Engagement in Early Intervention Services Among Mothers in Recovery From Opioid Use Disorders

Elizabeth Peacock-Chambers, MD, MS,^{a,b} Emily Feinberg, ScD, CPNP,^c Molly Senn-McNally, MD,^b Maria Carolina Clark, MSW,^b Briana Jurkowski, BS,^{a,d} Nancy E. Suchman, PhD,^c Nancy Byatt, DO, MBA,^f Peter D. Friedmann, MD, MPH^b

BACKGROUND AND OBJECTIVES: Opioid-exposed infants frequently qualify for early intervention (EI). However, many eligible families choose not to enroll in this voluntary service. This study aims to understand the perceptions and experiences that may impact engagement with, and the potential benefits of, EI services among mothers in recovery from opioid use disorders (OUDs).

METHODS: We conducted semistructured qualitative interviews (n = 22) and 1 focus group (n = 6) with mothers in recovery from OUDs in western Massachusetts. Transcripts were coded and analyzed by using a descriptive approach.

RESULTS: The mean participant age was 32 years, and 13 had a high school degree or less. Five major themes emerged revealing mothers' development through stages of engagement in EI services: (1) fear, guilt, and shame related to drug use (emotions acting as barriers to enrollment); (2) the question of whether it is "needed" (deciding whether there is value in EI for opioid-exposed infants); (3) starting with "judgment" (baseline level of perceived stigma that parents in recovery associate with EI); (4) breaking down the "wall" (how parents overcome the fear and perceived judgment to build partnerships with providers); and (5) "above and beyond" (need for a personal connection with mothers and concrete supports through EI in addition to the child-focused services provided).

CONCLUSIONS: Barriers to engagement in EI among mothers in recovery from OUDs include a range of emotions, perceived stigma, and ambivalence. An effort to purposefully listen to and care for mothers through a strengths-based, bigenerational approach may help establish greater connections and foster stronger EI engagement among families affected by OUDs.

abstract



^aInstitute for Healthcare Delivery and Population Science, ^bUniversity of Massachusetts Medical School-Baystate, Springfield, Massachusetts; ^cDepartment of Pediatrics, Boston University School of Medicine, Boston, Massachusetts; ^dUniversity of Massachusetts Amherst, Amherst, Massachusetts; ^eDepartment of Psychiatry, Yale School of Medicine, Yale University, New Haven, Connecticut; and ^fDepartment of Psychiatry, University of Massachusetts Medical School, Worcester, Massachusetts

Dr Peacock-Chambers conceptualized and designed the study, collected data, conducted the analyses, drafted the initial manuscript, and revised the manuscript; Dr Feinberg conceptualized the study, participated in the data analysis, and reviewed and revised the manuscript; Dr Senn-McNally participated in data collection and analyses and reviewed and revised the manuscript; Mrs Clark participated in analyses, drafted sections of the initial manuscript, and reviewed and revised the manuscript; Ms Jurkowski participated in data collection and analyses, drafted sections of the initial manuscript, and reviewed and revised the manuscript; Drs Suchman and Byatt participated in the study design, data analysis and interpretation, and reviewed and revised the manuscript; (Continued)

WHAT'S KNOWN ON THIS SUBJECT: Infants born to mothers with popioid use disorders frequently qualify for early intervention (EI) child development services. However, we have limited understanding of the factors that impact maternal EI engagement or the perceptions of EI in this population.

WHAT THIS STUDY ADDS: Mothers experience intense fear, stigma, and perceived judgment that discourage deeper engagement in El services. These barriers can be overcome when providers take a bigenerational and strengths-based approach to service delivery throughout the engagement process.

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Over the past 2 decades, the prevalence of opioid use disorders (OUDs) increased dramatically in the United States. 1,2 In New England, neonatal abstinence syndrome (NAS), a drug withdrawal syndrome characterized by a range of postnatal physiologic symptoms,³ affects >10 infants for every 1000 live births.⁴ The postpartum period is also a high-risk time for maternal relapse, overdose, and death.⁵ Providing adequate support for postpartum women with OUDs and their infants remains an ongoing challenge.

