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Vicki Mansfield (00:00:01):

Good evening and welcome everyone to tonight's webinar on the lived experience expertise supporting the transition to parenting. We'll go to our next slide. I'd like to acknowledge that I'm coming from Awabakal country tonight and acknowledge the traditional custodians of the lands, seas and waterways across Australia upon which our webinar presenters and participants are located and pay respects to the elders past, present and emerging and acknowledge the memories, traditions, cultures and hopes of Aboriginal and Torres Strait Islander people and also recognise the resilience and strength that have kept children and families' wellbeing for thousands of years strong and nurtured. So thanks everybody and welcome. I'm Vicki Mansfield, a practise development officer with Emerging Minds and I'm moderating tonight's session and we'll go to next slide. It's great to have you all with us tonight. We've got our learning outcomes there. My background is I'm a social worker and it's my joy to be tonight meeting with our panellists and talking about infant perinatal mental health, which is certainly my clinical background.

(00:01:26):

And we're exploring the unique role and contribution of peer workers within a multidisciplinary team and looking at how that supports perinatal and infant mental health in the transition to parenting and in the context of the neonatal intensive care unit as well. And we're doing that and exploring our learning outcomes today through a family story, which is Ruby, Alex and Baby Mia, who you'll meet in a moment. But for us to kick off tonight, let's meet our panellists. We have a panel of lived experience expertise. So first of all, I'd like to introduce Ashley Allan, who's a perinatal lived experienced peer worker. Welcome Ash.

Ash Allan (00:02:16):

Hi.

Vicki Mansfield (00:02:18):

And for us to get to know a little bit about everyone, I've got a question for each of you as I introduce you. What's something you've learned from families about perinatal mental health recently? Ash?

Ash Allan (00:02:31):

Thanks, Vicki. So I've recently co-facilitated between parents and their bubs through the shared enjoyment of being together and engaging in play. And our parents reflected on how much it meant to them to have a space that they could come to each week amidst everything they're navigating with their mental health and other stressor in their lives to just focus on being with their bub and enjoying those

moments of connection. So I've learned how impactful and healing it can be and what a privilege it is as a peer worker within a perinatal and infant mental health service to be able to offer and hold a safe, supportive space for parents navigating perinatal mental health challenges so they can connect with each other and just be able to focus on their connection with their little one.

Vicki Mansfield (00:03:17):

Oh, lovely Ash. That sounds just so delightful. And next I'll introduce Jess Jackson, who is a carer, peer support worker. Welcome, Jess.

Jess Jackson (00:03:29):

Hi, Vicki. Thank you for having me. And may I apologise for my voice this evening? I've been married for 22 years and I think my husband is the only one that's quiet. My voice is gone for a bit of peace of mind.

Vicki Mansfield (00:03:43):

Well, thank you for soldiering on for us tonight, Jess. And Jess, is there something you've learned from families about perinatal mental health recently?

Jess Jackson (00:03:53):

Yeah, I think I'm reminded of just families can feel really fragile during this period, but they're also incredibly resilient and I think it's not a straight trajectory and sometimes the pendulum swings from feeling really strong to feeling really vulnerable and just about holding families during that time. It's really

Vicki Mansfield (00:04:16):

Important. Yeah. Thank you, Jess. And lastly, it's a pleasure to introduce Viv Kissane, who's the CEO and founder of Peach Tree Perinatal Services. Welcome, Viv.

Viv Kissane, OAM (00:04:29):

Hi. Thank you.

Vicki Mansfield (00:04:32):

Lovely to have you with us this evening. And Viv, I know there's many things that families may have shared with you, but anything recently stand out for you that you've learned from a family about perinatal mental health?

Viv Kissane, OAM (00:04:46):

Absolutely. So when I was reflecting on this question, I was reminded that sometimes parents often carry a lot of strengths that they don't recognise in themselves until we reflect it back at them. So if we

are telling people or telling parents more often about how good of a job, how great of a job that they are doing and that positive reinforcement is really quite often immediate and really visible and it's something that can be done really easily and quickly.

Vicki Mansfield (00:05:18):

Yeah, absolutely. You often see people's face light up. So I think that's a great reflection. And so to start our panel discussion and to give us context for our audience this evening, Viv, I'm wondering if you can share with us what's meant by lived experience expertise and what that means specifically in the context of perinatal infant mental health, which we're discussing tonight.

Viv Kissane, OAM (00:05:46):

Yeah, sure. So in a nutshell, lived experience expertise is essentially people who have been through profound, often very life-changing mental health journeys and we intentionally use those experiences and those learnings to support other people who might be going through the same or through similar things. So lived experience workforce is considered emerging, but it's actually built on a very long history on the back of a consumer movement. So it began as a fight for rights essentially where consumers who were often harmed by the very institutionalised, very castoral systems came together and wanted to create and advocate for change. So it's important to recognise that lived experience work has origins of not only experiences of mental health distress and recovery, but also experiences of discrimination, of stigma, marginalisation, oppression, and often exposures to multiple traumas and using that as a focus for why they're drawn to do this work.

(00:07:04):

So the last 10 years has seen quite a push towards professionalising the workforce. A landmark milestone was in 2020 when the National Mental Health Commission actually published the National Lived Experience Workforce Guidelines. And these guidelines recognise lived experience roles as a distinct workforce that has a skillset that has a scope of practise and that has requirements around appropriate training, professional development, reflective practise and supervision. These guidelines also highlight the important difference between designated and non-designated lived experience work. So we acknowledge that many people who are drawn to do this work may have their own personal experiences of mental health challenges and parenting. However, they might use those experiences to sit in the background to inform or influence the way that they practise. However, designated lived experience roles specifically around for people who are employed because of their lived experience and that disclosure is a mandatory part of the role and those roles intentionally use those disclosures of lived experience as a core component or a primary lens of the way that we work with others.

