DESTIGMATIZING CARE FOR PREGNANT AND PARENTING INDIVIDUALS WITH SUBSTANCE USE DISORDER

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INTRODUCTION

Pregnant and parenting individuals with a history of substance use disorder (SUD) often report feeling stigmatized and discriminated against in a medical setting, which can impact their willingness to seek and engage in care and ongoing treatment. This can yield consequences to the health and wellbeing of both the primary patients and their infants.

Between 2021 and 2023, the Massachusetts Health Policy Commission (HPC) administered the Cost-effective, Coordinated Care for Caregivers and Substance Exposed Newborns (C4SEN) investment program. C4SEN provided funds for hospitals to implement initiatives providing wraparound services and improving care quality for infants exposed to substances in utero and their birth parents through at least 12 months postpartum. One key program element was providing culturally competent care free of stigma and bias. This poster highlights data on this program element from four awardee sites.

OVERVIEW

The HPC's evaluation sought to determine how and whether funded hospitals achieved the C4SEN program goals, including the provision of culturally competent care free of stigma and bias. The evaluation included review of patient surveys, patient and staff interviews, and quarterly qualitative reports developed by the HPC and completed by awardee teams. Thirty-seven surveys were completed by patients, 13 interviews were conducted by an external evaluator with patients, and 15 interviews were completed by the HPC with program staff. Qualitative data was coded and thematically analyzed. These data sources highlighted four primary tactics employed by program teams that facilitated the provision of stigma-free care; this poster details these tactics.

PROVIDING BIAS- AND STIGMA-FREE CARE

CARE LANDSCAPE

In interviews, staff reflected on attitudes in their hospitals regarding perinatal SUD and recovery prior to the implementation of their C4SEN-funded programs, which ranged from antiquated and harmful…

> "There was some kind of draconian behavior that went on […] It immediately made some people who would have come in seeking treatment preemptively, in the early months of being pregnant, in **stealth mode.** They did not want to tell anybody anything for **fear of repercussions.**"
>
> **– REFERRING ANESTHESIOLOGIST**

… to non-judgmental and supportive.

> "[SUD is] viewed as a medical condition. For many years we have [prioritized] **reaching out** and **serving** people where they are and trying to keep them **engaged** both in their substance use disorder treatments, but also in in their pregnancy care."
>
> **– INVESTMENT PROGRAM DIRECTOR**

TEAM APPROACHES TO ADDRESSING STIGMA AND BIAS DURING IMPLEMENTATION

Teams observed that a barrier to patient engagement in treatment was self-imposed stigma. This internalized stigma – in some cases based in prior negative experiences with health care providers – could make patients reluctant to share about their substance use or seek care. Awardees took multiple approaches to create care environments in which staff could help reduce the stigma patients experienced and internalized, such as:

Staff Education. Program teams took advantage of existing trainings and opportunities at their institutions to drive evolving knowledge of SUD and attitudes toward patients in active use and recovery. Staff unaffiliated with the programs were also included in trainings to ensure patients' experiences throughout the care setting were supportive and non-stigmatizing.

> "An important theme in recent trainings has been '**language matters.**' This is something we have put into practice, taking care and sensitivity in our word choice. Instead of using the word 'relapse' we now use the word '**recurrence**' to emphasize that it is an **anticipated part of recovery.**"
>
> **– PROGRAM MANAGER**

Patient Engagement. Teams worked closely with patients ahead of their delivery to set appropriate expectations for their experience. Some teams provided tours of the labor and delivery (L&D) floor, proactively introduced them to providers, or solicited feedback about previous births and potentially negative or traumatic experiences to share with L&D and obstetric staff.

> "We review what's going to happen at the hospital. I start **right from the beginning**, from the labor room, expectations that the staff has of them, expectations they can have of the staff. I give them a chance to **ask questions** and leave them my phone number."
>
> **– FAMILY ADVOCATE**

Non-judgmental Approach. Teams maintained a non-judgmental approach in their work, meeting patients wherever they were in their recovery journey, which increased patient comfort in seeking care and built trust.

> "Providing a **supportive environment free of judgement** has allowed for open communication to be facilitated throughout their pregnancy and parenting journey […] I am proud to be 'their person' who helps to **advocate** and answer any questions they may be hesitant to ask."
>
> **– FAMILY ADVOCATE**

Hiring Staff with Lived Experience. Teams provided patients with access to peer supports and sought to formally hire staff with lived experience. These team members were able to address stigma and bias with patients as well as other hospital staff; patients felt comfortable with them, and staff were able to ask them questions and learn from their experience.

> "For staff serving this target population, having the perspective of a peer recovery coach or someone with lived experience as a support person – not only for the patient but also for the care team to have a **better perspective** – is **incredibly important.**"
>
> **– PROGRAM COORDINATOR**

OUTCOMES

The C4SEN awardees' activities contributed to and strengthened efforts to normalize perinatal SUD and SUD treatment within care settings and with patients themselves. This had a positive effect on patients' willingness to seek care and engage in ongoing treatment and improved their experience in the care setting.

> "We have worked to **increase the visibility** that these are moms just like any other mom that's going to the floor and delivering a baby. A lot of moms have some sort of medical aspect to their care, and this is just **another example of a medical aspect to care.**"
>
> **– PROGRAM MANAGER**

> "**I would not be here today if it weren't for them** […] I decided to work with them because even as ashamed as I was when I was using while I was pregnant and afraid to show up for doctor's appointments because I was afraid I was going to be judged […] They tried to be as **supportive** as possible, and so **I felt safe** and they were actually on my side."
>
> **– AWARDEE PROGRAM PATIENT**

> "**I didn't feel alone.** Getting help while I was pregnant was scary, but they helped me every step of the way. I felt so supported and it made it **so much easier** to keep doing the next right thing."
>
> **– AWARDEE PROGRAM PATIENT**

CONCLUSIONS

Institutions and their awardee programs' efforts to provide culturally competent care free of stigma and bias were aided by teams' primary focus on addressing and reducing patients' internalized stigma. Staff shared that trainings on bias and SUD as a medical condition and learning from and working with individuals with lived experience helped them maintain a non-judgmental approach to care and engaging with patients. Patients noted that the presence of program staff with lived experience and teams' willingness to meet them wherever they were in their recovery journey made them more comfortable engaging in care, as they worried less about encountering stigma throughout their pregnancy and postpartum care. This increased comfort in seeking care and engaging openly with care teams may improve their wellbeing and health outcomes, as well as that of their infants. The positive experiences reported by program staff and patients suggest that these four tactics support the provision of stigma-free care and should be considered when designing or implementing programs that serve this patient population.

POLICY IMPLICATIONS

The perspectives shared by staff and patients that participated in the C4SEN program underscore the importance of regular training and professional development around stigma and bias with regard to perinatal SUD and recovery. These programs established a strong foundation that empowered providers to offer effective patient education, employ a non-judgmental approach to working with patients, and reduce the stigma patients encounter and internalize throughout their care. With this in mind, building in curricula that cover these topics for all hospital staff would likely be highly beneficial for patients.

Staff and patient reflections also suggested the promise of engaging individuals with lived experience in work supporting perinatal people with SUD and reducing the stigma they experience, both within and outside of the care setting. Policies that facilitate hiring and training of staff with lived experience could increase their presence across health care settings. Similarly, creating opportunities for insurance reimbursement for services provided by individuals with lived experience may also increase hiring of staff with lived experience.

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