One strategy for improving recovery support for postpartum women with OUDs and their infants' development is to strengthen parental engagement in child-focused services. Under Part C of the Individuals with Disabilities Education Act, states must offer early intervention (EI) child development services to children at risk for developmental delay.6 EI is an evidence-informed system of services shown to improve the developmental outcomes of young children with developmental delay or risk for delay by providing comprehensive home-based interventions.⁷ Building family capacity is central to the mission of EI because the home environment and the parent-child relationship are critical determinants of the child's future development.8-11 Parenting

support is especially important for this population because OUDs can disrupt parent-child attachment. There is a dearth of research examining the impact of EI on the development of opioid-exposed infants; however, interventions that support parent-child attachment can be beneficial for these families.

In 2009, Massachusetts made NAS an automatic qualifying diagnosis for EI¹⁴ because of short-term problems and the long-term risk for developmental, learning, and behavioral challenges. 15-17 Despite the availability of free EI services, fewer than half of eligible infants with NAS are enrolled in EI in Massachusetts.¹⁸ EI seeks to promote active parental engagement, which encompasses emotional involvement and commitment. 19,20 Understanding of parental health beliefs, thoughtful communication, and development of collaborative relationships between parents and providers facilitate the engagement of parents of children with developmental delay in ${\rm EI.}^{21-24}$ However, the factors influencing voluntary enrollment and engagement in EI among mothers with OUDs are not well understood. Our purpose with this study was to explore maternal perceptions and experiences that impact enrollment and engagement in EI as well as perceptions of its potential benefits

among mothers in recovery from OUDs.

METHODS

Participant Recruitment

Participants were recruited from nonprofit addiction treatment centers, EI programs, community service organizations, and health care facilities in western Massachusetts. We conducted convenience sampling from these purposefully diverse recruitment locations. Flyers describing the study were posted or distributed by staff, directing potential participants to contact the study team. Forty-one potential participants were screened by phone regarding the following inclusion criteria: age ≥18 years of age, English or Spanish speaking, biological mother to a child aged 6 months to 10 years, history of OUDs, and currently engaged in recovery services. A wide age range of index children was used to explore differences in experience with EI over time. Enrollment of a child in EI was not required for participation. This study was approved by the Institutional Review Boards of Baystate Medical Center and University of Massachusetts Amherst.

Data Collection

Interviews and focus groups impart different methodologic strengths and weaknesses when discussing potentially stigmatizing topics²⁵; thus, participants chose either form of participation on the basis of preference, availability, and logistic considerations. Participants met primarily with the principal investigator (E.P-C.) in addiction treatment facilities, participant homes, or private community settings to complete the informed consent, focus group or in-depth interview (60-90 minutes), and brief demographic survey. The interviewer was not known to the participants. All data collection occurred between February and September 2018.

TABLE 1 Interview Guide and Probes

Was your child enrolled in El?

If yes, tell me about your experience with El.

Probes:

Tell me about your decision and/or feelings about using the El services. What made you decide to enroll your child?

How easy was it to access EI? Tell me about the first time you met with an EI provider.

Was it of value? What did you like the most?

What do you think was the purpose of EI?

How was the experience for you as a mother?

How did you feel you were treated as a person in recovery?

How would you have liked it to be different?

Would you have liked it to end sooner or continue longer?

If no, have you heard of EI?

If so, tell me about your decision and/or feelings about using or not using the service.

Participants were asked about previous EI experience with the initial question "Were any of your children enrolled in early intervention?" followed by "Could you please tell me about your experience?" Different probes were used depending on whether a child was enrolled in EI (Table 1). The focus groups and interviews were conducted in the women's primary language, which for all participants was English. Interviews were audio recorded and lasted ~1 hour. Recordings were transcribed and deidentified. Concurrent with data collection, study team members met on a regular basis to discuss emerging codes, themes, and new topics raised by interviewees. Recruitment continued until thematic saturation was achieved.26

Analysis

Two study team members initially reviewed transcripts to develop analytic codes. This process defined major codes that followed questions from the interview guide and minor codes driven by the data.²⁷ The resulting codebook included each code definition, whereas memos documented discussions or guidelines for the use of codes. Two independent coders resolved discrepancies in interpretation of codes, which involved additional study team members to reach consensus. A descriptive thematic analysis was used to identify themes²⁸ by using NVivo 12 software to organize the analysis.²⁹ The study team discussed how their personal perspectives influenced their interpretation of the data. Descriptive statistics were used to summarize survey results.

