- Stolen/lost medication creating an illegal commodity on the street
- Proper use
- Diversion
- Changing one addiction for another
- Selling methadone
- Patient is still using drugs
- Many abuse it and even sell them for other drugs
- I believe people should not abuse their medication & take them as prescribed
- I believe facilities should take more precautions when giving the medications. My father died from an overdose of methadone & xanax, so I think they should take more precautions when giving it out. Methadone can also help you very good in recovery when used right and not abused. I am on suboxone and it has helped me greatly in recovery. It has given me a life and today I am an active participant in my own life. Thank you.
- State money paying to transport people daily to get methadone
- No bottom is reached
- Ongoing dependency
- I worry that addictions are simply transferred to another substance
- I worry that lots of money & effort are going into methods that aren't really helping people. I wonder because of therapists I've read, if recovery isn't really a personal choice much more than dependent on individual will
- I've heard of abuse of methadone by some people in recovery (selling it & etc.)
- I worry that use can at times lead to abuse of prescribed meds
- Developing a 2nd addiction
- Misunderstanding of the benefits & risks
- Timeline
- Expense – justifying vs other treatments
- That they are still using other drugs as well
- Feel people should stop medication at some point
- Concerned about cost to taxpayers
- Drug seeking
- Replacing one habit for another
- Case of diversion in certain venues
- Societies preconceived notions concerning people in recovery as a whole
- Biases
- Substituting one addiction for another
- Poor control at clinics – dealing drugs in the parking lot
- Patient misuse
- Effectiveness
- Control
- Are they simply trading behaviors?
- Using drugs with meds so double dipping

- Taking care of children while legally 'high'
 - Too many clinics in one area
 - Nonsupport from the state
 - Not enough clinics throughout state
 - Diversion of medication
 - All many other options must be available along with education / statistics about the options
 - State laws prevent programs from being closer to patients' homes – Washington County, etc. Too concentrated in Bangor & Metropolitan areas
 - Continuation of substance abuse with prescribed medication
 - *discrimination to those using prescribed meds, by false ideology and lack of knowledge = lack of support
 - The volume of clients (young) receiving methadone especially for prescription drugs
-

‘Post-survey’

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

- Brain biologically changed
- Chronic disease
- Life adjustments necessary
- It was a good reminder of what I already knew about my treatment
- That being addicted is a disease that's ok to be treated for the rest of life
- You can recover with medication
- Not all treatment centers work
- People on maintenance can be successful
- To advocate better for myself
- Not to be ashamed
- Who to contact to fight for our rights
- I always learn from others stories
- Remind myself that addiction is a disease
- Resources to be proactive
- Addicts & alcoholics – 2 different worlds?
- Not the drug methadone that is 'bad' – sometimes it is the method it is dispensed, etc
- Clinics & providers need more regulation or more help
- The different stigma's people with an addiction or recovering face
- That pharmaceutical companies are working on other drugs with less stigma attached to them
- Authenticity
- Case study valuable to learning
- Do not be judgmental – you don't know the whole story!
- Methadone is helpful for recovery- maybe forever
- It isn't easy to be an addict or glamorous – methadone isn't easy either – but it can prevent a relapse into drug addiction

- Disclosure issue- didn't think about moms on methadone/ subutex hiding their med use
- 'Drug affected baby law' – didn't think how this would encourage pregnant women to hide methadone use, which actually benefits the fetus
- Now understand the difference between people that can and can't (or shouldn't) come off methadone
- We need more education about this topic
- I will be more proactive in the future
- As caregiver we need more information about methadone & suboxone treatment
- We need to become experts or at least more knowledgeable in order to support women and their families who are in a treatment program
- Very interesting to hear personal experiences especially with a positive outcome
- Addiction crosses all socio-economic classes
- Medication for addiction can help a person have a fulfilling and productive life
- It is important for providers to understand and approach nonjudgmentally
- Pain issues of methadone maintenance
- Laws about addicted infants
- History of methadone
- I was unaware how 'judgmental' working professionals are concerning this issue
- I feel sorry for the mothers who feel the need to hide their addictions
- Hope in MMT
- Like your risk-benefit framework
- Simply, your story brought perspective
- Importance of solid knowledge base
- Methadone – benefits – 'no high'
- People who use methadone treatment can have very positive outcomes in having a very normal fulfilling life
- Methadone doesn't seem to impair how one thinks
- Home methadone therapy is liquid, street/pain methadone is not (tabs?)
- Stigma remains against addicts
- Attitude toward the addicted patient (NON judgmental)
- Treat people with dignity
- Importance of non-judgmental attitude
- Ability to have children while in treatment
- Methadone use and effects on brain functioning
- There is still so much we need to know
- Are all the patients who come to us looking to maintain their sobriety – or are some mandated to be on methadone
- Medication is very important to some people's recovery
- Methadone and how it reacts on the body
- What recovery is like for people who are addicted
- More about bio-chemistry and the addicted brain
- Reduced some 'stereotypical' thinking
- Complex thought process of people in treatment / recovery
- Encourage person to do it for her baby if it is hard to do it for herself
- Methadone does not give high
- Needed for life
- How judgmental I have been towards my patients

