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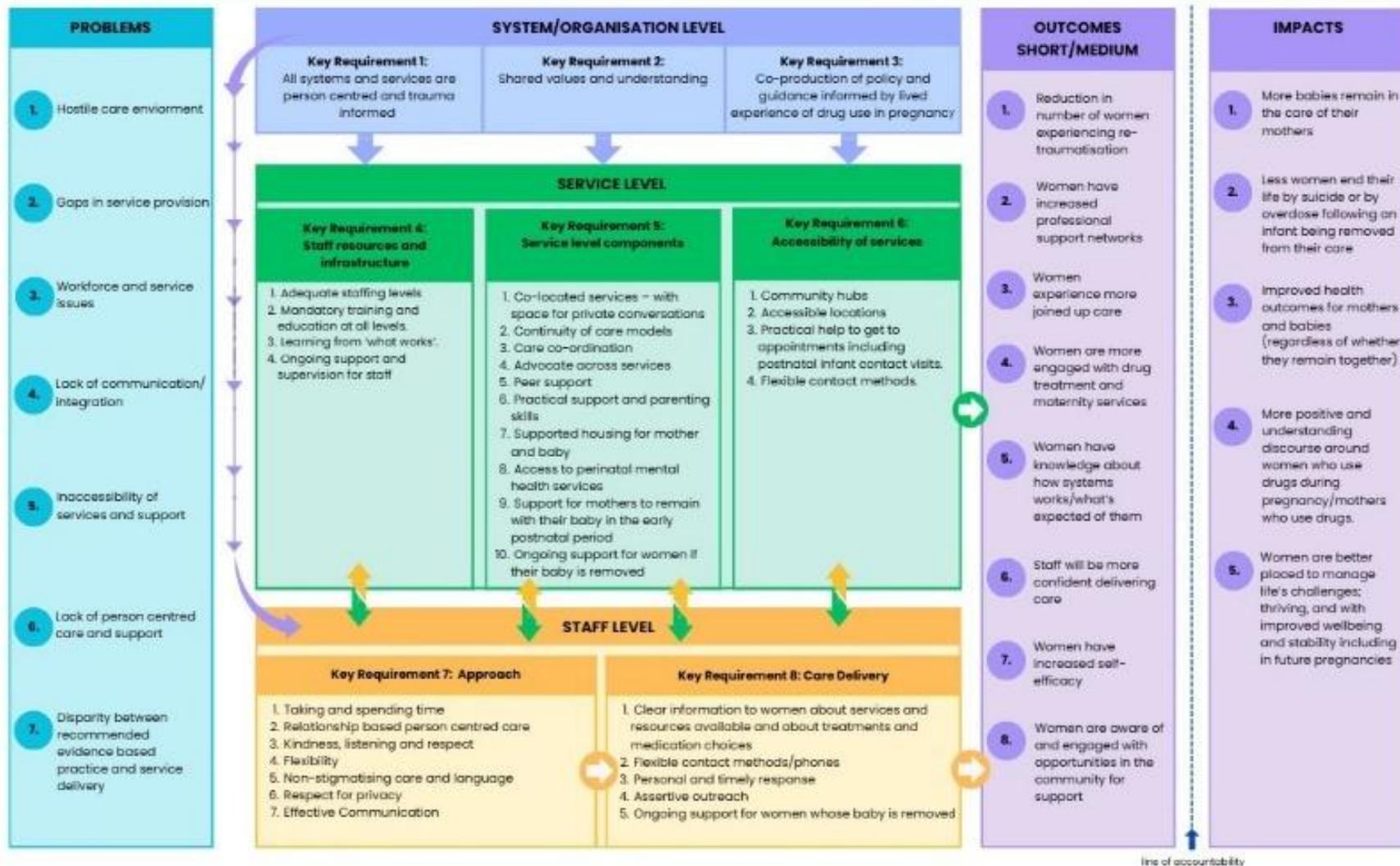
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Development of a co-produced Theory of Change for optimal health and social care services for women who use drugs or are in treatment for drug use during the perinatal period.

Key recommendations for services for women who use drugs or are in treatment for drug use in the perinatal period: supporting evidence examples.

Figure 1: Key requirements for the development of an integrated trauma informed, person centred service for women who use drugs during pregnancy (and their babies)



Extended data file 1. Key recommendations for services for women who use drugs or are in treatment for drug use in the perinatal period: supporting evidence examples.

