REDUCING STIGMA TOWARD FAMILIES IMPACTED BY OPIOID USE DISORDER

Resources for supporting providers who care for pregnant and postpartum women with opioid use disorder and their families

JUNE 2021

“[C]hanging ... deeply entrenched personal beliefs about opioid addiction. That was the biggest challenge. But seeing that change happen – and it has happened for many of the staff – has been really the biggest gift”

– BAYSTATE MEDICAL CENTER STAFF MEMBER
BACKGROUND

The Massachusetts Health Policy Commission’s (HPC) Mother and Infant-Focused Neonatal Abstinence Syndrome (NAS) Investment Program (“NAS Investment Program”), launched in 2016, contributed to the Commonwealth’s nation-leading efforts to address the opioid epidemic by funding enhanced care and treatment for mothers and infants impacted by opioid use disorder (OUD). The six hospital awardees achieved substantial improvements in the care of both mothers with OUD and infants with opioid exposure, including shortening infant length of stay in the hospital and reducing the number of infants requiring pharmacologic therapy or receiving intensive care (see NAS Investment Program Evaluation Report).

To achieve these results, all six NAS Investment Program awardees implemented various combinations of best practices including increasing non-pharmacologic interventions, optimizing pharmacologic care, and increasing access to wraparound clinical and social services. In addition, two awardees extended wraparound outpatient services for families through the Moms Do Care (MDC) Program, an initiative administered by the Massachusetts Department of Public Health’s Bureau of Substance Addiction Services, which was expanded to these hospitals with HPC funding. The MDC Program provides recovery services, including access to peer recovery coaches, to participants throughout the prenatal and postpartum periods.

During the NAS Investment Program, some hospital staff noted their own or their colleagues’ implicit and explicit biases affected how they cared for pregnant women with OUD. As a result, all awardees employed a variety of anti-stigma strategies, including hiring peer recovery coaches to both support patients and bridge gaps in understanding among staff based on their lived experience, providing trainings on biases and trauma-informed care, and providing staff with emotional support for caring for this population. Awardees noted that this type of intentional effort to change attitudes towards the care for families, mothers, and infants impacted by OUD represented one of the greatest achievements of their initiatives and helped to strengthen the relationships between families and care teams.

SIDEBAR: CHALLENGE OF STIGMA TOWARD FAMILIES IMPACTED BY OPIOID USE DISORDER

Pregnant women with OUD face the dual challenges of addressing their OUD and perinatal health and confronting a health care system that can feel judgmental and unwelcoming. Many women face stigma in the health care system due to their OUD and feel blamed for the impact their OUD may have on their infants. During the crack cocaine epidemic of the 1980s, the emphasis shifted from treating mothers with substance use disorders (SUD) to criminalizing them, which culminated in punitive laws and cemented negative perceptions against mothers with SUD. The expansion of the “war on drugs” in the 1980s and inaccurate portrayals of “crack babies” began an era of intrusive health care measures for mothers, particularly Black mothers, with SUD. These measures included state investigations of women’s reproductive decisions and punitive reporting of substance use to legal authorities that regarded pregnant or parenting women with SUD as unfit to parent.

Today, these perceptions can be compounded by a provider’s lack of understanding of SUD, recovery, and mothers’ life circumstances (e.g., missing medical appointments because of the lack of childcare and/or transportation). Whether the source of the stigma is the broad legacy of criminalization of SUD or the specific result of staff understanding and perceptions of OUD, or both, the impact can be significant.

Engaging with pregnant and parenting women with OUD requires health care organizations to reorient their approach to care in ways that intentionally seek to address the stigma that can diminish care for both mothers and infants. With that goal in mind, providers are beginning to implement family-centered care models that extend beyond traditional obstetric care, seek to reduce stigma and bias, and strengthen the patient-provider relationship.