- How uneducated the healthcare system is
- Evolution of methadone treatment
- Establish trust / acceptance with methadone patients
- Importance of social support in recovery
- Methadone Rx is key to recovery
- Effects of methadone on brain
- It is an art and science to treating addiction, therefore no standard method of care
- Best care provided to those who actively research & help manage their own care
- Be less judgmental for all nursing staff working with methadone moms
- Encourage new moms to feel less guilty delivering addicted newborn
- 'Just because something is simple does not mean it is easy'
- That the right dose of methadone takes away the cravings
- To be non-judgmental because the addict already feels guilty enough. I didn't realize that they felt guilty.
- Drug addiction runs in all social circles
- People need to be educated regarding methadone treatment
- People need to disclose to providers that they take methadone
- I was unaware of how ashamed people felt
- Better understanding of how methadone works
- Implications & necessity of awareness for practice
- Social class distinctions for drug choice
- Continued need for education – providers- to keep up with rapid changes in the field
- Can function as a professional and continue on methadone for a lifetime
- Need to educate all healthcare professionals & clients on recovery from opiates
- Need to lessen stigma and judgmental attitudes
- Reinforced the need to be supportive & nonjudgmental in interactions with our patients & babies
- Contacts to assist with setting up a supportive/effective environment – role of medications in recovery
- Stigma with recovery patients – need to change this
- The emotional trauma of taking methadone is tremendous
- This drug helps people with the disease of addiction live a 'normal' life
- Need to change policy
- Recovery-oriented treatment
- How little Acadia Hospital relates to recovery movement
- Opiate addiction is a neurological disorder
- Addicts using meds are still discriminated against in 12 step program
- The importance of a community voice about the injustices in recovery treatment
- I think it helped my family understand the medication I take
- Some medications CAN help addictions
- If someone fails they start over again
- Long-term methadone is acceptable
- Methadone treatment (done right) much more level, less choppy
- Good treatment as compared to heroin use in Maine is less than 3% of total budget, the rest are in jail
- Brain of heroin addict permanently altered for life
- Methadone works well for most

- Brain activity changes with drugs
- Addiction is a chronic disease – lifelong
- About med. assisted recovery
- More about suboxone
- reinforced how long they need
- That opiate addiction is a chronic disease
- Methadone / suboxone CAN work
- Consumers need to become more involved in getting government more involved in the recovery process
- 2.8% of budget (is spent) on recovery / meds for addiction
- Methadone is very effective
- Recovery is attainable
- Staggering need for legislative change
- How well medication in long term recovery can work
- The importance of empathy & openmindedness within the recovery community
- Not a specific time frame to become sober
- Possible life long need for medication
- That some of the main strengths of the 12 step program actually preventing adequate treatment
- That neuroscientists have done so much research on the brains of opiate addicts
- The reality of lawmakers being so far away from understanding these concepts
- Methadone treatment has been around a lot longer than I originally thought
- The differences between methadone and suboxone
- It's not just my opinion that methadone is expensive
- Methadone has been fighting addiction for decades longer than I originally thought
- Even though methadone treatment is a long process, it does help people recover from addiction if used correctly
- 12 step programs are only a part of our recovery
- Medication is needed in recovery
- The meds do not get you 'high'
- Acute care vs long term treatment
- Presenter's personal story
- Barriers to medication treatment
- That there is need for more education
- That it is o.k. for people who need medication assistance to continue as long as needed
- If it works, don't fix it
- We need to show the legislature more successes of treatment
- What methadone is about
- That I have support out there
- That you can overcome addiction
- Meds work as part of recovery
- That Maine needs more recovery care
- Suboxone is very alike with methadone
- Treatment needs to be not so expensive and be offered without paying
- How to explain why you need meds long term
- A great way to present a long term issue
- Methadone is not a 'cure all'

- Relapse can happen more than once
- It depends on the person and what they want to achieve out of their program
- Connection between...
- Long-term methadone maintenance is congruent with happy, successful life
- Methadone does not create euphoria
- Craving, blockade, stabilization are all benefits of methadone
- An 'addiction gene' has been isolated
- Difference in clinical treatment &...
- the human face of chronic disease – very powerful
- That there is a subset of patients on chronic treatment doing well
- Methadone alone is not a cure
- Clinics aren't necessarily a positive environment
- Maintenance methadone dosage may be a lifetime thing
- Lifetime maintenance is necessary sometimes
- Bangor has 3 clinics
- Bangor has overdose prevention worker
- The discrimination that exists against methadone consumers
- First-hand perspective of a methadone consumer – never heard it before
- I learned so much about how methadone can be instrumental in recovery
- How clinics work
- Resources in this area
- People who take methadone for recovery are not getting high
- The faces of recovering addicts is across the spectrum
- Stigma associated with methadone use
- Clear explanation of methadone effects and benefits
- Addicts have many faces
- Methadone can work!
- The medical model has become the professional standard
- There is advocacy for methadone treatment
- Some people, gifted to begin with, thrive on methadone
- Barriers people face in their recovery
- Bits and pieces of pharmacology of methadone
- I learned a bit about the pharmacology of methadone
- I learned a bit about methadone as a system and how the clinical aspect can work
- There are other medications available now other than methadone
- Methadone does not cause euphoria, feeling 'high'