Requirement	Evidence Source & Illustration
System Level	
<i>System Level refers to policy and strategic planning, commissioning of services</i>	
<p>Requirement 1: All systems and services are person centred, and trauma informed</p> <p>Everyone involved in perinatal services policy, development and delivery should have a shared understanding of how trauma and addiction impacts on an individual. Those in strategic planning and leadership positions must work together to plan and deliver effective services that avoid causing further harm or traumatisation.</p> <p>Training about addiction and trauma informed care and the needs of women who use substances during and after pregnancy, and their infants, should be provided for all those with responsibility for planning, funding and prioritising perinatal services including commissioners, policy makers and service providers (19 & *).</p>	<p>Most of the women in the Stepping Stones study had experienced multiple and complex trauma. They shared positive care experiences but also numerous instances where services failed to meet their needs and often appeared to be setting them up to fail. In particular, casual ill-informed comments and judgemental attitudes could be retraumatising.</p> <p><i>“You’ve been banging on about past traumas, and yet all you seem to be doing, at the moment, is bringing on these traumas in me.” (P01_02_IV4 referring to contact with social worker)</i></p> <p>Stepping Stones Study focus groups with staff also highlighted that although many of the specialist services do practice trauma informed care this can be under-mined by ill-informed workers, practices and systems that do not respect women’s trauma histories.</p> <p><i>‘child protection’s important, but so’s () humanity, and looking at that person as an individual with a history, with a story, with a trauma. Not just an addiction and the fact that they’ve lost their child.’ Site 3, Focus Group</i></p>
<p>Requirement 2: Shared values and understanding</p> <p>All those involved in policy, planning and delivering services that impact on women who use or are in treatment for using drugs during the perinatal period must understand the particular challenges faced by women who used drugs or are in treatment for drug use, and for the staff providing care. At all levels it is recognised ‘why this population matters’.</p>	<p>The Expert Advisory and Co-production Group (EACPG) noted that all staff who come into contact with women who use drugs during pregnancy should be trained in trauma-informed care, and that services overall should be trauma-literate. They recommended that people across the spectrum of care including commissioners, policy makers and service leaders are taught about “why this population matters”, but also that training should recognise the challenges that staff are going through often working in stressful and challenging environments with short term funding and job insecurity. (EAPCG)</p> <p><i>“it comes from the top, it’s a management/leadership-led approach. Being kind, being thoughtful, being - you know, reflective all the time. We are working hard on that, but if there’s poor practice up there it just feeds right through.” Site 3, Focus Group</i></p>

<p>Requirement 3: Co-production of policy and guidance informed by lived experience</p> <p>Policy and guidance should be co-production and informed by women with lived experience of drug use in pregnancy</p>	<p>The scoping review (19) found that only 13% of reviewed documents included consultation with women with lived experience of use of drugs during pregnancy.</p> <p>The Stepping Stones study found that there were considerable gaps between policy and guidance and service capacity and care delivery, women with living and lived experience had valuable insights into what worked/ did not work and their voices should inform and shape policy and service development.</p> <p>The EACPG noted that lived experience should be embedded into services, with individuals with living and lived experience able to contribute to, and shape service development.</p>
<p>Service Level</p>	
<p><i>Service level refers to local service planning, development and management for example at NHS Board or Trust level (UK)</i></p>	
<p>Requirement 4: Staff Resources and Infrastructure</p>	
<p><u>4.1 Adequate Staffing levels</u></p> <p>Services must be appropriately staffed to allow practitioners to provide care in-line with both their organisations and national recommendations regarding care schedules and proceedings.</p> <p>Third sector and specialist services require secure and on-going funding to allow them to provide continued support to women, as well as maintain and develop staff expertise.</p>	<p>From our EACPG and Stepping Stones Study staff interviews and focus groups we heard how across all services, challenges of staff shortage, high turnover, and lack of consistent 3rd sector funding impact on staff capabilities and capacity and meant that care delivery is inconsistent. Women recognised that services were understaffed, underfunded and experiencing high turnover of practitioners which impacted their care experiences for example, making it harder to contact staff and appointments being cancelled.</p> <p><i>“I don’t think there’s enough support in place. ...I know they’re understaffed and that. That’s probably the problem, why you don’t get enough help. Cause like I don’t see anybody.” (04_P1_d woman’s interview)</i></p> <p>In Stepping Stones Study focus groups staff described the impact of staff shortages on their ability to develop trusting relationships with women and on their own mental health.</p> <p><i>“I spent a lot of my own time as well, running around, chasing things, going home late, taking food parcels at six o’clock at night, when I actually finish work at half four. So how do you sustain that? .. we don’t get the time, even to reflect on those cases. Or have any time to think about the impact that it is having on your own mental health, and your own family life.” – Site 3, Staff Focus Group</i></p> <p><i>“staff need time to work with that family, to build up relationships.. Especially if there’s some kind of issue or crisis happened within that family.. it can be really difficult. And we need to be afforded the time for that really intensive piece of work to go ahead. And unfortunately we’re not afforded the time.” – Site 3, Focus Group</i></p>
<p>4.2 <u>Mandatory Training & Education at all levels</u></p>	<p>From all sources of evidence gathered during the Stepping Stones Study, the need for training was highlighted as being essential for improved care delivery and outcomes (19). Women described how they often encountered</p>