PURPOSE OF THIS RESOURCE GUIDE

The purpose of this resource guide is to share practical strategies and resources implemented by NAS Investment Program awardees for addressing OUD stigma in hospitals treating pregnant and parenting women with OUD. The NAS Investment Program awardees received technical assistance from the Neonatal Quality Improvement Collaborative (NeoQIC) and evaluation support from NeoQIC and Advocates for Human Potential. The resource guide also draws on findings from quality improvement surveys administered to Massachusetts birthing hospitals by the Perinatal-Neonatal Quality Improvement Network of Massachusetts (PNQIN).
Peer recovery coaches—also known as peer moms or peer mentors—are staff members in recovery who have lived experience of OUD and for those serving mothers in recovery may also have lived experience of pregnancy. They are trained to support families from the prenatal to postpartum periods, encouraging women to feel safe and confident during their pregnancy journeys. Peer recovery coaches may provide childbirth education, lactation consulting, and treatment and recovery services in addition to providing case management. They can also strengthen relationships with providers, increase treatment retention, and improve access to social supports.

Beyond their functional roles, peer recovery coaches can contribute to overall culture change in care settings through their proximity to the other members of the care team. As they work side-by-side with the care team, peer recovery coaches can bridge the gaps in understanding of lived experience with OUD through their own stories and experiences as mothers in recovery. However, awardees noted that recruiting, hiring, and supporting peer recovery coaches may be challenging for health systems that are unfamiliar with the peer recovery coach role.

WHAT IMPLEMENTERS SAY ABOUT HIRING PEER RECOVERY COACHES

- Develop the workforce pipeline beyond traditional recruitment pathways. Build relationships with community-based resource centers and local community-based organizations serving people in recovery, where staff may be able to help make connections to promising candidates.

- Clearly define roles and expectations so peer recovery coaches can understand how they fit in with the rest of the care team and can be successful in their roles. Other members of the care team—including clinicians, social workers, and administrators—should also be aware of the roles and responsibilities of peer recovery coaches to encourage better collaboration and communication within the team.

- Establish a clear supervisory structure with peer recovery coach supervisors who are familiar with the role and can provide the peer recovery coaches with the support and resources they need. Peer recovery coaches are themselves people in recovery and their supervisors should be equipped to support them appropriately. Consider providing specific training for supervisors in this role.

- Integrate peer recovery coaches into patient interactions throughout the prenatal and postpartum periods. Have them meet with patients prenatally to establish goals, set expectations for delivery, and build relationships so they can continue to provide services post-discharge.

- Foster a safe and trusting environment for peer recovery coaches to share their experiences. Offer training in public speaking to boost confidence in sharing their insights and providing constructive feedback to staff. Create a safe space for sharing personal stories to cultivate trust among the team. Amplify the work of peer recovery coaches by inviting them to internal staff trainings to speak about their personal and professional experiences.
The four NAS Investment Program awardees that hired peer recovery coaches noted a positive shift in hospital staffs’ attitudes, leading to a reduction in stigma and a more welcoming environment for patients in care settings (See HPC NAS Evaluation Report).

The two NAS Investment awardees that implemented the outpatient MDC Program, of which peer recovery services were a key component, saw that:

- Peer services made up 36% of the nearly 9,300 patient interactions delivered by the program.
- The top peer services were coaching/mentoring (52%) and pre/postnatal support (24%).

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**RELEVANT TOOLS**

- **Peer Support Toolkit**, City of Philadelphia Dept. of Behavioral Health and Intellectual Disability Services, ACHARA Consulting, and the Yale Program for Recovery & Community Health
  - Job Description Components (pg. 181)
  - Considerations when Interviewing a Person with a Legal Record (pg. 183)
  - Interview Questions for Peer Recovery Coach (pg. 184)
- **Substance Use Disorder Peer Supervision Competencies**, The Regional Facilitation Center
- **Moms Do Care Resource Guide for Moms by Moms**, UMass Memorial Medical Center
- **Appendix 1**: Peer Recovery Coach Job Description

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“[T]he presence of our peer mentor has improved the trauma-informed care delivered in our [neonatal intensive care unit (NICU)]. We believe that families have had a more positive experience, feeling more respected from our staff, due to the education and presence of our peer mentor.”

— UMASS MEMORIAL MEDICAL CENTER STAFF MEMBER

“There is immense power in a woman being able to walk into a room and know that everyone else in that room is in the same boat, and that is [why] the peer recovery moms...[were] really critical in engaging women in care.”

— BEVERLY HOSPITAL STAFF MEMBER
Many pregnant and parenting women with OUD require treatment for co-occurring mental health conditions and polysubstance use, as well as support for health-related social needs – all of which can lead to further stigmatization. Implicit biases among staff about patient attributes or life situations can be difficult to identify, much less address, though they have the potential to profoundly influence staff behavior and patient experience. Even subtle prejudices could be perceptible to patients and may affect not only a mother’s experience in the hospital, but also her ability and willingness to engage with the care team for the duration of her infant’s stay.

