

# Integrating lived experience insights into practice

## Topic 1 – Welcome and introduction

### Welcome

**Narration:**

Welcome to the module “Integrated lived experience insights into practice”.

The module will take between 15–45 minutes to complete depending on how many videos you choose to watch.

### Overview

**Narration:**

In this module you will hear from Autistic people and healthcare professionals sharing their lived experience of pregnancy, birth, and early parenthood.

You’ll then be given the opportunity to reflect on what you’ve heard and apply this with some activities focussed on how you can support Autistic people through the perinatal period.

### Introduction

**Narration:**

In the “Implementing good practice principles in clinical care” module you were introduced to evidence-informed strategies to support Autistic people through the perinatal period.

In this module Autistic people and healthcare professionals share their lived experience of pregnancy, birth, and early parenthood.

Their stories are powerful, and they all share practical ideas for how you can support them.

After listening to their stories, take some time to reflect on their experiences and your own, and how you might be able to improve your own practice to effectively support Autistic people through the perinatal period.

We’ve designed some activities to guide you in your reflection.

## Topic 2 – Lived experiences

### Lived experiences

#### **Narration:**

Watch the videos to listen to Cecilia, Ainslie, Kimmi, and Kayla share their lived experiences.

You can watch as many, or as few videos as you like. If you watch them all this module will take closer to 45 mins to complete. There were so many incredible moments in these videos that we found it hard to only include a few.

Additional clips from the interviews are available on the Aspect digital hub.

### Cecilia's Videos

#### Video 1 – Strengths as an Autistic professional social worker

##### **Transcript:**

I think there's lots of strengths I bring. I think be it, you know, the way I approach the situation, the way I problem solve, the way I see alternate perspectives, and even the way I question why things work the way they like, the way they do, or you know, why we do things in a certain way. It's not always well received, mind you, but you know it. I think it's sort of it's allowed me to sort of bring a different way of working with individuals, with people within systems. And yeah, and now that I, I think since my own diagnosis and since kind of learning more about myself as an Autistic person, I can see how I think about the world and move about in the world is like how I'm impacted by that and yeah, and I guess I now look at the way I work and look at the different perspective I bring and I see that as a real strength that I can bring to my workplace.

#### Video 2 – Having and initial conversation

##### **Transcript:**

Well, in some ways it's not that different to how I would approach a lot of people. You know, I think even though hospitals are really alien environments to all of us really, even after a decade of working in them you know, so I think I with anyone, I always want to know what's a helpful way that I can communicate with them. And I guess if someone has identified as being Autistic, then I, I like to acknowledge that and depending on the rapport I've been able to establish with them, I will more often than not you know, identify myself as being neurodivergent or being Autistic with them. So, that they can feel comfortable in in in the hope that that would sort of make them feel comfortable with me. But I think, you know, for a lot of people coming into hospital, you know, is surrounded by clinicians who speak a very different language, who operate in a very,

we operate in a very different way you know, normal people do in the real world. And our perception of time and risk and, you know, process is, is really quite alien for any other sort of space in our community.

So, the questions I ask people who identify as Autistic are often really similar to the questions I ask everyone else. You know, what is a good way out? How can I communicate with you effectively? What is like a helpful amount of information to for you to have you know, how do I know? You know, if you are not able to tell me is there a way that I can know that you are feeling comfortable or not with, you know, the situation at hand. Do you have strategies that you can use if things are feeling difficult or even just, is there anything that you know, we as your treatment team and I make sure I always include myself when talking about everyone that this person may encounter in the hospital. Is there anything that we can know that will make, which will mean that we can provide you with better care? And the control to actually tell us, yeah, how we can provide them with the most appropriate care.

### Video 3 – Identifying patient needs

#### **Transcript:**

I think if someone said to me, "I don't, I think I need someone, but I think I need something, but I don't know what it is," I think the first thing I would say is that's OK. You know, you don't – I don't expect anyone to know what they need at any given moment. And I would say, you know, thanks for letting me know that there's something you need. That's really helpful. Would you feel comfortable if I maybe tried a few things out with you? We could try a few things to see how you know if they work well for you, or would you prefer if we maybe came back to this conversation a bit later?