<p>Training should be developed within organisations to ensure all staff understand the experiences and complex needs of women who use drugs during the perinatal period and trauma informed care. Training should include:</p> <ul style="list-style-type: none"> • Communication skills / empathy • Person centred care • Trauma informed approaches • Domestic abuse • Stigma • Addiction & Opioid Substitution treatment and implications of treatments during the perinatal period, including breast feeding. <p>All midwives and medical staff should receive training on identification and care of Neonatal Abstinence Syndrome and Neonatal Opioid Withdrawal Syndrome (EACPG).</p>	<p>stigmatising and or unsupportive attitudes and care practices within services, in particular, involving intrapartum and in-hospital services where specialist drug services may not be available. However, casual interactions e.g. GP receptionists, social workers could also communicate a lack of awareness, understanding and compassion. <i>"They weren't very kind. I felt very judged by some of them. The way some of them checked on [baby] was very unfriendly and a few comments here and there, which just weren't very nice, and yeah. Just it made me feel very, very uncomfortable and very stressed."</i>(P01_03_IV1)</p> <p>Women spoke about staff on the labour and postnatal ward having a lack of knowledge about addiction and prescribing of OST.</p> <p><i>"I went to breastfeed...they stopped me ...'you've got opiates in your system' " didn't know dihydrocodeine was an opiate ...everyone else on the ward had had an opiate so why could they breastfeed, and I couldn't?"</i> (P03_01_IV1)</p> <p>Focus group interviews with staff also highlighted the need for regular education including disciplines and areas such as medical staff and scan departments.</p> <p><i>'understanding and knowing what the pathway is that that mum, that pregnant lady will have been through before she has given birth, the meetings that she will have been through.</i> – Site 2, Focus Group</p> <p><i>"Training can't be a one-off, it's a philosophy isn't it for understanding addiction through trauma"</i> – Site 2 Focus Group</p>
<p><u>4.3 Learning from what's working well</u></p> <p>Service leads and those responsible for developing services should seek to learn from examples of good practice.</p>	<p>EACPG recommends that services seek to learn from examples services that are working well.</p> <p>Maternity services quality improvement work has typically focussed deficit-based approaches such as analysis of adverse events. Lessons from safety in other healthcare environments suggest that the principles of Safety-II such as learning from successes and taking a positive strengths-based approach will have applicability in maternity care</p>
<p><u>4.4 Ongoing Support and Supervision for staff</u></p> <p>All staff providing care for women who use or are in treatment for use of drugs during the perinatal period should have access to appropriate regular clinical supervision that helps them to reflect upon</p>	<p>The EACPG discussed experiences of staff's secondary trauma, and the emotional intensity of providing compassionate care to women who use or are dependent on drugs throughout the perinatal period stressing the importance of mentoring, supervision and counselling.</p> <p>During Stepping Stones Study focus groups staff shared examples of being impacted by the vicarious trauma of managing and supporting complex and challenging cases and of the benefits of support and supervision.</p>

<p>their experiences and the emotional impact of their work.</p>	<p><i>“I feel like we are really well supported, like we have things like restorative supervision, and I know that if I was struggling, I could go to someone.” – Community PH Midwife, Site 1</i></p> <p><i>“the child was removed within the meeting...and Mum was on the floor, and she was upset, and she was screaming and crying. And [addictions worker] came out..and she just burst into tear, and I thought, we need to recognise that it’s challenging for parents at the meetings, but it’s also challenging for a worker to witness.” – Site 3, Focus Group</i></p>
<p>Key Requirement 5: Components and Interventions</p>	
<p><u>5.1 Co-located services with space for private conversations.</u></p> <p>Co-located and one-stop-shop models of care should be offered for maternity and drug treatment services, where women can also access a range of other practical and community supports, such as childcare; benefit advice; parenting support and education and peer support groups.</p> <p>At a minimum multi-agency / non-siloed approach with clear communication channels and information sharing systems between agencies and to women, should be provided.</p>	<p>The Stepping Stones Study found that there was evidence of benefits associated with co-located services. The mixed methods systematic review (*) found that women reported improvements in their own, and their child’s health and wellbeing and co-located services were associated with a self-reported reduction in substance use. Women also reported maintaining or re-gaining custody of their babies because of the integrated support offered in co-located service models.</p> <p>Practitioners in the Stepping Stones Study focus groups identified one-stop-shops as supporting engagement, and de-stigmatising seeking care for women.</p> <p><i>‘there is something about being co-located. Somewhere that’s accessible to the maternity service, that is really meaningful. ..a lot of the time we find that women with substance misuse or alcohol issues might have comorbid medical or obstetric conditions that are quite tricky, quite complex. So being able to be in a place where you can get them that care and work around that at the same time is good.’</i> Site 1, Focus Group</p>
<p><u>5.2 Continuity of care and carer (all services)</u></p> <p>Continuity of care from those supporting women prior to pregnancy and throughout (relationship building) where possible a named worker.</p>	<p>The Stepping Stones Study found that fragmented care leads to women having to repeat their stories and medical experiences to different professionals which is confusing, frustrating, time consuming and can be re-traumatising. The scoping review (19) found that continuity of care is recommended to support effective communication between services during multidisciplinary working.</p> <p><i>“I never had the same midwife twice. They’d often forget things. They’d get my name wrong. The nearly gave me the wrong injection once”</i> (O1_P3_a)</p>