As a result of the opioid epidemic, providers and staff that have traditionally had limited exposure to or specific training in treating patients with OUD now must care for them and often can feel ill-equipped to navigate the complex medical, behavioral health, and social needs of this population. Misunderstandings of the patient population can lead to stigmatizing behavior, which can negatively affect the provider-patient relationship. Poor relationships, in turn, may worsen health outcomes for the mother and infant.

SIDEBAR: SHIFTING FROM STIGMA TO EMPATHY BY ACKNOWLEDGING THE HISTORY OF TRAUMA AMONG MOTHERS WITH OUD

Many mothers with OUD also have histories of trauma that should be addressed by their providers. Seventy-seven percent of women enrolled in the HPC-funded MDC Program reported one or more traumatic events as a minor and about one-third met criteria for post-traumatic stress disorder. Patients’ trauma histories may impact their perception of the medical system and their adherence to treatment. In addition to basic maternity and neonatal care, these families need additional assistance in supporting mothers’ OUD recoveries, managing infants’ NAS symptoms, working with agencies like the Department of Children and Families, and other services specific to families impacted by OUD.
PROGRAM HIGHLIGHTS

The three NAS awardees that provided trainings and educational opportunities focused on trauma-informed care and addiction medicine noted improvement in staff’s overall knowledge, skills, and attitude when working with the target population. The Provider Perceptions Survey of the MDC Program, which aimed to measure the attitudes and training needs of providers potentially working with pregnant women with OUD, reported:

- 25% completed both SUD and OUD trainings/certification, 17% completed SUD only, and 11% completed OUD only based on the responses of 166 providers and staff.
- 60% believed that trauma-informed care training was the most helpful training for staff based on the qualitative responses of 79 providers and staff.
- ~14% increase in Role Adequacy, which suggests that more providers felt they had adequate knowledge to work with individuals with OUD.

Providers and staff who participated in PNQIN’s 2020 Provider Attitude, Knowledge and Skills Survey reported knowledge gaps in screening for OUD, referring to the Early Intervention Program—a publicly funded national program which provides support to families and caregivers to enhance the development and learning of infants and toddlers; and criteria for mandated reporting to the Department for Children and Families.

CASE STUDY

Lowell General Hospital put a high priority on training staff in trauma-informed care and launched their effort by training all nursing staff in the Maternal Child Health Department. “The trauma-informed care helped staff really understand where women are coming from...to approach [them] in a supportive and collaborative way, rather than in any kind of judgmental way.” Staff members on all shifts who attended the trainings were paid for their time and received continuing medical education hours from the hospital. Seeing the success of this practice, other departments have requested the training, including the emergency department, whose staff often encounter patients with OUD. “I think the fact that we did mandate it for our nursing staff, but we also compensated them to go, was really one of the most beneficial things that we did. Everybody found it very impactful.”

RELEVANT TOOLS:

- Institute for Health and Recovery
- Boston Medical Center Office-Based Addiction Treatment
- Neonatal Quality Improvement Collaborative of Massachusetts
- Appendix 2: Brochure on Opioids in Pregnancy
- Appendix 3: NAS Infant Transition Plan
Providers caring for patients living with OUD may feel stressed, overwhelmed, and powerless in the face of their patients’ challenges with recovery, trauma, and life circumstances. In some cases, the logistically and emotionally challenging nature of caring of this population can lead to what is often characterized as “compassion fatigue.” Supporting this population can be stressful, which may inhibit providers’ and staff’s decision-making abilities and push them to default to their implicit biases. This, in turn, can inhibit staff’s ability to maintain effective therapeutic relationships with patients. Health systems may avoid this by acknowledging these stressors and creating a supportive, understanding environment that enables providers and staff to openly communicate challenges they may experience in working with this population and obtain support as needed.

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**WHAT IMPLEMENTERS SAY ABOUT PROVIDING SUPPORT TO THE CARE TEAM**

- **Introduce activities and structures that encourage staff to partake in self-care.** Set up a small area such as a coffee cart where staff can take a few minutes for themselves before re-entering a challenging situation or discussion.