Sometimes, you know, if you're working with an Autistic patient or a neurodivergent patient and they say to you, "I don't know what they need," that could be them coming from a place of absolute exhaustion and overwhelm. And you know, neurodivergent people are asked to do so much just in their day-to-day life. So you know, it's one thing to kind of feel a bit awkward and try to get to feel confident with working in a neuro-affirming way. But I think it's also important that we remember that it shouldn't be on the person sitting in front of us for them to be able to come up with the answers every single time.

And that doesn't mean that we as clinicians need to have all the answers all the time. It just means that we need to be open and humble enough to say, "I don't know exactly what is going to be helpful in this moment, but I'd really like to try and figure it out. And I'm really happy to try and work out what it is that I can do to help you, or I'm really happy to just try and support you while you try and regulate and we can come back and have this conversation later."

I think sometimes within medical systems, you know, because of the medical hierarchy which is still present, as healthcare workers we can feel like we have to be seen as professional and knowing exactly what we're doing at all times.

## Video 4 – Providing neuro-affirming care

### Transcript:

Well, I think I think being able to learning to identify and reaffirm someone's strengths and you know, in terms of what that will mean for their ability to parent their ability to yeah, respond to their child, is, is really really important because you know, we talk about in the maternity space, we talk about the assumptions and the pressure that is placed on pregnant people in terms of how they should be feeling during pregnancy or how they should respond to their child, how they should feel towards their child. Like, you know as soon as they give birth and everything and we know that that has really negative impacts on a person's mental health, especially in that really vulnerable perinatal period. Well if you think about experience for an Autistic person they're already dealing with such a negative stereotypes and negative perceptions of who they are as a person. Their ability, their you know, strengths or lack thereof in terms of being able to just move around the world. And that's before we add pregnancy and children into the equation. So I think definitely helping to identify a person's strengths and their resilience. I mean, if you're Autistic and you've gotten through life far enough and you become pregnant and you're about to become a parent, like that in and of itself is a sign of incredible resilience, let alone all the challenges that they will continue to face. Yeah. So, and I guess also the idea that there is no, there is no uniform way that parents have to respond to their child or they have to parent, as long as they are reflective of their parenting approach they are going to do a good job. You know, and yeah, and I think it's really important for for all healthcare clinicians to know what, and everyone generally to know that, you know, Autistic people, contrary to popular belief, are actually incredibly empathetic, incredibly you know, good at identifying other people's or, you know, connecting with other people's emotional responses and that sort of stuff.

## Video 5 – Final words

### Transcript:

Well, like all the all the other things that we say about pregnant people generally like, they still stand you know, like everything that we bring to every other person that doesn't identify as Autistic that we're aware of, you know, in terms of how we provide safe and supportive maternity care. That's no different for someone who is Autistic as well. Like, an Autistic parent and a non Autistic parent want to do the absolute best that they can for their baby. And, you know how they approach that and how they understand that and what supports they may or may not need in every given moment may be different, but everything else still stands. And you know that sometimes the difference is just how we can approach that person in our work in the care that we provide.