	<p><i>'she [specialist midwife] was at the panel meeting, and I'm thinking to myself, I've seen you for five minutes....What input have you got into this? I don't see the point in that. (03_P7_e)</i></p> <p>Staff in Stepping Stones Study focus groups highlighted the importance of practitioners being engaged with women across the span of their care, and having a named worker who they could rely on.</p> <p><i>"We make the women aware that myself, and whoever the social worker is, we work closely with each other, and just try and support them as much as we can. I think that's a huge benefit, that they know (us) - and there's not all different workers coming in" – Site 3, Focus Group</i></p>
<p><u>5.3 Care co-ordinator</u> One named worker takes a lead role in co-ordinating all care and support being offered to a woman. They will have an overview of all the women's needs, the agencies involved and their role.</p>	<p>The EACPG highlighted the need for one named practitioner to act in a co-ordinating role to link across services and streamline care for women and their babies (1 & *).</p> <p>Staff reported that they would ideally like one point of contact to co-ordinate care between agencies involved. <i>'sometimes it feels like women are being flung around to different agencies and expected to be the middleman for this'</i></p>
<p><u>5.4 Advocate</u> Women should have access to a trained professional advocate, independent to her care team who can help to support her to understand and negotiate the complexity of the care system and if needed can attend meetings with her and speak on her behalf.</p>	<p>The EACPG and mixed methods systematic review (*) highlighted that there is a need for an independent, trained advocate who can assist women navigating the system and support them through challenging experiences (case conferences, social work involvement etc.) They noted that systems and processes can be re-traumatising, confusing and stressful and having an independent person with specific training could support and advocate for women.</p> <p>Staff in Stepping Stones Study focus groups also highlighted the benefits and specific role of advocacy.</p> <p><i>"Recently, we got (a woman) an advocate because they were quite vulnerable. ... they were able to go out and meet her a couple of times before and really discuss what she wanted out of this meeting rather than us sort of saying .. 'What sort of things do you want?' and giving her some suggestions. They were able to come up with some really different stuff, so that worked quite well." Site 2, Focus Group</i></p> <p><i>"The other thing where I think there's a real gap is the advocacy of the woman herself. The social worker is actually for the baby but my personal view is that the woman should have her own social worker as well because the interest of the unborn shouldn't necessarily trump the interest (of the woman)." – Site 1, Addictions Psychiatrist</i></p>
<p><u>5.5 Peer Support</u> Social support either through one-to-one mentoring or group work facilitated by someone</p>	<p>EACPG The EACPG felt that peer support was an effective and important way of supporting women through a potentially challenging, busy and difficult time. Peer support was considered helpful as it was inspirational/aspirational rather than instructive and authoritarian. It was noted that it is essential to include formal support structures within services for peer support staff.</p>

<p>who has experience of using or being in treatment for drugs during the perinatal period.</p>	<p>In the Stepping Stones Study staff in focus groups suggested that there may be benefit in providing inspiration or role models within the context of formal support structures for peer support staff.</p> <p><i>“We need to get away from the negativity and start showing these people who have turned their lives around and who are in a better place now.” – Site 4, Focus Group</i></p> <p>Women in the Stepping Stones Study also reported benefit in having contact with women with similar lived experience but who have gone on to have positive outcomes.</p> <p><i>“I don’t actually know what her role, her job was but just kinda spoke of her experiences and basically she went through the same thing as me and it was just nice to hear that and now she’s doing good for herself, she’s got her kids back into her care and now she’s working and helping other people, it’s just something I want to do.” (04_P1_c_LH)</i></p>
<p><u>5.6 Parenting skills & support</u></p> <p>In-person parenting skills education and support tailored to the women’s needs should be offered. This may be provided in the woman’s home or in a community venue or multi-agency setting.</p>	<p>The qualitative element of the mixed methods systematic review (*) found that in various interventions women reported that being offered parenting skills and education was valued, increasing parenting confidence and supporting engagement with services.</p> <p>The Stepping Stones Study interviews with women also found that women valued parenting support. . <i>“[specialist education midwife] came out to the house and just showed me, like, how to bath properly, how to feed properly, the sleeping things, because I wouldn’t have known half the stuff” (04_P7_c)</i></p> <p>Staff in Stepping Stones Study focus groups also highlighted this as important to build the woman’s confidence in parenting. <i>“it’s about working with people and trying to enhance life skills, you know they might not have had positive experiences of parenting when they were a child, and they’ve no really got a real idea of where they’re going, ...so just having somebody there to reassure them, to say, “We can work with you, we can look at skills, we can look at other things that you might be able to get into.” and giving them options,” – Site 3, Focus group.</i></p>
<p><u>5.7 Supported housing for mother & baby.</u></p> <p>Supported housing options should be available for mothers and their babies which should include:</p> <ul style="list-style-type: none"> • Mother and baby rehabilitation units • Supported tenancies for mother and baby and family units in the community. 	<p>The EACPG agreed that there is a need for more supported housing where women and their babies can receive care and a range of supports whilst still maintaining their independence. Residential places are not always appropriate or necessary, but many women are also navigating challenging public housing systems and need stability and support.</p> <p>Overall, the Stepping Stones Study found that women experienced a lack of stable, supported housing options for women who are pregnant and using drugs. Women who experienced supported accommodation found it valuable.</p>