(00:08:37):

So in the perinatal mental health space, this becomes a further specialisation because as we know, the transition to parenthood is uniquely vulnerable, it's relational and it's developmentally significant for both the parent and the infant. So perinatal mental health lived experienced workers, we understand that our work has a dual purpose in not only fostering nurturing environments of care for infants, but

also recognising and responding to what can be sometimes very complex trauma histories of parents. So the importance of that perinatal specialisation is understanding that parent and infant relationship, understanding attachment, the fundamental identity shifts that happen at this time of life, the historical and intergenerational traumas that impact people's experiences as well as the broader social context that families live in and the services that they might be navigating.

Vicki Mansfield (00:09:41):

Yeah. Thanks, Viv. That's a really great context and helps us gain a broad perspective. And before we dive into talking about our family story, so thanks, Viv. That really helps us set the scene. And so we'll introduce our family story that will help us explore the components that Viv was just discussing. So let's meet Baby Mia and hear their story. So we know that lived experience expertise can make a meaningful difference for parents and families in the NICU environment, similar to Ruby who we'll be hearing about tonight. So Ruby is 35 years old with a lived experience of an eating disorder and Ruby's partners, Alex, and works as a paramedic on shift work and he's practical and supportive. And during pregnancy, Ruby sought private counselling under a mental health care plan for anxiety due to three prior miscarriages and medical complications. And Ruby delivered her daughter, Baby Mia, at 34 weeks and Baby Mia had to be admitted to the neonatal intensive care unit due to respiratory issues.

(00:11:01):

And whilst tonight Ruby, Alex, and Baby Mia are fictional stories, this is not necessarily an uncommon experience. And so for us tonight we're going to hear from Dr. Natalie Duffy, now a neonatologist talking about transitioning to parenting in the NICU. So we get a little bit of a context around the environment of the NICU.

Dr Natalie Duffy (00:11:32):

I think that for our first time parents or even parents that have had a baby before, if you've never been in the NICU, you're having to completely adapt your parenting style and skills to this whole new environment. And parents tell us they feel completely overwhelmed. They're scared. They're scared of the equipment that's touching their babies. They're scared of the equipment that's housing their babies and all the other stuff that's surrounding them. So they are the expert in their baby and they're the people that can love and nurture and support them, but we have to help to guide that probably in those initial moments, days and weeks. But together we can be inquisitive and curious about who this little person is, whether they're a tiny little preterm baby or a term baby that's in the hospital. If we partner with the parents at the cot side and we're curious to understand this baby, this person and understand their behaviours, we all learn together.

(00:12:37):

And often once the babies are a little bit older, the parents have hopefully with our help and support have settled in a little bit and then you can see that they become the experts in their baby's care in their behaviours and they often can tell us when things aren't quite going the way that they want, but that's

also part of it empowering them to speak up, allowing them to advocate for their child and it being a partnership, us walking the walk with them as they walk the walk with their child.

Vicki Mansfield (00:13:15):

We heard from Dr. Duffy there that parents are the experts in their baby, but the early days and weeks of NICU can be overwhelming and she highlighted the importance of supportive partnerships with parents. And Jess, I'm wondering from your experience how peer support workers partner with parents in NICU or what unique skills peer support workers bring to that context

Jess Jackson (00:13:43):

Yeah, thanks Vicki. I think one of the big things is that we, even though we haven't necessarily walked exactly in the shoes that they've walked, we can definitely identify with many of the feelings that are going on and just seeing that Duffy there, I was lucky enough to get to know her last year and she's incredibly attuned to the families and the babies that she works with and she kindly took me back into the NICU where we began seven years ago, early eight and those feelings came right back and I was remembering how hopeful and terrified I was, how much I was putting on a brave face a lot of the time to the hospital staff and then sometimes I'd just hold it together and just go into my car and cry at lunchtime and then I'd just hold myself back up. I think knowing that sort of experience that the families are having and not necessarily portraying to the staff is something that's really special about our job.

(00:14:46):

In terms of partnering with families, our experience naturally dug it out last night that we had a welcome pack from Miracle Babies and in there I had a little which was gorgeous, but also there were already resources there from the start and sort of a helpline. There were sort of morning teas that happened, to be honest, I'm a bit hazy. It might have been once a week, it might have been once a month. We were in there for a while, but where families could connect and I think that is such an important thing, bringing families together because our family was so lucky. I've got a very close family and friendship network, but I found that I was in such a bubble. I couldn't really communicate much with everyone in the outside world. It was the people that was in there that were in there with me that I just felt like they got it understood.

(00:15:49):

I didn't need to explain all the feelings and I think that's one thing that doesn't happen often, but I would love to see more of it and that's peer support caught side in NICUs and the reason for that is ironically I'm a peer support worker. I didn't attend a few groups in NICU and the reason is because I was too scared to leave my son who stopped breathing all the time and I also just, I think I just felt a bit anxious to join a social group at that time. It was just too much going on. So just having peer support bedside means that you can get what you need, you can feel really isolated, but you can have someone come in to your circle that understands and is able to give the hope that here is someone that went through something similar and came out the other side and has got generally a really hopeful story and that post-traumatic wisdom, the growth that they're able to impart.

(00:16:55):

So for me personally, I got that from the families that I was in NICU with and that's the reason why I'm in the position I am today because they were like our lifeline and I'm so grateful for those families and one in particular. And just in terms of what we can actually help the families with, it's about meeting them where they're at. So if I were to meet Ruby and Alex, I would let them know what my role was about, things that we could look at when they're ready, for example, resources, helping them to advocate and really use their voice and you know they really are the experts in their child's care as Nat Douglas was talking about. We know how overwhelming the service can be. It feels like you're being dropped onto another planet. We can help them navigate that. And also sometimes parents, new parents might feel too scared to speak up to, especially doctors, I feel like we can be a bridge to the clinical staff as well.