## Ainslie's Videos

### Video 1 – Pain tolerance (Interoception)

#### Transcript:

OK, so the story, I have two children. The story I'll be talking about today is in regards to my second child. So by this stage I'd already had one child, so I knew what it felt like to be in labour and understood sort of the signals from my body as to what was happening. So with the labour of my second child, I felt as though I needed to go to hospital at about 5:00 in the morning and my sister came and took me. I speak with a pretty flat affect most of the time. I very rarely sound excited, angry. This is pretty much what you get most of the time with me. And if I'm tired or exhausted or in pain it becomes even more flat. So I generally won't scream at anything even if I'm extremely angry or in a lot of pain. So back to the story. My sister came and got me at about 5:00. We rang the midwife, turned up at the hospital and they said I was about three to four centimetres dilated. The baby wasn't coming in to go home because I didn't look like I was in labour. And they said but they kept me around for a little while for observation. I think that was about two hours and we were left in a room and my sister and I were just chatting and, and sort of passing time. At the end of it, I could tell that I was in active labour towards transition. And I was like, Mandy, we, we can't go home. Like I've got a toddler at home. I'm in active labour here. We cannot. And she's like, I agree. I don't think it's super safe to be doing that. I don't really want to be delivering a baby. And so we, when the midwife came back to sort of say, Yep, OK, here's some painkillers, go home and rest. She was like, you need to check her again because she needs to stay here. And I was like, I, and with this sort of level of tone and affect, I said, yeah, I really think I need to be here. And she's like, no, if you were actually in active labour, you would be screaming and writhing in pain. And I'm like, well, I can tell you this is my second child and we are there. And she just didn't believe me and my sister at this time and knowing that you cannot be too aggressive in hospitals, she was starting to lose her temper. And I'm like, no, no, we have to leave the, the I'm also very rules focused. So we ended up going back to her house. About half an hour after we got there it became apparent that the baby was coming now. So this was within maybe an hour and a half of leaving the hospital. And I was crying because the nurse had said that we weren't allowed to go back. And I said but we can't break the rules. And she's like, I don't really care. And she was agitated by this stage and really upset for me. So she got the midwife on the phone. The midwife said you can't come back. This baby's not being born today. My sister had a few strong words to say about that. And, she said I, I believe I remember her saying, I don't think you really get to determine that the baby has decided that they are coming. And we get in her car and race to the hospital and I get there and she's still like, oh, yeah, this looks a little bit more like you're in labour. And my sister insisted on her checking me. And the baby was about to be born. So, my sister called my husband to say, essentially, get here or you're going to miss the birth of your child. Took him about 15 minutes to get there. He was there for about 2-3 minutes before the baby was born. So this experience was extremely traumatic. It's 10 years ago, and it still sits with me and could have been completely avoided if she had of listened to the words that were coming out of my mouth as opposed to trying to read body language or my tone.

## Video 2 – Masking

### Transcript:

OK, so the story, I have two children. The story I'll be talking about today is in regards to my second child. So by this stage I'd already had one child, so I knew what it felt like to be in labour and understood sort of the signals from my body as to what was happening. So with the labour of my second child, I felt as though I needed to go to hospital at about 5:00 in the morning and my sister came and took me. I speak with a pretty flat affect most of the time. I very rarely sound excited, angry. This is pretty much what you get most of the time with me. And if I'm tired or exhausted or in pain it becomes even more flat. So I generally won't scream at anything even if I'm extremely angry or in a lot of pain. So back to the story. My sister came and got me at about 5:00. We rang the midwife, turned up at the hospital and they said I was about three to four centimetres dilated. The baby wasn't coming in to go home because I didn't look like I was in labour. And they said but they kept me around for a little while for observation. I think that was about two hours and we were left in a room and my sister and I were just chatting and, and sort of passing time. At the end of it, I could tell that I was in active labour towards transition. And I was like, Mandy, we, we can't go home. Like I've got a toddler at home. I'm in active labour here. We cannot. And she's like, I agree. I don't think it's super safe to be doing that. I don't really want to be delivering a baby. And so we, when the midwife came back to sort of say, Yep, OK, here's some painkillers, go home and rest. She was like, you need to check her again because she needs to stay here. And I was like, I, and with this sort of level of tone and affect, I said, yeah, I really think I need to be here. And she's like, no, if you were actually in active labour, you would be screaming and writhing in pain. And I'm like, well, I can tell you this is my second child and we are there. And she just didn't believe me and my sister at this time and knowing that you cannot be too aggressive in hospitals, she was starting to lose her temper. And I'm like, no, no, we have to leave the, the I'm also very rules focused. So we ended up going back to her house. About half an hour after we got there it became apparent that the baby was coming now. So this was within maybe an hour and a half of leaving the hospital. And I was crying because the nurse had said that we weren't allowed to go back. And I said but we can't break the rules. And she's like, I don't really care. And she was agitated by this stage and really upset for me. So she got the midwife on the phone. The midwife said you can't come back. This baby's not being born today. My sister had a few strong words to say about that. And, she said I, I believe I remember her saying, I don't think you really get to determine that the baby has decided that they are coming. And we get in her car and race to the hospital and I get there and she's still like, oh, yeah, this looks a little bit more like you're in labour. And my sister insisted on her checking me. And the baby was about to be born. So, So my sister called my husband to say, essentially, get here or you're going to miss the birth of your child. Took him about 15 minutes to get there. He was there for about 2-3 minutes before the baby was born So this experience was extremely traumatic. It's 10 years ago, and it still sits with me and could have been completely avoided if she had of listened to the words that were coming out of my mouth as opposed to trying to read body language or my tone.