	<p><i>"It's like supported accommodation, so it's like staff there during the day on a week day, but you've got their phone numbers and stuff if you've got anything wrong, and they used to help with sorting out permanent housing and benefits and anything like that really." (01-05ESa)</i></p> <p>Staff in Stepping Stones Study focus groups also highlighted the frustration of lack of supported housing options.</p> <p><i>"They're in horrible housing situations and they just don't want to be there. I wish there was a safe place that we could take people when they're not surrounded by other people that are using drugs, or other people that are maybe influencing their choices." – Site 1, Safeguarding midwife</i></p> <p><i>'it seems nonsensical to send a woman so vulnerable back out into the community without her baby and then make her wait for six weeks in inadequate housing in a very vulnerable situation around all of the kind of the things in the first place that maybe had driven her towards being in that situation.' – Site 1, Focus Group</i></p>
<p><u>5.8 Perinatal Mental Health Support</u></p> <p>Women who use or are in treatment for drug use during the perinatal period should be offered perinatal mental health support and interventions independent to their drug treatment support.</p> <p>This should include tailored psychological assessment and treatment including assessment of potential for intimate partner violence and post-traumatic stress disorder as well as the women's social support systems.</p>	<p>Our EACPG highlighted different models and capacity for delivering mental health care and support. However, access to perinatal mental health and longer term, trauma informed mental health care (for women who want this) was seen as essential.</p> <p>The Stepping Stones Study found that whilst perinatal mental health teams were in place across the country access to support was patchy. Some women could not access mental health support because they were receiving drug treatment services and had an allocated drugs worker. Drugs services were often limited specifically to drug treatment, rather than mental health and wellbeing overall.</p> <p>Staff in focus groups reported that there was often no perinatal mental health support for women who have lost custody of children, and in some areas, very little mental health support in general.</p> <p><i>"who looks after her from a mental health perspective if the baby is going to be removed and she can't actually access perinatal mental health because she has had a child removal?" – Site 1, Focus Group</i></p> <p><i>"there's too great a gap between perinatal mental health and perinatal substance misuse. I think that there is a strong argument that there should be some overlap or combination. ...I think that there's a gap in the provision of maternity-specific psychological interventions before birth that could have a positive impact on women in terms of anxiety, depression, post-traumatic stress disorder and grounding techniques." – Site 1, Addictions Psychiatrist</i></p>
<p><u>5.9 Support for mothers to remain with their baby in the early postnatal period.</u></p>	<p>The EACPG agreed that early postnatal care in the hospital postnatal ward can provide opportunities for women to develop parenting skills and confidence including education for breast-feeding support and provision of emotional support to the mother when an infant is given NAS diagnosis and treatment.</p>

<p>Mothers should be supported to remain with their baby in the early postnatal period where possible.</p>	<p>The Stepping Stones Study interviews with women identified both positive and negative experiences of postnatal hospital care.</p> <p><i>"they didn't want me to bond with her" "I was getting conflicting information" re skin to skin. "they're assuming I'm a drug addict ... even if I was, I've got a right to bond with my child" very judged "Not blatantly" but other moms encouraged to bond. 07Esa</i></p> <p><i>" it was really nice you know, they supported me" helped her with learning about baby's care.' 09Esa</i></p> <p>Staff in focus groups also highlighted the importance of supporting mothers in early postnatal ward care</p> <p><i>"I think women get really good care antenatally and there is lots of services available to them. I think where it falls down is postnatally, Site 2 specialist midwife</i></p> <p>Focus groups found that midwives in different sites provide this (support) differently – but felt <i>' this was really important to build the woman's confidence in parenting.'</i> Site 3 Focus groups</p>
<p><u>5.10 and 8.5 Ongoing support for women whose babies are taken into care.</u></p> <p>All services must provide ongoing support for women whose babies have been removed, independent of the baby, this includes individualised care planning and tailored treatment addressing psychological needs.</p>	<p>Women who experience removal of their baby are at greater risk of suicide or accidental drug overdose (3). The scoping review found that there was a lack of guidance and recommendations around the specific support to be provided to women whose babies are taken into care.</p> <p>Our EACPG, and evidence from the focus groups with practitioners identified that service involvement with women whose babies have been taken into care is primarily focused upon the needs and protection of the baby, and not on the women's health and mental well-being. Women in the study whose babies were taken into care reported relapsing, suicidal ideation, and attempts.</p> <p><i>"what's the next thing I try? I don't want to wake up, d'you know what I mean. And I'm not wanting that happening...I was on the bridge. I just felt so hopeless." (03_P12_LGc)</i></p> <p><i>"what they [social work] say to me is, 'We're not there for you, we're there for [daughter].' So it's like, 'Well, what support have I got?' I have none now.' (02_P5_SLe)</i></p> <p>Staff in focus groups confirmed the women's perceptions and expressed concerns about gaps or potential gaps in services for these women.</p> <p><i>"I think women get really good care antenatally and there is lots of services available to them. I think where it falls down is postnatally, especially for those women who go through care proceedings and their babies, for whatever</i></p>