(00:17:56):

But the most important thing, and often it's all that happens is just that we can listen from a place of understanding for these channels.

Vicki Mansfield (00:18:05):

And that listening, Jess, as I am reflecting on what you just said there, that listening is validating and empathic and like a really felt sense of being where they've been, but it also brings hope, which was something that really stood out in what you were saying there, which is such an important value by the sound of it in that lived experience peer work is bringing that hope through your own experience and you said post-traumatic wisdom as well.

Jess Jackson (00:18:36):

I think families sometimes would leave the NICU and come back with their babies and it sounds so stupid, but I would think, oh my God, people leave. We just felt like we were in this eternal waiting place, but just to see that someone's left the baby's dream well, everyone would just light up and rushing to see how that would go. So that's really lovely and peer support is a big part of that. You can make it to the other side, it's possible.

Vicki Mansfield (00:19:04):

And that bridge between parents and staff in what's a really busy, quite a busy and acute setting, that bridge I think and your aspiration for more cotside peer support sounds like something for us to strive to.

Jess Jackson (00:19:22):

Yeah.

Vicki Mansfield (00:19:23):

I'd

Jess Jackson (00:19:23):

Love to see that. I'll keep strive.

Vicki Mansfield (00:19:25):

Yeah. Thank you, Jess. And let's hear a little bit more about the family story now and hearing what's happening for Ruby, Mia and Alex. So at 10 days postpartum, Ruby is advised she'll be discharged from the maternity ward and Mia will remain in the NICU. And on the day of Ruby's discharge from maternity, she's very teary and shares with the social worker that she's hardly slept or eaten in the last 24 hours due to her worries about Mia. Ruby also shares that she's expressing breast milk and is feeling frustrated by the amount she's getting and is worried that it won't be enough for Mia. And the social worker encourages Ruby and Alex to speak with the perinatal mental health team, but they are uncertain and not sure about the next steps. And I'm wondering, Ash, how might perinatal peer support assist Ruby and Alex to navigate next steps and what would in guide and inform your work with them?

Ash Allan (00:20:42):

Thank you. And yeah, just Viv and Jess have both spoken so beautifully and I think I'll be mirroring a lot of what you've both already touched on. I'm really grateful for this opportunity to reflect on the context and practise of the perinatal peer worker role in the perinatal and infant mental health service and speak a bit to what the support that I could provide as a perinatal peer worker could look like. As a perinatal lived experience peer worker, I'm part of the PIMS multidisciplinary team. I work alongside and in collaboration with our specialised PIM clinicians to provide trauma-informed perinatal mental healthcare that really acknowledges that the emotional wellbeing of parents and their babies is interconnected and is really centred on nurturing that attachment relationship for the wellbeing of both.

(00:21:38):

Connecting with Ruby and Alex as they're preparing to be discharged home with their baby Mia staying on in the NICU is a really key touchpoint for the perinatal peer worker role to hopefully support early engagement with PIMs so that Ruby can access pinatal mental healthcare at this point if she wants to, or to foster that relational connection that could enable her to reconnect with PIMs for support in future. So when connecting with Ruby and Alex, I'd check in with how they're feeling about engaging with PIMs and hold in mind that they might be feeling uncertain and the possible reasons for that, which could include shame around pinatal mental health challenges, experiences of trauma, child protection fears, or previous negative experiences with mental health services. I'd speak to and explain my role as a perinatal peer worker within the PIM team and in doing so, offer that empathic connection that's grounded in shared lived experience and a safe and supportive space for them to share and reflect on their experiences.

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I'd meet them where they're at in their experience and be guided by them as to what's important to them and what they want and need. So within my scope of practise as a perinatal peer worker and as

we've said, guided by the lived experience peer practise values, I'm not there to undertake screening or assessment in the way that PIM clinicians would need to do within their roles and our focus is really on building that relational connection and just really holding space for them to share what they're experiencing and offer that empathic validation and share hope and support them in navigating services and systems. I'd be able to offer normalisation without minimization in the context of their experiences. I'd be drawing upon our collective perinatal lived experience or safely and intentionally sharing parts of my own lived experience to really speak to what it's like to experience perinatal mental health challenges and distress, shame and stigma, and to share hope alongside holding in mind the really uniquely personal nature of Ruby and Alex's experiences and what it means to them as people and parents.

(00:24:04):

In supporting Ruby, I'd really want to acknowledge her perinatal experience and all that she's holding. So offering that empathic validation for her overwhelm in the context of what's going on and with her transition into motherhood, her pregnancy and birth, her previous losses, the medical complications, and then with Mia being born Premie and now in the NICU, Ruby's not sleeping or eating, experiencing challenges with expressing and feeding Mia and she's understandably feeling really anxious about going home and Mia needing to stay in hospital. Ruby's motherhood journey is likely not what she'd expected or hoped for and I'd want to hold space and offer validation for feelings that she might be experiencing of grief or anger, fear, uncertainty, overwhelm and shame. I might have the opportunity to plant a seed around metrescence and really share that knowledge and a language for making sense of what's going on within the complexity of that perinatal mental health landscape and really holding space for her experience of her birth and the potential impacts of having a traumatic birth experience.

(00:25:21):

I'd speak sensitively to the way that that can impact our sense of ourselves as mothers and the way we feel about our connection with our baby to really hold space for Ruby to share how she's feeling about her bond with Mia and space for her to talk about her breastfeeding challenges and worries and to explore with her what it's been like being separated from Mia and how those challenges with breastfeeding can, again, be a real source of shame and guilt and distress and can have a significant impact on how we feel about ourselves as moms.