RESULTS

Participants

Of the 28 participants, 6 participated in a focus group at a residential treatment center for women, and 22

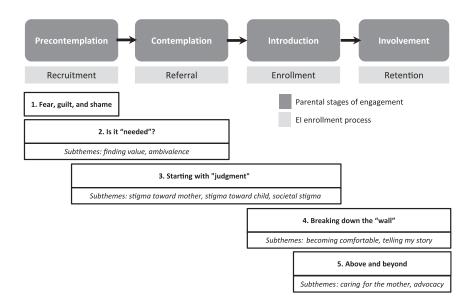


FIGURE 1

Mapping qualitative themes onto an El engagement framework.

completed individual interviews. The average age of participants was 32 years (range 20-48), and 13 had a high school diploma or less. Women had an average of 2.2 children (range 1-6), of average age 8.8 years (1 month-31 years). Of the 22 interview participants, three-quarters had children enrolled in EI. Fourteen of these women identified as white, and 6 identified as African American, Hispanic, or other race and/or ethnicity; 13 received medication for OUDs perinatally and averaged 5.6 years in recovery (range 0.5–17) (n = 20).

Themes

Five major themes and 11 subthemes emerged describing a range of maternal perceptions and experiences related to EI. These themes informed the development of a novel framework that described how mothers progressed through internal stages of engagement during the EI enrollment process (Fig 1). This framework was also informed by the transtheoretical model of change,³⁰ theories of adult psychosocial development,31 and descriptions of EI engagement among other populations.²⁰ The 5 themes map onto different stages of the

framework, highlighting barriers and facilitators throughout enrollment: (1) fear, guilt, and shame related to drug use (emotions acting as barriers to enrollment in EI); (2) the question of whether it is "needed" (deciding whether there is value in EI for opioid-exposed infants); (3) starting with "judgment" (baseline level of perceived stigma that mothers in recovery associate with EI services); (4) breaking down the "wall" (how mothers overcome fear and perceived judgment to build partnerships with providers); and (5) "above and beyond" (need for personal connection and concrete supports through EI in addition to child services provided).

Theme 1: Fear, Guilt, and Shame

Fear was among the primary emotions that discouraged maternal participation in EI. Fear was often associated with judgment or stigma related to drug use: "I got really scared when thinking of people coming to my house... I always had a fear that you couldn't be too honest... like I know you guys are mandated reporters." Many mothers were automatically referred to child welfare and EI at the time of their peripartum hospitalization. They

frequently associated the 2 services and feared that EI participation could inadvertently result in loss of custody of their child(ren).

In addition, feelings of guilt and shame related to drug use discouraged some mothers from considering EI. Disclosing their drug use forced them to face how it may have impacted their child(ren): "I think that obviously there's guilt and shame involved. I mean for me, ...I had it for an extremely long time... I had a double life... I think that [there] would be mothers who did hide it." Even after disclosing and seeking treatment, intense feelings of guilt persisted. One mother said, "To know that... I wasn't there for him every day... I would do anything to be able to change that but I can't." When some mothers first encountered or considered EI, they described coming from a place of unwanted emotional vulnerability, possibly reflective of their internal psychosocial stage of development. To engage in EI, mothers with OUDs had to cope with and overcome this vulnerability as a critical first step.

Theme 2: Is It Needed?

When mothers considered enrolling their child(ren) in EI, they questioned whether there was benefit in services offered to opioid-exposed children and came to differing conclusions. Some women saw value in the expertise of the providers, which was most notably expressed when mothers had firsthand knowledge of EI: "I've known about early intervention for quite a while. Both of my younger sisters were in it... I knew it was definitely helpful... I took it just because I was like you know what? It's going to help him." Other women expressed ambivalence about the appropriateness of the service for opioid-exposed infants. They described perceived value for children with developmental delay but did not believe it offered the same value for their own children: "I think

[EI is] a great program for people who need them... I just don't think me being on maintenance should be the only qualifying reason." Still, some mothers did not feel they had any decision-making power at all with respect to EI enrollment. EI is a voluntary service; however, when EI was recommended as part of a service plan by the Department of Children and Families (DCF), it was frequently perceived as mandatory: "It wasn't like really voluntary [laughs]... It was sort of like this was what I needed to do to get DCF out of my life."