- **Share positive recovery stories and patient feedback with staff** to illustrate the impact that their care has on patients (see “Sharing patient success stories to motivate culture change”).

- **Show staff appreciation for their commitment to their work and to changing the culture of the hospital.** Set up an event to allow them to take a break, socialize, and share some of what they have learned and enjoyed about working with this population to signal that their wellbeing is a priority.

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“[T]hese are really tough clients at times and [clinicians and staff] know they can call me or call my social worker, or have a peer come visit if they’re having a difficult day with the patient or … need some extra support.”

— BEVERLY HOSPITAL STAFF MEMBER
PROGRAM HIGHLIGHTS

Of the providers and staff that participated in PNQIN’s 2020 Provider Attitude, Knowledge and Skills Survey:

- 37% reported notable levels of stress associated with caring for infants with opioid exposure.
- 50% reported notable levels of stress associated with caring for mothers with OUD.

The providers and staff who participated in the Provider Perceptions Survey of the MDC Program reported that 18 months post-baseline:

- ~10% increase in Role Support, which is the degree to which a provider can turn to their colleagues to support effective job performance. This suggests that more providers felt they had colleagues who could support their job performance in working with individuals with OUD.

RELEVANT TOOLS:

- Appendix 4: Staff Survey
- Appendix 5: Example Update Boards

PATIENT SUCCESS STORY

SHARING PATIENT SUCCESS STORIES TO MOTIVATE CULTURE CHANGE

A first-time mother at Boston Medical Center had a history of OUD and continued to use illicit opioids throughout her pregnancy. She delivered an infant born at 29 weeks gestational age, an event that became the turning point in her recovery. At that point, she enrolled herself in a buprenorphine program and an intensive outpatient treatment program. She roomed-in with her infant for his entire NICU stay, only leaving to attend her programs, and successfully provided milk for her infant during their NICU stay. She established strong relationships with the NICU staff, helping to change their perceptions of women with OUD. Ultimately, she was able to take her infant home with her upon discharge and staff noted that they had watched her transform during her infant’s hospital stay.
GOAL: REESTABLISH TRUST AND EMPOWER PATIENTS

Many pregnant and parenting women with OUD have experienced long histories of negative encounters and stigma within the health care system. Reestablishing trust and engaging these patients in their infants’ care can take time and requires action and strategy. Leadership can provide resources and set up the necessary infrastructure to enable staff to engage women with OUD and their families in their infant’s care.

Anti-stigma strategies are based in the understanding that it is important to center the needs of the families in all care. To promote this, health care systems can encourage families to participate in and build confidence in infant care and can ask patients for feedback on their care to remind them that their experience in the hospital matters. Health systems may consider implementing some of the strategies based on lessons learned from the NAS Investment Program to destigmatize care for families affected by OUD and empower them to care for their infants.

“I am most proud that I think that we had a really strong number of women who came here and, because of this program, felt really good and supported and confident and not shamed by their history of addiction, or substance use disorder... [They felt] confident that they could parent their baby and be the kind of parent that they wanted to be.”

– LOWELL GENERAL HOSPITAL STAFF MEMBER

ABOUT THE MASSACHUSETTS HEALTH POLICY COMMISSION

The Massachusetts Health Policy Commission (HPC), established in 2012, is an independent state agency that develops policy to reduce health care cost growth and improve the quality of patient care. The HPC’s mission is to advance a more transparent, accountable, and equitable health care system through its independent policy leadership and innovative investment programs. The HPC’s goal is better health and better care – at a lower cost – for all residents across the Commonwealth.

14. Cite NAS Eval Report
APPENDICES

1. APPENDIX 1: PEER RECOVERY COACH JOB DESCRIPTION

2. APPENDIX 2: BROCHURE ON OPIOIDS IN PREGNANCY

3. APPENDIX 3: NAS INFANT TRANSITION PLAN

4. APPENDIX 4: STAFF SURVEY

5. APPENDIX 5: EXAMPLE UPDATE BOARDS
APPENDIX 1: PEER RECOVERY COACH JOB DESCRIPTION

JOB TITLE: PEER RECOVERY MOM

DEPARTMENT NAME: HOSPITAL INTEGRATIVE CARE PROGRAM

REPORTS TO: PROGRAM MANAGER OF THE INTEGRATIVE CARE PROGRAM

POSITION SUMMARY:
Funded under a grant from the Health Policy Commission, the NAS Initiative/Integrated Care Program was created to address the complex social and medical needs of substance-exposed neonates and their mothers. The outpatient Integritive Care Program will provide prenatal care and substance use treatment to pregnant women during pregnancy through delivery and 1 year postpartum. A Peer Recovery Mom is a support paraprofessional and part of an integrated program who promotes recovery to women with substance use disorder (SUD) by encouraging, mentoring, educating and linking women with SUD to the resources in the recovery community.