(00:25:58):

And then I really want to focus on supporting Ruby and Alex to advocate for themselves and Mia and their family, exploring with them what support they want to need, get an understanding of what safe and sensitive care looks and feels like for them and what strengths and support network they already have and then what's available to them and how to access. So sharing knowledge and resources for navigating the complexity of maternity and perinatal services. I'd be able to speak from the lived experience perspective about the care and support that Pims can provide. I'd explore with Ruby her experience of reaching out for mental health support during pregnancy and encourage her to continue to connect with the mental health support that she needs for her own wellbeing as well as for Mia. Again, really acknowledging that that shame and stigma we can feel around perinatal mental health

challenges can be a barrier to connecting with care, but reinforcing that taking care of our own emotional wellbeing is a really important part of taking care of our child.

(00:27:03):

And then for Alex too, as Ruby's partner and as a new dad and me as other parent, it would be such an important opportunity to explore with him his experience and what support he might need. So I'd be holding in mind that Ruby's expressed he's really practical and supportive, but she sometimes feels that her worries are dismissed by him. So be exploring with Alex,

(00:27:26):

What does he need to be able to support Ruby and Mia and what support might he need for his own mental health and then helping him to connect in with those supports that are available.

Vicki Mansfield (00:27:37):

Thanks, Ash. Gosh, there's so much there. It really highlights the depth. Sorry, Jess, I just cut you off there.

Jess Jackson (00:27:47):

Sorry. It was beautifully said. Yeah, really lovely.

Vicki Mansfield (00:27:51):

Thank you, Jess. Yeah. And Ash, I'm curious, and there's also a question from our audience as well, in your conversation with Ruby and Alex, maybe that Ruby bravely also shares that she's worried that her past challenges with eating are resurfacing. And Jess spoke about being a bridge between teams. How might a lived experienced peer worker work alongside or work with Ruby about those worries but also be a bridge or collaborate with the team?

Ash Allan (00:28:38):

Yeah. So again, I'd be able to offer that empathic validation and really speak to the shame and the stigma that can exist with eating disorders and really acknowledge Ruby's courage in sharing her experiences with me. I'd be able to speak to that intersection of eating disorders in the perinatal experience that it can be a really challenging and vulnerable time when eating disorders can resurface or intensify. And I'd want to really share with Ruby that she's not alone and that there is support that she can connect with. Something I would want to reflect on with her is how the experience of disordered eating can interweave with our experiences with breastfeeding, that it can be complex and layered. And I just want to hold really sensitively that Ruby could be feeling shame or triggered by the physical experience or having feelings of failure or that she might be failing Mia and just know that these feelings can be entwined with how she's seeing herself as a mom.

Vicki Mansfield (00:29:46):

And Ash, is that an important part of your role to also provide, because clinicians don't always have all of that knowledge and resources as well, but is that also in Important part of educating staff as well around what might be happening for Ruby.

Ash Allan (00:30:08):

Yeah, I guess that's just one of those really important layered ways of what we're able to offer as peer workers, that support to Ruby, but also alongside that is being able to articulate that within the clinical team and speak to that from the lived experience perspective and really support that communication and that connection to go both ways and to be done gently and sensitively and with all that in mind.

Vicki Mansfield (00:30:40):

Yeah. And through that, that as you said, reduces shame and potential isolation. And you mentioned, what do you think makes it work well for a lived experienced worker in terms of supporting that bridge between the team and Ruby in this instance?

Ash Allan (00:31:11):

I guess that it's that opportunity to be there alongside Ruby and to talk it through with her with that sensitivity and transparency and letting her know that we can navigate it together, supporting her to feel empowered and have knowledge and choices around the care that she wants and needs and with supporting her in advocating for that, advocating on her behalf if that's what she wants and then working collaboratively with her clinical care team to support them to navigate with Ruby in a really sensitive and trauma-informed way.

Vicki Mansfield (00:31:53):

Awesome, Ash. And I think that you highlighted there that important of choices and advocacy and how important choice is after when we're in feelings of overwhelm and when we may have had a really traumatic experience of starting into motherhood. So yeah, it's such a powerful role to be able to be bridged between that. And it's a great segue for us to hear from a multidisciplinary team member. And so lived experience, as Ashha said, often are sitting within a multidisciplinary team. And so we have Danielle Pretty, who's the Eastern Suburbs Perinatal Infant Mental Health Clinical Manager and Clinical Nurse Consultant and Nurturing Connections Clinical Manager. And Danielle has a question for our panel. So let's hear from Danielle.

Danielle Pretty (00:32:48):

Thanks, Vicki, and hello everyone. I'm lucky enough to work closely with three amazing perinatal peer workers, I thought I'd ask what might be at risk if a peer worker wasn't involved at this point.

Vicki Mansfield (00:33:03):

Thank you, Dan, for a great question. And it makes me curious and I invite all of you to share your perspectives. How might the system of care benefit from lived experience expertise at this point? Because Danielle has asked about what might be the risk if a peer worker wasn't involved. So yeah, what is it that they're bringing to that system of care that at this point of transition?

Viv Kissane, OAM (00:33:38):

I'm happy to jump in there first. So I think where my head goes with that is really that services and care may very unintentionally become very clinical and very medically focused and lose that person-led kind of approach. So understandably, particularly in a NICU environment, there's a lot of critical medical work and care that's going on and that could be very busy and whatnot, but it also might mean that early signs of parental distress could perhaps be missed, whereas having a lived experience or a peer worker there who really brings that relational and that experiential lens to their practise might be able to help identify that's going on and that needs to be addressed.

Vicki Mansfield (00:34:40):

And I think Ash and Jess, you also mentioned before the power imbalances that it can feel like as well, which I think is what you're also talking and sharing there as well, Viv. Anything you'd like to add, Jess? Yes, go ahead. Yeah.

Jess Jackson (00:34:58):

Yes. I sit in a community mental health team and a multidisciplinary team. I'm not representing them directly today, but I think the relationship we have within the team is also really important. I have found sometimes disengagement could be one of the risks that may come from peer workers not being involved and that is not because clinicians aren't doing an amazing job. It may be that the families are just feeling so overwhelmed, they're starting to shut down. So I feel that through the connection that we're able to have with families by being able to open up a little bit about our lives, it's not about us telling all the details of our story, but just what may be relevant and important. And we always ask the families whether they would like to hear a bit of our experience and we are curious about the families and we invite curiosity as well.