Theme 3: Starting With Judgment

Mothers described their initial interactions with EI providers through a lens of perceived judgment. They felt that they were judged as parents and that their children were judged as a result of opiate exposure. Mothers described subtle forms of perceived stigma through provider interactions. Specifically, mothers implied that providers' observations of their children may not have been fully objective: "It's almost like they're looking for a delay, which is fine but it's not." Perceived judgment was not always associated with discrete EI experiences. One mother described a newspaper article in which authors discussed the developmental consequences of NAS and the costs to society:

It's not like it was my [EI] worker's fault but... after reading that article, I just had so much anger... I was like, "I'm not doing these services anymore." If they think that my kids that are born substance exposed are so troubled and such a burden... then I'm just going to remove myself from the program.

Despite having positive interactions with EI providers, this perceived societal judgment caused the mother to disengage from EI.

Theme 4: Breaking Down the Wall

Some mothers expressed an ability to overcome the barriers to engagement

in EI and ultimately build relationships and partnerships with their EI providers. This process required resolving the fear expressed in themes 1 and 3, giving the program "a chance," and adjusting to the discomfort of having people in their homes. Mothers identified personality and time as important factors in developing trust with their providers: "I had to get over the fear of [EI] invading my privacy... it took time to build that relationship." Sharing their stories helped transform their relationships by allowing mothers to feel understood and heard, as 1 mother shared, "I actually told her my story a little bit more and... I guess it helps... her understanding of some of the things like where I come from and... of him and you know my family."

Over time, mothers no longer viewed EI providers as "strangers" and were able to be more vulnerable. This vulnerability differed from the forced vulnerability described in theme 1 because they chose this vulnerability. Within the context of their EI relationships, they felt empowered to ask directly for specific help they needed while experiencing emotional connection and support.

Theme 5: Above and Beyond

Historically, EI services were "geared toward the baby" with limited parental involvement. The approach to promoting child development recently changed to become increasingly family focused, including parent coaching and parents' direct involvement in child therapies. Although the former approach was seen as "definitely helpful," mothers articulated interpersonal distance between themselves and EI providers. One mother stated, "I haven't personally felt like I've gotten anything out of them - besides knowing that you know my son's going to be like okay."

In contrast, other mothers described successful partnerships with their EI providers that included a sense of personal connection and support beyond the therapies provided to their child(ren). Feeling that EI providers acknowledged or addressed their concrete needs, such as housing, diapers, or transportation, provided an initial entry point for many mothers to begin building stronger relationships with providers. One mother described how appreciative she was of her provider, saying, "You know, there's been times where [my provider] has just sat with [my children] so I could take a shower." These actions allowed mothers to feel heard and cared for.

Other EI providers took their services to another level beyond the scope of standard EI programs, resulting in women feeling central to the program and often identifying EI as their greatest support. Several mothers reported that EI provided critical advocacy on their behalf by masterfully using their professional knowledge, skills, and authority for their benefit: "She was here when DCF came for our last visit... She had asked questions that I didn't think of asking. She really advocated [for] me... with the supervisor and the investigator... and she's very knowledgeable about recovery." This advocacy imparted power onto mothers who frequently felt disempowered as a parent in recovery navigating systems that could determine their future success or failure. This was particularly true when providers showed a greater interest or understanding of addiction.

DISCUSSION

In this study, we identified 5 themes that highlight the progression of parental engagement in EI for mothers in recovery from OUDs. Fear and perceived stigma were

major deterrents forengagement, yet some mothers experienced deeper levels of engagement when they felt central to the program. EI providers facilitated engagement by taking a bigenerational approach: caring for mothers, listening to their stories, and addressing concrete needs and emotional vulnerabilities as well as needs of the child(ren). In these cases, EI served as 1 of the strongest sources of support and advocacy.

We identified barriers in the precontemplation and contemplation phases of engagement (Fig 1) that are common to other subpopulations. 19,20,24,32 The ambivalence regarding the need for services for opioid-exposed children was similar to that expressed by families of children with developmental delay who based enrollment decisions on peer influence and past experience.21 However, some mothers in our study internalized the automatic qualification for EI as another form of stigma against their child. Perceived stigma in our study also came from society at large. Regardless of the source, stigma directly impacted the extent to which mothers engaged in EI. Messaging that communicates the need for EI on the basis of a child's developmental risk may discourage parental engagement in this population. EI is more likely to engage mothers by taking their perceptions of EI seriously and highlighting the support they will receive directly from the program.