ESSENTIAL DUTIES & RESPONSIBILITIES:
• Attends peer recovery, trauma informed care and seeking safety training classes
• Receives a caseload of women with SUD and makes routine periodic contacts with all women assigned.
• Gives basic recovery information and support and helps women maintain connections to the recovery community
• Provides support to increase completed health visits
• Counsels by telephone, text messaging, home visits, and/or program or hospital visits at scheduled intervals determined by the Program.
• Respects each woman by keeping her information strictly confidential.
• Keeps accurate records of all contacts made women in accordance with state and federal confidentiality laws.
• Refers women to professional treatment for any physical or emotional problems.
• Attends and assists with gender-specific, trauma-informed therapeutic groups.
• Attends program staff meetings and conferences/workshops as appropriate.
• Reads assigned materials that may be provided by the supervisor.
• May assist staff in promoting recovery through special projects and duties as assigned.

MINIMUM QUALIFICATIONS:

Education: N/A

Licensure, Certification & Registration: None

Experience: Has lived experience with addiction, pregnancy and medication assisted treatment

SKILLS, KNOWLEDGE & ABILITIES:
• Able to connect and navigate support resources in the community
• Able to encourage hope and optimism in regard to living a healthy lifestyle
• Able to serve as a personal guide for healthy living for the management of personal and family recovery
• Reliable transportation and phone; willing and able to travel to designated locations
• Attends initial and ongoing training as determined by the program
• Able to effectively communicate and work as a contributing member of the program team
• Able to relate without judgment and as an equal, peer to peer with women
• Willingness to work with individuals in any stage of their recovery from addiction, including pre-recovery and relapse
• Flexible schedule to meet the needs of program participants

Source: Adapted from position posting by Lahey Health – Beverly Hospital Integrative Care Program, February 2018.
APPENDIX 2: BROCHURE ON OPIOIDS IN PREGNANCY

Opioid Use During Pregnancy

Information for Patients

Neonatal Abstinence Syndrome (NAS) is a group of problems that occur in a newborn who was exposed to addictive or prescription drugs while in the mother's womb.

Lawrence General Hospital is offering an opportunity for pregnant women who are either addicted or in recovery to visit the hospital and become familiar with the level of care that will be provided for their family.

Got Your Questions Answered

- What happens if my child is born addicted?
- Will my child have withdrawal symptoms?
- What is a Neonate Coordinating Center?
- How long will my baby be in the Hospital?
- What will be involved in my child’s care?
- What is the Special Care Nursery?
- Am I liable to breastfeed?
- Where will we be staying?

For more information or to schedule an appointment, call a Lawrence General Hospital social worker at 978-946-6815 or email nasprogram@lawrencegeneral.org.

Source: Lawrence General Hospital NAS Program, July 2017.
APPENDIX 3: NAS INFANT TRANSITION PLAN

TRANSITION TO HOME

Once your baby no longer needs Neonatal Morphine Solution for 48 hours, your baby is ready to go home. Before your family’s transition home, you will have a final meeting with the healthcare team to review the discharge plan, address any questions or concerns, and confirm follow up appointments. In accordance with the Federal Law, a referral for a developmental evaluation will be made for any infant exposed to opiates in utero. Your family will also be provided with an appointment for Early Intervention services and an appointment with your child’s pediatrician within the next week.

Your baby may continue to have symptoms of NAS for several weeks after leaving the hospital. Here are some helpful tips to ensure your baby is comfortable and safe:

1. PROVIDE A QUIET, CALM ENVIRONMENT
   • Keep lights dim and try to limit noise.
   • Keep the room warm.
   • Speak softly, use a gentle touch.