(00:35:57):

So I think being able to add more of a holistic approach to the service could be really beneficial to what is already great clinical work.

Vicki Mansfield (00:36:09):

Thanks, Jess. That's fantastic. And I'll ask this question now because it is relevant to this section of the story. Are perinatal lived experienced peer workers and carer peer support worker available at most major hospitals and how do mothers and fathers get in touch with these wonderful women to support them? Jess, I think you alluded to before that sometimes there might be groups, but it's not necessarily available at all hospitals. Happy to hear from you guys. Yeah,

Jess Jackson (00:36:44):

Just from my personal experience, I'm in Melbourne, so there's wonderful representation in my personal experience from the Miracle Babies Foundation and Life's Little Treasures Foundation, which are not-for-profit organisations predominantly run by former NICU families. So they do wonderful work and not just in Melbourne. I think Miracle Babies is based in Sydney and they work in several states, but I'd love to hear from ASH in particular about your

Viv Kissane, OAM (00:37:24):

Special service. I think that the difficulty is that it's different in every state. I wouldn't say that there's any national consistency in terms of embedded services within each hospital health system, but certainly there has been a lot of progress made in terms of perinatal and infant mental health teams sitting in community mental health, which ASH is one of those. So I'll throw to ASH.

Ash Allan (00:37:57):

Yeah, I think we are definitely still very much an emerging workforce, the specialised perinatal and infant mental health peer workforce within the broader peer workforce. So we do have all that, I guess, scaffolding within services where the peer workforce is really well established and valued and supported. But yeah, the perinatal and infant mental health spaces, in my experience, it is a very new space that's still really emerging for us as a workforce. But yeah, there is so much need and so much value that perinatal peer workers bring in this space. So hopefully the workforce and the scaffolding around us will continue to grow so that we can offer support and be accessible to as many parents and families that need us and want to access peer support.

Vicki Mansfield (00:39:06):

And I think what someone's reflected also in the chat is that the transition into parenthood is a major life change for everyone, but also when we've heard here from Ruby where there's some additional things that their family is navigating, that is so vital for that early support and for having someone walk alongside. And that's a different experience having someone walk alongside to maybe having a clinical screening process. There's a very different feel and experience of that. So that's not an either or, but a complimenting of, and as you said before, that bridging of services and advocacy as well. So let's hear some more about our family story and what's happening for Baby Mia. So Baby Mia remains in hospital for a further 21 days and when Mia is discharged, Ruby and Alex are both feeling exhausted due to poor sleep and trying to establish breastfeeding through additional expressing and they're eager to settle into a routine at home, but they're feeling lost at times.

(00:40:25):

And Mia's very unsettled in the car and they're limiting going out to reduce distress. And we know from the literature that coordinated care and connection to community are really strong preventative and protective factors for infant and family mental health. And we've heard also mentioned several times that shame can be pervasive barrier and can silence women and reinforce isolation. And we've also

listed in our resources some research that's showing that this is a common for women with a lived experience of eating disorders and also when women are experiencing breastfeeding challenges. And so I'm curious, Viv, what role does compassionate lived experience support play in coordinating care and connecting to community and particularly when shame or isolation or distress might be high?

Viv Kissane, OAM (00:41:28):

Oh yeah, just building, I guess, on what Jess was saying in terms of being that bridge. So it's really important that as people are discharged out of hospitals, that they are reassured and that they feel confident that they're still going to be help and support for them in the community. And in that community, in our lived experience role, what we can do is that we understand that mental health doesn't live in isolation and that we actually live in complex ecosystems and there's actually a wide range of contributing factors that parents can experience such as as this couple are in terms of sleep and breastfeeding and medical and care needs of the babies. So lived experienced workers, I think we are able to recognise the unspoken or we often at Peachtree talk about the unspeakables and that is that shame often masks as coping and that feelings of disconnection with the baby still feel quite taboo and intrusive thoughts are also terribly confronting and scary.

(00:42:45):

So we also intimately understand that invisible load that parents are carrying in terms of the infant care needs and navigating all of the different types of services, not just mental health, but there's many intersecting services that they will need to access and navigating that can be really overwhelming and stressful. And like you said, Vicki, that the most up-to-date research that we have around perinatal suicide is called Making Sense of the Unseen and that research really supports that perinatal suicidality is driven by shame and specifically thoughts can lead to being like, I am defective or I'm unworthy or I'm failing at this and my family would be better off without me. So it's very interesting in our perinatal specialisation that risk and protective factors actually exist at the same time. So while a mother may feel deep love and responsibility for her baby, she can also simultaneously be experiencing profound distress around the caregiving responsibilities.

(00:44:08):

And I think Ash spoke really well as well around the shame as being a major driver of parental distress. So in this case example, and I'd like to throw it to Jess and perhaps ask specifically in a NICU context, is shame a major driver of distress?

Jess Jackson (00:44:30):

I think for my experience and thanks for asking, I think it was a lot of guilt and for me it was just first time mom, it's my only son and you just have these ideas of what motherhood's going to be like and just seeing my son multiple times in deep distress, not knowing whether we get to bring him home, I just felt like I couldn't protect him and I felt like that's my one job as a mom, as a parent. And yeah, it made me think when I was reflecting upon shame of when I rang my mom on the side of the road when I was on the way into hospital one day and I just broke down in tears. I decided I just can't protect him. I can't

protect him. And for me, even when he eventually came home, which was amazing and he was safe and we knew that he would survive, it was something that stuck with me.