The fear of involvement of child welfare systems was another significant barrier to engagement for mothers in recovery. Other subpopulations within EI express fear that judgment of their parenting could result in loss of their child's custody. However, fear was heightened for mothers in our study because of automatic referrals made for opioid-exposed infants. The

expressed fear stimulated by external sources seemed to coincide with the mother's own internal emotional vulnerabilities.

Respect, trust, empathy, communication, and a shared vision have been identified as important factors for overcoming fear and judgment to build relationships and progress toward deeper involvement in EI.^{23,24,33,34} The development of trust and strong collaborative relationships is essential for mothers to feel that EI is successfully meeting the family's needs.^{22,35} In our study, the opportunity for mothers to share their stories with providers helped them develop successful partnerships. This finding is consistent with other studies revealing that greater understanding of the mother's life circumstances may help reduce feelings of shame and stigma.36,37

For mothers with OUDs, therapeutic relationships with EI providers could have direct benefits to their recovery and to the child's development by serving as a model of secure attachment. 11,24 However, maternal mental health and recovery is insufficiently addressed among families receiving EI despite the presence of mental health clinicians in many EI programs. 10,11 Development of deeper therapeutic relationships may require a reconceptualization of the provider's role.²² Our study findings support a movement away from a deficit-minded approach (focusing on problems) toward a strengthsbased approach, identifying parental strengths and priorities, while also recognizing each parent's stage of psychosocial development at all points of the engagement process. Greater collaboration with substance use disorder treatment and peer support programs could also help EI programs identify gaps in traditional service systems to intentionally

address individualized needs of mothers in recovery.

This study has several strengths and limitations. Although our study solely involves mothers in recovery in western Massachusetts, our approach provides new insights regarding experiences with EI services among this population. In addition, we made a conscious choice to focus on maternal experiences; fathers with OUDs may have different experiences engaging in El.38 Our results are also most applicable to English-speaking mothers despite concerted efforts to also recruit Spanish speakers. Cultural beliefs likely impact engagement in research studies and EI, representing an important area of future study. 21,32,39 Finally, we did not capture perspectives of people not using any recovery services. Recall and social desirability biases related to stage of recovery may impact reporting of past events;

however, our study included women with a wide range of recovery durations.

CONCLUSIONS

Given the national reach of EI programs, EI could be a powerful source of support for mothers with OUDs caring for young children. However, mothers in recovery from OUDs frequently experience fear and perceived stigma as a barrier to enrollment in EI programs. Mothers may also have varied perceptions regarding the value of EI for opioidexposed infants, primarily based on their past experience. An explicit effort to care for the mother beyond services provided to the child can help build critical relationships between parents and providers at all points of the EI engagement process. A strengths-based, bigenerational approach that respects the mother's

own developmental process and concerns may help providers foster stronger service engagement among mothers with OUDs during a critical period of parental bonding and addiction recovery and lead to better outcomes for both parent and child.

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ABBREVIATIONS

EI: early intervention

DCF: Department of Children and Families

NAS: neonatal abstinence syndrome

OUD: opioid use disorder

Dr Friedmann conceptualized and designed the study, participated in the data analysis and interpretation, and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Elizabeth Peacock-Chambers, MD, MS, Department of Pediatrics, University of Massachusetts Medical School-Baystate, 3601 Main St, Floor 3, Springfield, MA 01199. E-mail: elizabeth.peacock-chambersMD@baystatehealth.org

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POTENTIAL CONFLICT OF INTEREST: Dr Byatt has served on the Medscape and WebMD Steering Committee on Clinical Advances in Postpartum Depression. She received honoraria from WebMD and Miller Medical Communications. She has served on the Perinatal Depression Advisory Board for the Janssen Disease Interception Accelerator Program, advisory boards for Sage Therapeutics, and is a council member of the Gerson Lehrman Group. She has also served as a consultant for Ovia Health, Sage Therapeutics or their agents, and has received speaking honoraria from Sage Therapeutics. The other authors have indicated they have no potential conflicts of interest to disclose.

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