	<p><i>reason, are removed into foster care, I think still, very much services seem to follow the baby and the woman just you know, gets well (dropped)– Site 2, Specialist midwife</i></p> <p><i>“(there is a) distinction between women who lose their babies and women who keep them. Whereas, one set can access perinatal mental health and the others don’t. Also, once a woman has delivered, she is considered vulnerable if she keeps her baby and would have a right to housing. With the other person, four days after pregnancy, you’re just number 27 on the homeless (list)– Site 1 Addictions Psychiatrist</i></p>
<p>Key Requirement 6: Accessibility</p>	
<p><u>6.1 Community Hubs</u></p> <p>Women should be able to access a range of services and professionals in one easily accessible location.</p>	<p>There is evidence that having services accessible in one place could improve access to different services and support engagement (*).</p> <p>The Stepping Stones Study found that women are over-burdened with appointments during pregnancy, and they reported that transport and work schedules are not considered by staff.</p> <p><i>“I don’t think they really get how tired I actually am and how exhausting it is to have ..an appointment every single day of the week so, there is no day I can just rest [yeah], that is overwhelming” (01-P8_a)</i></p> <p>Staff also highlighted the benefits of locations which provide a range of services including additional supports which are also de-stigmatising spaces.</p> <p><i>“We kind of try and make this place as trauma-informed as possible, so it almost feels like a house. So we have like showers here, we have a washing machine, a tumble dryer, a living room area, a pantry area. They can get pyjamas, clean underwear, any kind of selfcare, toiletries that they might need as well. We’d always tell women to come in and get something to eat” - Service manager, site 3, focus group</i></p>
<p><u>6.2 Accessible locations</u></p> <p>Women’s care should be provided in accessible locations (facilitated by 6.1). Staff should take into account women’s schedule of appointments and locations when planning appointments.</p>	<p>Women in Stepping Stones Study said they prefer in-person meetings, but these can be hard to get to – especially for women living in rural areas, but also for women in large, urban areas. Barriers included cost, and the physical demands of making multiple journeys whilst pregnant and postnatally.</p> <p>Staff in focus groups recognised this problem.</p> <p><i>“just being flexible with them. And sort of assertive outreach, as well. You have to be able to sort of meet with them where is convenient for them, a lot of the time.” – Site 2, Focus Group</i></p> <p>Women who needed residential rehabilitation, were often offered placements which were located far away from their home which could be logistically and culturally difficult (from focus groups and from women)</p> <p>For example, a woman in the Stepping Stones Study who was discharged from a residential rehabilitation service was housed in a hotel within a large urban area several hours away by public transport from her childcare and the</p>

	<p>substance use service she was court mandated to attend (and found useful). This resulted in her traveling upwards of 5 hours each day just to attend her recovery group. This was eventually rectified, and she was rehoused, but this took several months. She felt she was being “set up to fail.”</p>
<p><u>6.3 Practical help to get to appointments.</u></p> <p>Practical assistance should be given where necessary including transport fares to attend appointments.</p>	<p>Providing support (transport fares or vouchers, appointment reminders) can be helpful to support engagement, and acknowledge that often this group is also struggling financially. The systematic review (*) found that interventions which include additional practical support (transport vouchers, food vouchers etc.) supported increased engagement in treatment as well as reduced substance use during the perinatal period.</p> <p>Women in the Stepping Stones Study reported various difficulties in attending appointments, including lack of finances for bus / taxi fares, and often the logistical challenge of having to negotiate several buses /modes of transport as a pregnant woman or with a new baby. Where support was provided either by the provision of a bus pass, or taxi fares women found this helpful. Additionally, some women were supported in person to attend appointments including child protection meetings and supporting their engagement.</p> <p><i>“I have got a social worker and they pay for cabs for me to get there and back [yeah] so, that’s also an option so, yeah, pretty easy. Yeah, no excuses not to go unless I am sick or something, yeah.” (01_P8_a)</i></p> <p>Staff in focus groups agreed.</p> <p><i>“And half the time, once we were able to give them maybe, a bus pass, or help them with their benefits, they become - d’you know, like it was totally night and day.” (Site 4, Focus Group)</i></p>
<p><u>6.4 and 8.2: Flexible contact methods</u></p> <p>Services should enable staff to offer a range of ways for women to get in touch and maintain contact. Appointments and important information should be communicated verbally, and / or by text as well as in writing to ensure that women know about them and understand re: expectations.</p>	<p>Staff recognised the importance of providing options for women to make attending appointments easier. They highlighted that text reminders can be useful, and that asking women how they prefer to be contacted is essential. This was also recommended by our scoping review (19).</p> <p>Women reported receiving letters about appointments after the appointments have happened and forgetting appointments. Women receiving calls or texts between appointments appreciated this, were more responsive and it supported engagement.</p> <p><i>‘I tend to find that the letters don’t come until after you actually have your appointment, ...I just missed one with the perinatal team’ (04_P8_LGa)</i></p> <p><i>“that one I’ve got just now she’s really, really nice and I couldn’t speak high about her enough, like, she always texts me to check up on me and she’ll phone me every week just to make sure I’m getting on alright and I’m taking my iron tablets and my vitamins and stuff, she is really nice.” (04_P7_LGa)</i></p>
<p>Staff level</p>	