(00:45:31):

So thinking about those intrusive thoughts, it's like, I think I can protect him until something big happens and what if ... So for me, that's something I did end up getting my own mental health support about and I found that really helpful just so I didn't go down the anxiety swirl the older he got and just the feelings of helplessness, that's a big thing.

Vicki Mansfield (00:45:58):

And I think that Jess, you beautifully articulated that sense of loss of control and as you said, helplessness and I think Ash, you referred to this as well before, is that there might also be within that guilt of guilt, but also grief, guilt and grief around this is maybe not how people had envisaged the start of their journey into parenting.

Jess Jackson (00:46:32):

It's not like the movie at all, Vicki, when you have your baby before you're supposed to have the baby shower or ... Yeah, it's so weird the first night after my son was born and people were sitting through congratulations, but I was like, "Are we going to have a baby tomorrow? I don't know." So it was just such a push and pull. It was so weird. You thought you'd get to celebrate and you're not celebrating. I mean, I should say there are so many beautiful moments, hope and love in the NICU. And like I was talking about that pendulum, it absolutely goes, but there is that grieving process that you ... I mean, you can be so grateful if you're lucky enough to have that baby that gets to come home. We're not all that lucky, but yeah, just that feeling that you are grieving for something that you missed out on that was a huge part of what you thought motherhood would be or parenthood.

Vicki Mansfield (00:47:29):

And Jess, as you said, that there can be a lot of myths, but there also can be a lot of social expectation. I know you said, Viv, about how mothering or parenting might be or how those initial experiences might be. And I'm wondering, reflecting on the family's journey, what points for preventative support might there be in their journey for ... We heard a little bit about their antenatal period as well. I'm wondering, are there moments that there might've been support or preventative actions that can support rather than the spiral, Jess, you mentioned, or the increasing or isolation of shame or increasing distress. Viv, have you got any insights?

Viv Kissane, OAM (00:48:28):

Yeah. Well, if I refer again back to that making sense of the unseen study, they basically have created this really grounded theory in terms of pathways through shame and essentially the pathway is around compassionate care and rehumanizing care. So I think we need to focus on initiatives that are destigmatizing and planting seeds early. So it would've been great if Ruby and Alex could have been

connected into community or have established supports through antenatal connections and being a little bit more proactive in terms of making sure that those seeds are planted and that expecting parents have information that they need for informed decision making, but also for pathways in terms of finding services and support should things get a little difficult and Peachtree I'll give a shout out to in terms of the work that we're doing in terms of lived experience community, we're normalising and validating that parenting can be really challenging and that like you say, that role modelling of hope and support and putting a lot of reframing around the fact that early relational supports can really shift that trajectory of both mom, dad and infants.

(00:50:08):

So a little bit of more proactive work instead of reactive work.

Vicki Mansfield (00:50:16):

Yeah. And that proactive work, as you said, is so powerful for both supporting wellbeing of parents and also for wellbeing of infants as well. And one of the questions which I might just ask here is that sometimes people are resistant to any service counselling or outside help preferring to work it out on their own or within their own family. How do we reach these people while respecting their decision? And I think you probably have touched on this a little bit, but yeah, I'm wondering if anyone wants to kind of reflect on that. Yeah. How do we reach people while respecting their decision?

Viv Kissane, OAM (00:51:06):

Yep. So what we have to realise is that people don't fit into tidy little boxes and because risk factors, protective factors, psychosocial factors, social determinant of health factors, contributing factors, there's such a diverse range of experiences that people ask, which is why we really need to approach this from a person-led point of view. So what we have to understand is that there will be some people who we are asking them to go back into environments where perhaps they received or were exposed to trauma. So providing options and choice, it's one of the principles of trauma informed care is choice and options. So I would say that that's where a lived experience or a peer worker, that's where the real gold and the real great stuff can happen because they hopefully understand that we're not approaching them to try and tell them what to do or to tell them they have to do this or not to do that, but we're just there to sit with them and to help muddle through all of this stuff that's going on and hopefully through that we're using our lived experience to build trust, to build rapport, to make people feel that we're genuine and authentic and hopefully sitting through that we can perhaps get to a point where they are able to access some type of support.

Vicki Mansfield (00:52:48):

And that is support what you just described, isn't it, Viv? That is support. That's very around support. And so we'll just come back as we start to think about there's a couple more questions, but before we think about the questions, I wanted to help us explore a little bit around Baby Mia, who we will certainly discuss more in our next webinar series, but thinking about how do we bring forth that compassionate

care that connects families with support like we were just discussing and what would that mean to have those connections and how might that influence Baby Mia's development and wellbeing? Because Ash, you mentioned before that that's interrelated and as Viv said, it's not in isolation, it's kind of a system of support. So Jess, I'm wondering what would you be mindful of for Mia based on your experience of advocacy work and role with families?

(00:54:04):

And then yeah, maybe Ash, you might have a perspective as well.

Jess Jackson (00:54:09):

Yeah. Thanks, Vic. It's certainly an area that I'm really passionate about. I think things are changing slowly, but they're changing our experience in NICU and we had such beautiful care, so I'm definitely not taking anything away from that. We were so lucky, but often when all these really difficult things were happening to our son, we heard a lot, "Oh, lucky you won't remember." So just keeping Mia in mind that her experiences in Nico are actually building her mental health for her future and that's good and bad. So it can be really positive as well. So what I've learned a lot through research and reading and from my own experience is that those first couple of months for a baby are crucial no matter whether they're in hospital or not And the brain develop and their nervous system development is happening at such a trajectory and they're really wiring for whether the world's feeling safe and that is going to let them explore in the future or whether things are feeling really dangerous and they're sort of amygdala, their sort of stress response system, maybe building to be on a heightened alert.