## Video 3 – Supporting predictability

### Transcript:

I think regarding the whole process, some really important things are letting, making sure they know what comes next in the process because you don't think having a baby is not something you do frequently, for most people anyway. And knowing what come, first of all at the first appointment, knowing what the whole process is going to look like for them and what that's going to mean for them and what they are going to have to do is really important. But then at each appointment, knowing what comes next I think is really important. And being really clear when communicating with an Autistic person who's pregnant, I think ensuring that your language is literal and clear is really important. And, listening to listening to mothers as well. They know their body best. So really listening and listening to the words that are coming out of their mouth, not just how they look or how they seem.

## Kimmi's Videos

### Video 1 – Making accommodations

#### Transcript

I would say like good support is having someone who understands that you need more time. Like you need more time. You may need to info dump. You may need to ask 50 questions, whereas, you know, someone who may be being neurotypical might have one or two, you might have 100. So I was very lucky that a lot of the health professionals I came across did have, I guess, some basic understanding of autism and, and and that understood that, OK. For example, my labor, delivery and breastfeeding class that I did go to, luckily I was able to go to those those two classes. The midwives who ran those classes did understand autism and knew that I was Autistic straight off the bat before I even walked in the door. They'd been advised that based on my paperwork. So they already had an understanding, OK, I might need more support. They did pull me aside when I walked in and said, look, if you've got any extra questions, we'll stay back. We can answer everything for you. And I did do that. So I was able to stay back after the class. All the questions I had, I could just sit down with the midwife. She'd answer every single one of them. If I needed more information, she's like, I can send it to you. So I think that that the fact that I had that sort of support where they were like, OK, well, if I'm able to give you that little bit extra time, then you're not going to be so stressed have a lot more anxiety when you're going into the end. I mean, I think that whiteboard is such a good tool. And, because it's available on every room I think like for anyone, like even just having the nurse tell you what is on the schedule for the day, whether or not that changes. But at least you sort of have a guide as to what's gonna happen. Oh, Yep, you're gonna get discharged today. And that's great. I can put that on the white board. I can get excited about that, you know, and then you can sort of plan for that discharge too. OK I need to do this. I need to do this. Like you can sort of plan. Cause a lot of people with autism like a plan and like to know what's gonna happen before it happens. And this is something I need to know, like I can't leave the house

without knowing what's gonna happen. So I think going into the hospital experience and having things so sort of just shoved in your face, this is, you know, having more of a I guess a more structured approach to someone who has autism ADHD or any sort of disability, just finding out what works for them and then working with them along that that route. you know, whether or not that's just giving them an idea of what's gonna happen during that day.

### Video 2 – Support

#### **Transcript**

I had a team put in place as soon as I found out I was pregnant. I'd already mentioned that we were looking at trying for a baby. So I guess obviously it's different if someone just falls pregnant without knowing that they were trying. But, because I already had the OK, we're going to try for a baby. I'd already spoken to my GP about what that meant with medications and everything else that I was on. It meant a change completely of what we were doing. So I had to go, you know, through with my GP, but then also my psych had to be on board, my OT had to be on board, my speech therapist had to be on board. So sort of having everyone on board at the beginning and having a plan for what it would look like when the baby arrived.