<i>Staff level refers to direct care staff</i>	
<u>Key requirement 7: Approach</u>	'Approach' in this context is defined as being the way in which practitioners engage with women, and how care is delivered. Many domains are overlapping but an underlying culture and ethos of practice whereby the person's experiences and their social and emotional context is central to care delivery.
<p><u>7.1 Taking and spending time</u></p> <p>(Enabled by resources provided at strategic and service levels) Practitioners need to have time available to spend with women, to get to know them and to allow them to adopt a relationship based and trauma informed approach.</p>	<p>In Stepping Stones Study focus groups and interviews with practitioners, it was noted that being able to spend time getting to know women, their families and their circumstances enable practitioners to develop stronger relationships and deliver more person-centred care that is centred on individual needs.</p> <p><i>"we don't think that detox and rehab that narrative needs to be for everybody and we want to give them as much options and the discussion to happen over time."</i> Site 1 Focus group 1</p> <p>Women also appreciated where staff were able to give time enabling person centred care.</p> <p><i>"she came back out and seen me again after and she was finished with me, she even come back out. She's phoned me a few times as well to make sure that everything's still going alright and that, aye she has been really good. ...(she kept saying) we need to make sure not just [baby]'s alright but you're alright' ... she wasn't just a midwife to look after the wean, she says 'I'm here for you, to support you as well and make sure you're getting the support you need'"</i> (04_P4_LGa)</p>
<p><u>7.2 Relationship based and person centred</u></p> <p>Staff should prioritise provision of continuity of relationship-based care for this group of women</p>	<p>The scoping review (19) found that many documents suggested a named worker or lead professional should be allocated (such as a specialist midwife, health visitor or doctor) who is easily accessible/contactable. It was suggested that this could improve engagement in some documents.</p> <p>The qualitative papers included in the mixed methods systematic review (*) reporting on a range of treatment approaches and models of care consistently stated that relationship-based practice was fundamental. Within certain interventions (Specialist substance use treatment, integrated model of care) a person-centred, individualised approach to care was recommended.</p> <p>Stepping Stones Study interviews with women revealed that when they did have a named worker who got to know them and provided consistency throughout that it improved engagement and their experience of the service. Where this relationship was lacking women reported negative experiences of care provision.</p> <p><i>'I'm comfortable with her because she's always been the same worker, d'you know what I mean, I've never had anyone else stand in for her and she's known me through my worst as well. So I feel comfortable with her.'</i> (03_P6_b)</p>

	<p>Staff also identified the importance of building and continuing a relationship with mothers and babies. <i>"I think relationships are key. It's kind of what you're all highlighting, that relationship, being able to build with that person, and how safe they are able to feel with you. The benefits of consistency, containment, knowing that you have some element of control over what's going to happen to your care and the care of your baby as well. ...that is what lends itself to more positive outcomes and keeping families together."</i> – Site 4, Focus Group</p>
<p><u>7.3 Kindness and listening</u></p> <p>Practicing kindness and holding the women in positive compassionate regard not only supports engagement but a greater understanding of the woman and her needs ensuring that support can be tailored to her circumstances. Listening to the woman's experience, and point of view will also help to ensure a trauma informed approach is taken and that care is delivered in a person-centred way.</p>	<p>The EACPG noted that kindness and listening is an essential factor in providing care to this population, as evidenced in multiple maternity care reviews.</p> <p>In the Stepping Stones Study women reported feeling more confident to engage with services when practitioners and staff were kind and empathetic. <i>"especially with [specialist midwife]. She does listen to me and has suggestions for stuff that I'll be comfortable with. Yeah, I definitely feel listened to."</i> (01_P12_c)</p> <p>Women had negative experiences when they felt unheard or that they weren't listened to. <i>"I don't think I've been listened to at allI'm just seen as the drug addict who harmed her baby, I get that. ."</i> (02_P3_d)</p> <p>Staff in the Stepping Stones Study focus group interviews also recognised the importance of kindness and empathy. <i>"It's being able to think, 'I wonder what it's like to sit in mum's shoes? I wonder what this is like for her. And will this help any of the healing process if we actually think about what this is like for mum a bit more?' and I don't think they are thought about enough. I think that very much gets lost in the process."</i> - Site 2, Specialist HV</p>
<p><u>7.4 Flexible</u></p> <p>Practitioners need to provide care that is responsive to a woman's needs and situation. Being able to offer appointments at short notice or change their time or format if needed (1).</p>	<p>The mixed methods systematic review (*) found that in integrated and multidisciplinary models of care, women noted that a flexible, individualised approach benefitted them.</p> <p>In the Stepping Stones Study women reported not feeling that their needs were properly listened to or accounted for, and that providers could often be inflexible in their responses.</p> <p><i>"She's very resistant to helping me find a solution to the problem that I'm having. Yeah, she's not very flexible. She's just like, 'I'm not doing that' sort of thing. Yeah, there's no sort of compromise. Yeah, she's not helpful at all really."</i> (01_P8_ESd)</p> <p><i>"she wanted me to go all the way up to the [local sexual health clinic], but I could hardly walk and it's miles"</i> (04_P5_LHd)</p> <p>However, when women were offered different ways to get in contact, or felt that their provider was able to be accommodating they felt supported and secure.</p>