(00:55:36):

I feel like it falls in the gaps because there's so much love plus there's the really scary stuff and then keeping in mind that parents can't be there at night in most cases so the babies are alone with different caregivers, different experiences. Sometimes they have some really painful procedures and what I've also learned is that even as parents we were told, for example, when our son had a lumbar puncture, "Don't be there. It's really hard to see. It's fine. We'll be back soon." And then we got told he took it like a man and at the time we're like, "Well, he's brave." And now I'm just thinking, "Oh my God, is he dissociating with what was happening for him?" And I've learned that if parents can be with their babies, especially if there can be procedures done when they're skin to skin with the parents, so like the heel prick tests, which happen daily for memory, the babies can actually produce oxytocin in their brain, which is a natural painkiller.

(00:56:44):

So things like that, they're really easy to do. I would love to have more recliners in hospitals and just promote in general, even if there aren't too many recliners, just promote as much skin to skin coming as we can because that's when the babies are planning to co-regulate and developing that sense of safety. Again, nurses and we absolutely adore our nurses, they're on such a high rotation, you hardly get the same nurse twice. So just if they could be more regular rotations of nurses, especially I'm thinking the night shifts when parents can't be there, then that builds that sense of safety for the babies as well and just encouraging clinicians to slow down and connect to the babies because it may seem like a nice thing

in the moment, but it's actually, again, changing the trajectory of Mia, for example, of her life makes a huge impact.

(00:57:42):

So I feel like that's really empowering and I'd like to acknowledge too that some of these things that may seem quite ideal, not always possible can be really, really difficult for a parent in the hospital who is struggling and there might be, again, that sense of shame or guilt around that. So I think that's where peer workers well can really come into play to support the parents and as we've heard highlight how much they're doing right and how strong they are and about the connection that they're building with their baby and then we can promote these things that are also going to protect baby Mia because it's all about the health of the household even within the hospital space. Everyone's mental health has a knock-on effect to the family. And just finally, I think in general of the way the hospital's set out, it's not ideal, but where we can do low light soft voices, those softer sensory experiences for the baby possible avoid waking them for procedures if it can wait, let it wait and music again is really good for co-regulation and nervous system development as well.

Vicki Mansfield (00:59:04):

Yeah. Thanks, Jess. There's some really great advocacy for how our systems might support babies in NICUs, but also families. And as you said, them being the linchpins for regulation and safety and all of those aspects that's so powerful in terms of neurodevelopment. Ash, did you want to add anything there around reflecting on Baby Mia before we move to questions?

Ash Allan (00:59:37):

Yeah, thank you, Jess. That was just really powerful hearing you speak then. I think the thoughts I had building on what Viv was speaking to as well around that compassionate and deeply relational and human care that wraps around Families and enables them to connect with the supports and build their villages in communities so vital. And yeah, I feel really passionately that enhancing access to perinatal peer support is such an important part of that care. So like Jess has spoken so beautifully too around we know the mental health and wellbeing of parents and their babies is deeply interconnected and that supporting the wellbeing of parents is really vital to supporting the development and emotional wellbeing of their bubs, especially in those crucial formative first 2000 days of life. And yeah, as Viv said around that goal that is the heart of perinatal peer work, we embody that knowledge and through offering and sharing our own experiences in the support of other parents of what it feels like to navigate mental health challenges alongside our own transition to parenthood and our own lived and living experiences of the resilience and the hope and healing that exists in that relationship between a parent and their child and being able to walk alongside parents and offer connection that allows them to really know that they're not alone, it's never too late and reaching out and connecting with care and support that they need means that they're nurturing and supporting the wellbeing of their baby too.

Vicki Mansfield (01:01:28):

And I think that's a great message for us to hold is that it's never too late, that there's always choices and options. And one of the questions in the chat here is how do I as a clinician best support or introduce involve a peer worker to a family? That's a question from Jess. Would one of you like to, because we've talked a lot about being bridges and I'm sure you probably have many ways of doing that, but yeah, what would be your input from the panellists to Jeff around how to introduce?

Jess Jackson (01:02:08):

Yeah, I think that's a really good question and especially because having peer workers in multidisciplinary teams is very new for a lot of services. For my service, a lot of us have come in in the last two years. I acknowledge that it can be really tricky for clinicians who are so used to going it alone and all of a sudden a new discipline comes in. It's like, how exactly do you fit into the space? So I think being open to peer work, a really handy thing could be doing a warm referral to a family if you're working with them. And even if you are a bit tentative, just do it. And then I think the more you see peer workers work with families, you'll see the magic happen and I think that will give you confidence then to refer more families. So my particular service, we don't rely on referrals.

(01:03:03):

We just reach out to families. We're a voluntary service, but we just let them know we're here, this is what we can do if you need us. And then are you happy for us to check in on you again? Yeah. So that's another way we can do it.

Vicki Mansfield (01:03:19):

Thanks, Jess. Viva, Ash, did you want to add anything because there's a few questions, but so I can move to the next question because I think that it might be in a similar helping people get their head around how lived experience is working as well. And when lived experience workers are sharing, how does the systems around them support them in terms of limitations, boundaries and too much sharing? So what's informing that decision making for you as a lived experience worker or how does the system support that as well?

Viv Kissane, OAM (01:04:08):

So this is all around the work around professionalising the workforce and understanding that we do have a scope of practise and that we do have boundaries and that we do have professional development and supervision needs as well. So I think that lived experience work has a really strong foundation of ethics and lived experience work is values-based work. We really lean heavily on our values and also training and skillset comes into that as well in terms of understanding how we use our lived experience stories to connect with the person that we're in, we're sitting beside in that moment. So that's the skill in terms of knowing when it feels okay even within yourself to share things. And that can be a day-to-day kind of fluctuation as well. There's some days that I feel like I can talk about my suicidal experiences and somewhere I realise that I'm feeling I shouldn't do that.

(01:05:19):

So certainly oversharing and that vulnerability hangover is something that we are quite aware of and in that building the skillset and capacity of the lived experience workforce really focuses on being able to understand that as well as a lot of other different things as well. Yeah.