### Video 3 – Sensory

#### **Transcript**

And so instead of thinking about everything you should be thinking about, you're thinking about, oh, this is itchy. This doesn't sit right. This is digging in. This tag is scratching me. I'm thinking over everything I shouldn't be thinking about. And so you know, it heightens the anxiety around, OK, now I'm thinking about all these things. With pregnancy, you've already got your heightened senses as well. Like you're more into what, what you're hearing, what you're smelling, what you're tasting. Everything is changed because your hormones have changed. So I think it's, it's as much as you might have had, you know, as you, you didn't have too much issues with this before you're pregnant. The biggest for me that I mean, I still have issues with this now, was the noises. Like as much as they weren't too overstimulating at the time 'cause the, the, I guess the special care nursery NICU that I was in, my son was in a one-on-one NICU. So it was just him in one room. So it was only his monitor beeping at any time. But when it went to him being on three three to, I guess three to one staff that's when it started getting a lot more sensory issues for me because I could hear the other cots beeping. There was a lot more overstimulating in that environment. Whereas I guess in the NICU, NICU environment it's, you're only focusing on, OK, I can see his monitor, I can see what it's doing. It's making these noises this is what it's gonna do. So I sort of knew what I was looking at when he was on his own. But when he went into a room with more than one baby, that's when I sort of got a lot more distracted because I'm hearing the the beeping and they're not stopping it. And then, you know, it sort of gets really over stimulating very quickly.



## Video 4 – Communication

### Transcript

I guess in terms of the whole, I guess, journey is I found that I had a lot more questions than the average person because obviously I just wanted to know everything I needed to know what I could expect. And I guess going into those more details in terms of what can I expect about stretch marks? What am I supposed to be feeling? What am I not supposed to be feeling like that sort of stuff. I was always like, is this normal? Is it not normal? Because I, I sort of overanalysed everything about pregnancy. I was like, OK, on this many weeks, what, what should I be doing? What shouldn't I be doing? And then also when I got diagnosed with gestational diabetes, then it was, oh God, now I'm going to add a food issue as well. And, having autism and, and already having issues with certain foods and textures and flavors and that sort of stuff, then having to get that restricted even more. So a lot of my favourite foods, like I was craving Kit Kats, Kit Kat's out of the question. So then I had to find some new foods. And then obviously the the whole barrier of trying new foods and then, you know, finding that texture that works, what doesn't work, what puts your sugar up. It was just added stress, but I did have I, I, I will say I did have some very good people that I was transferred through to that understood autism anyway. So I think just having that, that they'd already had some form of, I guess exposure to autism was very helpful with them being able to provide me with information because instead of just giving me a pamphlet going here you go, off you go. They were able to sit down with me, explain everything, give me pictures, which was a lot more easier for me to understand and just break it down a lot more. So I think just having that understanding that someone with autism might need you to sit down with them a little bit longer explain it from A-Z and just give details, very detailed step by step. And I love things being visual and I, I do know that a lot of Autistics are the same. They love visuals because obviously a lot of the time you can't communicate properly. So having a picture that explains it that you can then go Google if you want to and find more information out about rather than just be like, oh, it's this. And you're going what? And then you spend the next three hours thinking about what the doctor said or you forgot completely what the doctor said because that happens a lot, I think. I wish I recorded my doctor's appointments because I walked out of half of them. and I'm like what did the doctor say again? And then you'd be like, they said this. And then you're trying to remember what they've said. And because it's so much information at once, they sort of spill it to you. I didn't retain half of the conversation. And like, sometimes looking back, I'm like, I wish, I wish I would have had to, you know, take some notes or you know, whether or not I had somebody else with me that could sort of explain it to me after or even if they were able to send you an e-mail and on the things I talked about, just because not only like, yes, I might look like, like I'm listening, but then yes, I'm listening in that moment. But whether or not I've retained that information was a gap for me because I get, you know, I get out of an appointment and I would think, oh, no, OK, he talked about this and they talked about this. And then, you know, yeah, we need to do this. And, you know, by the time you've got home, you've got so many things you're thinking about that a lot of it gets jumbled.

## Kayla's Videos

### Video 1 – Sensory overload and support person

#### Transcript

So like, just like literally getting to the appointments was very difficult. Like the it was, I only lived like 10 minutes drive from the hospital, so I was very lucky in that respect. But I was unable to manage the trying to find a park, so it's a little street side parking around there and so I would catch a tram. But trams happen to be something that I find is a sensory thing to be utterly overwhelming and they require quite a bit of time for me to decompress after going on them unless I've managed to like block out the experience sufficiently.

They're getting actually to the clinic appointments involved going through a bit of a sensory nightmare for me where by the time I got there and having been on the tram and dealing with all the all the noises and sounds and people and everything to get in there. Then I was in this waiting room that didn't have very clear instructions. And that required me to sit amidst a bunch of other people waiting for an unknown amount of time for somebody to call out my name and for me to just potentially not be able to hear them call out my name or not know where they're going to come from or where would be best to sit and wait. Or like there was, it was, it was very difficult for me to create strategies to manage the waiting room because they just went options there.