2. ESTABLISH A ROUTINE
   • Keep the baby’s surroundings quiet and soothing.
   • If you are feeling stressed and no one is home to help you, put your baby down in a safe place such as a bassinet or crib, and take a break. It is normal to feel overwhelmed at times.
   • Set a routine for daytime naps and nighttime sleeping.

3. SOOTHE YOUR BABY
   • Hold and cuddle baby when fussy or crying. Gently rock or sway.
   • Skin-to-skin or a gentle squeeze can be very soothing.
   • Bundle baby in a blanket (not too tightly!).
   • Consider using a pacifier.
   • Gently rub baby’s back. Avoid patting and never shake your baby.

4. FEED YOUR BABY OFTEN
   • Look for signs of hunger like sucking on hands, increased movement, and crying.
   • Breastfed babies: every 1.5-3 hours.
   • Bottle-fed babies: every 2.5-4 hours.

5. ENSURE SAFE SLEEP FOR YOUR BABY
   • It is normal for babies to sleep 16-20 hours per day.
   • Always place baby on his or her back to sleep.
   • Babies should sleep in a crib near their parents but should not sleep in the bed, couch, or chair with their parents.
   • Keep the crib bare. Never leave toys, soft objects, or loose bedding in the crib with your baby.
   • Do not let baby sleep in carrier, sling, bouncer, rocker, car seat or stroller.
   • If you are tired, put your baby down in a safe place.

IF YOU FIND THAT YOU NEED MORE HELP, PLEASE ASK. YOU ARE NOT ALONE.
APPENDIX 4: STAFF SURVEY

Your ideas are very much appreciated! This survey should take less than 5 minutes to complete.

PLEASE SELECT THE TOP 3 PROJECT IDEAS THAT YOU WOULD MOST LIKE TO SEE THE HOSPITAL INITIATE IN THE NEXT YEAR.

POLICY UPDATES
• Toxicology policies
• Feeding guidelines
• Marijuana policy
• Breastfeeding policy
• Skin-to-skin contact policy
• Rooming-in policy

NEW PROJECTS OR SERVICES
• Gift bags for families
• Develop a dedicated SEN cuddler program
• Provide inpatient psychiatric counseling for mother
• Offer inpatient MAT
• Survey staff on cultural sensitivity
• Monthly newsletters for NAS program including statistics on length of stay
• Regular Q&A sessions for staff on NAS topics

OUTREACH AND INFORMATION
• Creation of a dashboard
• Prenatal educational packet for parents
• Outreach to OB offices
• Outreach to local MAT providers
• Educate parents about NAS scoring
• Provide breastfeeding education to mothers
• Physician education: non-pharmacologic interventions for NAS
• Physician education: breastfeeding
• Physician education: toxicology screening
• Physician education: patient support and SUD sensitivity
• Physician education: NAS treatment guidelines
• Nurse education: non-pharmacologic interventions for NAS
• Nurse education: breastfeeding
• Nurse education: toxicology screening
• Nurse education: patient support and SUD sensitivity
• Nurse education: NAS treatment guidelines

OTHER IDEA AT NO-COST OR LOW-COST:

WHAT ARE SOME ITEMS YOU WOULD LIKE TO SEE INCLUDED IN A GIFT BAG FOR FAMILIES? (I.E., BOOKS, SWADDLES, DIAPERS, ETC.)

PLEASE LIST ONE OR MORE THINGS THAT YOU FEEL THE HOSPITAL DOES WELL TO TREAT OPIOID-EXPOSED INFANTS AND THEIR FAMILIES.

PLEASE LIST ONE OR MORE THINGS THAT YOU FEEL OUR HOSPITAL COULD DO BETTER FOR OPIOID-EXPOSED INFANTS AND THEIR FAMILIES.

OTHER COMMENTS OR IDEAS:

The results of this survey are confidential. Thank you for participating!
**APPENDIX 5: EXAMPLE UPDATE BOARDS**

- **EMR ENTRY INSTRUCTIONS**
- **SCREENING PROTOCOLS**
- **PRACTICE GUIDELINES**
- **PROGRAM METRICS AND OUTCOMES**

**WHITE BOARD FOR STAFF ENGAGEMENT**

**MATERIALS ON SPECIAL TOPICS FOR BOTH STAFF AND PATIENTS**

Source: UMass Memorial Medical Center, photos taken March 2018.