Vicki Mansfield (01:05:40):

Which there was another question around that the importance of self-care and at the end of the day as well. So I think you've touched on that as well, Viv. And Ash, did you want to add anything or Jess? Yeah. And then there are a couple of questions that are sort of around, we are talking about that context of transition and community as well. So there was a couple of questions around the intersection of care and trans-inclusionary care. Are there currently options for parents who identify as trans or non-binary in accessing this kind of perinatal care and support? And are you able to speak to the intersection of experiences about gender diverse birthing parents and what they might uniquely need? And so I'll ask the panellists, but I also recognise if that's not an area you can speak to. But yeah, that was a question from Sarah if anyone knows of services or supports or peer work in that area.

Viv Kissane, OAM (01:06:59):

I think it's a gap. I think it's still an area there a lot more work needs to be done and certainly a service gap as well in terms of making services that are safe and inclusive of gender diverse families. Certainly at Peachtree, we lean heavily into our trauma-informed principles as guiding principles that kind of underpin everything that we do and certainly that is around being a space that is non-judgmental and safe and inclusive for all people. So we certainly do have transparents that do access our services and programmes, but yes, in terms of more broader services, I think there is still a real need.

Vicki Mansfield (01:07:49):

Yeah. And thanks, Viv. And the other question that we had highlighted was around, you mentioned the scope of practise and each of you will have a scope of practise within your role, but you also mentioned the lived experience guidelines as well. And so there was a question around wondering around what training do perinatal peer support workers have or in identifying, responding or referring around family and domestic violence. And I know that's not in our case study or our story today, but yeah, I'm wondering if that might be other areas of scope, but yeah, is that something that's within scope or how do you bridge that with your teens?

Jess Jackson (01:08:49):

Yeah. I think bridge is the word there for here. I certainly have supported a lot of families in this space and it wasn't something I have to experience with fortunately, but I think I've grown and I've learned a lot from those families and I've let them know that as well, that they've really helped me to support other families. It's very clear in our role that we are not to do any risk assessments or so we don't do or anything like that. We can do in my service a very informal one, but the main thing is that we hold what the family has told us. We can explore the feelings around that. And then even on the outlay when I first

meet a family, I always say to them that our conversations can be completely confidential unless it comes up that there is a risk of harm to yourself or someone else.

(01:09:44):

And then I don't say to them we'll report it. I say then we'll work together to bring it to a clinician and I might mention their case manager's name and just say, "We'll work together to bring it to them to keep everyone safe." And then I would do sort of a warm handover back to that clinician and then also be supporting that family in the background

Vicki Mansfield (01:10:07):

And Jess, what stood out there is I think something that Ash said earlier is you're also drawing on the collective experience of lived experience. So the values are kind of guiding you in those conversations and the collective lived

Viv Kissane, OAM (01:10:24):

Experience

Vicki Mansfield (01:10:28):

That you might be drawing on as you meet more families or support them. Yeah. Viv or Ash, anything that you'd like to add?

Viv Kissane, OAM (01:10:39):

Yeah. Sorry, Ash. So perinatal mental health is like an umbrella is what I say. So we see a little bit of everything under the umbrella. We see DV, we see child safety, we see alcohol and other drugs, we see housing issues and homelessness, that type of thing. So we can't possibly be experts of everything and be what everybody needs 100% of the time. So for me in terms of our lived experience workforce, it's like what are the skills, what are the training, what are the supports that we need that it doesn't matter what people are bringing through the door when they walk into us, have a good enough response in terms of making it a safe space for them to step into and hopefully do that lovely lived experience work that we've been talking about the whole time. So fundamentally it is a skillset. So it's not just having your lived experience.

(01:11:42):

There really is a skill around being able to do this work and it's not just with one issue, it's with a whole heap of different intersecting issues

Vicki Mansfield (01:11:53):

And Viv, I know Peachtree have done a lot of work around building up the capabilities and the training and the skillset and that might be listed in our resources, but it's also something we might explore on in our next webinar. Ash, did you have something to share?

Ash Allan (01:12:10):

Oh, I guess just to speak to us as perinatal peer workers being embedded within multidisciplinary teams in services and in systems that we have those scaffolding and policy and framework and training alongside our clinician colleagues, but our role in that space and in supporting that family as Jess and we've both spoke to is through that lived experience practise lens. So we're walking alongside them and providing that support alongside what needs to happen in terms of responding to what's going on in that sense.

Vicki Mansfield (01:12:54):

I think that's a great point for us to draw our discussion in with each of you because I know, I think it was Viv earlier mentioned that holistic care and the values has really shone through in everyone's discussion about all the transition points and the role and the ways you would walk alongside. So thank you all, Viv, Ash and Jess for sharing your wisdom and insight, but also really giving us a much fuller picture of the role peer and perinatal lived experience provides in the emerging and we've set some visions I think about what we would like to see in future or keep developing for families as well. And so thank you everybody. We've looked at NICU, how the complexity and overwhelming nature of that can be supported by lived experience work. We've looked at how that transition into the community is a key touchpoint for lived experience workers to support in terms of navigating systems, accessing care, and definitely being an advocate for families.

(01:14:15):

But also what really stands out to me is that relational holding space of safety and supporting people through this journey and transition into parenting. And we would love to hear from everybody about ... We have another webinar coming up in a month and we'll have panellists and we'll share and explore what's happening for Mia, Ruby, and in early development and also consider how we continue to bring forth the lived experience expertise as well. Bid you all goodnight, thank you very much and I hope you take a discovery you made about lived experience expertise into your role in the near future and we hope to see you next month. Thank you again, Viv, Ash, and Jess. Thanks so very much for your wisdom. Thanks

Jess Jackson (01:15:12):

Vicki. It was great turning to you all. Thank you.

Vicki Mansfield (01:15:16):

Thanks everybody.