Like it was, it was crowded. There's a big space, but it was crowded. So there's a lot of a lot of families in there and not many, not much choice in regards to where to sit. So I couldn't like I would normally if I'm anxious about hearing if I'm being called, I'd normally sit as close as possible to where the person comes to call out the names, but that wasn't really an option. So just thinking about it kind of makes me anxious and kind of makes my brain freeze up, which is exactly what I kept finding would happen by the time I was in the appointments.

My yeah, my ability to verbally phrase what is going on to check in with my body to register what's happening around me and react to it in a timely manner. All those things kind of get a bit inhibited, a bit delayed. I find that somebody might do something like might I don't know push on an area and ask if it hurts, for example, at a doctor's office and I won't be able to tell them because I won't be present in my body by that stage. Because of all the things that I've had to kind of manage in the lead up to getting to that spot, I've pretty much just like turned off my kind of internal senses as much as possible, which is not ideal.

And then when I get asked things like, oh, how's like, you know, people always ask vague questions to how has your how's your pregnancy been so far? I was just like, "What pregnancy?" because to me, in that moment it's just like not really a thing that is present in my mind anymore. So it takes a lot of effort to try and focus on being present and sometimes I can't do that. So I had my partner there for all of those appointments though and he was able to step in and help with that a lot.

## Video 2 – Communication

### Transcript

Yeah, so the getting a making sure that I managed to get an epidural was like one of the main things in my birth plan because I was extremely anxious about experiencing the extreme pain that comes with childbirth. So, I as someone who already struggles with finding sensations overwhelming and knows that that like experiencing overwhelming bodily sensations can lead me into a meltdown. I was scared that the experience of childbirth would trigger a meltdown and I was scared that I would not be able to manage that and I was scared of any impact that that might have on my baby for the whole process. So, so the epidural was absolutely essential for me.

And so, to plan for that, I talked to the Women's Individual Needs Clinic about my birth plan and they were super supportive and said that I can come into the hospital to when I in the early stages of labour and they can make sure that there's enough time to get the epidural. And also can support me with my quite extreme anxiety around the whole process and around the sensory experience of going into labour. And they made notes of that on my files and things, and that was all really comforting.

But then I had a clinic doctor appointment wherein the doctor was extremely dismissive of my fears about not getting an epidural. So he yeah, he just said that they don't, they don't they don't deny people epidurals and and said about the coming into the hospital early that or if, if everyone came into the hospital and labour's like earliest stages of labour, then the hospital would just be full. And which really made me feel extremely bad because made me feel quite, quite guilty, like I was draining on the resources by having additional needs.

I ended up having what's called a precipitous labour because I was in less than 3 hours of active labour. So it was really luck that I was there early enough to get the epidural because it was very rapid once it started. If I'd waited for the warning signs, I might have missed the the opportunity to get the epidural and which was another area that I was really worried about with, with the whole going into labour experience. They tell you all these things to look out for like that are heavily based on what you feel and experience in your own body. And for somebody with interception challenges that's insanely anxiety inducing to think that the time that I need to go to access like absolutely essential medical care is dependent upon my ability to read my own body's physical cues, which is something that I am very well aware that I do not do very well.

So that was another reason why I really wanted to go into hospital earlier then waiting until it was at the kind of the latest stages of labour. Because I was worried that I wouldn't notice the the progression or I wouldn't notice at the right times as it happened. Or that, by the time I by the time I noticed my body would be completely overwhelmed and freaking out and unable to manage getting into the hospital. There was this so many anxious variables my primary support person is also Autistic, so I didn't feel like I would necessarily be able to get us both into the hospital for like, at later stages when my body is already in overwhelm as well.

## Video 3 – Meltdowns and shutdowns

### Transcript

Since childhood, I've experienced some meltdowns that have been pretty much what people typically think of when they hear the word "meltdown"—like rocking and banging my head when I just can't cope with something that has happened. It might be an emotional trigger, it might be sensory. There are a bunch of things that might trigger it, or sometimes it's multiple compounding factors. I just can't deal with it.