	<p><i>"I missed a lot of appointments because I had so many for my physical health so, my maternity appointments sort of went, took a back seat for a little while which was concerning, obviously, I missed like a couple of scans and stuff, but [specialist midwife] sort of like yeah, she made sure that everything got done swiftly"</i> (01_P8_ESa)</p> <p>Staff in Stepping Stones Study focus groups also highlighted the importance of flexibility <i>"But also just being aware that, you know, sometimes these women are having to engage with so many different professionals, so many different appointments, and they can really struggle with that. You know? And I think it's about us ensuring that we're flexible with them, and trying to get the best outcome for them and their baby, as much as possible, really."</i> - Site 2, Focus Group</p>
<p><u>7.5 non-stigmatising care and language</u></p> <p>The way in which support is provided should not stigmatise the woman. All services should be respectful of their privacy and dignity. For example:</p> <ul style="list-style-type: none"> • Appointments should not solely be available within buildings and spaces associated with drug treatment. • Conversations about drug treatment should only be held in private spaces where a woman's right to confidentiality can be respected. • Practitioners should be careful • about their choice of language and not assume prior knowledge of a woman's situation or history based on her substance use history or drug treatment. 	<p>The Scoping Review included many documents that recognised that women will often have experiences of stigma within healthcare settings, and that this may impact on their presentation and engagement in antenatal care. Documents also highlighted the importance of challenging stigma within services and providing non-judgmental, stigma-free care to women and their families (19 &*).</p> <p>In the Stepping Stones Study women reported feeling judged and stigmatised by services, which made them fearful. <i>"some nurses were lovely... a lot of nurses were judgemental because of baby's meds, (I was) made to feel guilty"</i> (03_P6_a)</p> <p><i>"Very judged, yeah. And maybe sometimes that makes it a bit harder, because I get really worried that whatever I do is going to be seen in a negative light."</i> (02_P3_SLc)</p> <p>Staff in focus groups also recognised the importance of ensuring women's privacy. <i>"(staff are) advocating for side rooms when it's safe for a woman to have that so that they have their privacy and that they can have these meetings (case meetings) like in a separate way where they're not being listened to"</i> – Site 1, Focus Group</p>
<p>Key recommendation 8: care delivery</p>	
<p><u>8.1 Effective communication</u></p> <p>Accessible information must be available for women about services and resources available, treatment and medication options, choices and</p>	<p>The EACPG suggested that services should provide a booklet/information for pregnant women who use drugs on key stages of pregnancy and about the different staff that will be involved in their care, and their role as well as definitions of key issues (NAS/NOWs etc).</p> <p>Women in the Stepping Stones Study appreciated clear and honest communication, especially in relation to child protection proceedings.</p>

<p>expectations, child protection proceedings and about wider social support agencies (1).</p>	<p><i>“this is my main midwife for now. She’s lovely, she makes sure that she tells you every single detail and you know what’s going to happen next and you know what’s happening down the line and she’s really nice.” (04_P7_a)</i></p> <p><i>“Just transparency, really. I would have appreciated that and also, better communication between the people who were dealing with my care.” (03ESa)</i></p> <p>Staff in focus groups also highlighted the importance of provision of clear information.</p> <p><i>“And as long as they know kind of what the plan’s going to be, and there’s no kind of - they’re not going to get blindsided and they think someone’s going to take their baby away, cause that’s what they always think when you go out for that first visit. So I think you need to be honest from the very beginning, and setting expectations is key.” - Site 4, Focus Group</i></p>
<p><u>8.3 Personal & timely response</u></p> <p>Communication to women who use drugs during pregnancy should be timely as women’s circumstances may change quickly. Services should develop protocols for appropriate responses and response times for women who call seeking advice / support / appointments.</p> <p>*this approach will also be supported by continuity of care and a care co-ordinator</p>	<p>Interviews with women in Stepping Stones Study revealed that they were often calling services to ask to speak to their worker or healthcare professional and being told they were unavailable. They were left waiting on a call back that sometimes didn’t happen, or was days later, or was from someone who knew nothing about their case / care plan and couldn’t offer any support.</p> <p><i>“it’s just the frustrating part of not being able to get a hold of them for so long cause like I feel it kinda knocked me back about ten steps” (04_P8_LGa)</i></p>
<p><u>8.4 Midwifery care – assertive outreach</u></p> <p>Staff should adopt an assertive outreach approach to engage with the woman.</p>	<p>Members of the EACPG highlighted examples within their own practice of assertive outreach and working hard to engage women. They noted that this is time-consuming and challenging but often yields positive results.</p> <p>Staff in Stepping Stones Study focus groups described benefits of assertive outreach.</p> <p><i>“assertive outreach, as well. You have to be able to sort of meet with them where is convenient for them, a lot of the time.” Site 2, Focus Group</i></p> <p><i>“I have spent the best part of the last year, and for the Children and Family social worker that was involved in the case, just chasing one person around the city. All over the city, not just in the south, sometimes she was in other places with- like weekends, evenings, taking food parcels. Accessing grants and things and trying to engage the person in that way.” - Site 3, Focus Group</i></p>

References

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19. Gilmour L, Honeybul L, Lewis S, Smith E, Cheyne H, Aladangady N, Featherstone B, Maxwell M, Neale J, Radcliffe P. Scoping review: mapping clinical guidelines and policy documents that address the needs of women who are dependent on drugs during the perinatal period. BMC Pregnancy and Childbirth. 2024 Jan 25;24(1):84.

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