My body gets completely overwhelmed, so I rock and sometimes hit my head against the wall. That's generally the upper end of the spectrum of meltdowns for me.

I also seem to have earlier-stage meltdowns where I can't manage a situation, and I lash out in other ways. Like I might just get exceedingly angry or become hyper-focused on only the critical things. I can't see outside of that. Everything feels too overwhelming, and all I can see are the problems—the issues and challenges. I can't see past them.

In those moments, I'm not 100% certain what it looks like from the outside. But there are some basic things that help me, though they may not apply to everyone. One of the key things is to give me space—and definitely don't touch me.

Touching seems to be a go-to response when someone is distressed. That reminds me of when I was in the maternity ward. I was in a constant state of being absolutely overwhelmed, just at my limit. One of the ways I regulate when I'm overwhelmed is by sobbing. So I was pretty much sobbing 24/7 in the maternity ward, except when I was looking after Bob. Any chance I had, I was sobbing to release the pressure.

The midwives were all ridiculously lovely, but I had to ask them not to touch me. It's such a natural instinct to comfort someone with touch when they're visibly distressed. But for me, that was one of the worst things people could do, unfortunately.

So, yeah—one of the biggest things for me when it comes to managing meltdowns is: just don't touch me.

## Video 4 – Making accommodations

### Transcript

So in order to manage that, I do a lot of research into what I can expect from the situations and I try to—it helps me get my head into a space where I can more easily transition into that space and still be present.

So one of the benefits of the Royal Women's is that they have heaps of information online, but still, I wish they had more—like, I wish that they had more information on what the clinic was like and, you know, just like basic info on what to expect when you get in there and what the general wait time is. Or even just a better system for managing large numbers of people waiting because it's—it gets—it was quite noisy in there. Oftentimes I ended up getting stuck sitting over the other side and there's like three different hallway

entryways between me and the one hallway—or the two different hallways that the person may come out of in order to announce my name.

And that's a lot of moving parts. That's a lot of moving sounds, a lot of moving visuals, a lot of a lot of people to kind of comprehend and to focus through—to focus on these two potential places that somebody might come from and announce my name. It was very, very hard for me to like—I just—that if my partner wasn't available to go with me to those appointments, I simply would not have been able to get to them and manage them. Like they—that is inaccessible to me just the way that it's set up.

But my partner was there waiting and listening as well. I think there was like spaces of that main room where—it might have been a breastfeeding room or something that I feel like once I might have clocked a sign or heard somebody say to somebody else that they can use this room. So there may be additional supports available in that area already. But there was no way for me to know unless I was supposed to go up and ask them.

But yeah, I don't—I'm not sure if—if there is—if there is the ports and—like, if there is another room, then that's something that they would do—that should be like told to people and advertised.

## Video 5 – Masking

### Transcript

They don't understand. Like with that NICU nurse, I was pretty certain that a lot of the reason she was uncomfortable with us was because I had no capacity to mask by that stage. I wasn't engaging with what she was saying. I wasn't responding to her. I wasn't smiling. I wasn't even trying to make eye contact. I couldn't do any of the things that made it seem like I was following normal social conventions.

I just would have been perceived as a bitch and as disliking her. And it's just rude, disrespectful, angry—I don't know, all sorts of negative things. But I just did not have the capacity to even try to mask at that time. It was taking all of the energy I had from the maternity ward to the NICU and then to sit in the NICU and feed the baby, where it was an extremely uncomfortable and painful experience. The NICU is obviously not set up for anyone's comfort.

I think the masking thing really gets in the way of a lot. If I'm engaging with a health professional at one point and I am heavily masking—smiling, trying to make eye contact, trying to really do all the body language—then I'm focusing intently on what they're saying, presenting myself as engaged. But I miss other things. Then when I don't have the capacity to do all of that, I fear that people think I'm not engaged at all, whereas I'm probably more engaged because I'm doing it in a way that allows me to process better.

I think people get a bit thrown by that, especially in the medical setting. So I'm trying to hold in what normally comes out as looking like an overexcitable child. I'll be super into something, invigorated by a

conversation or idea, and I'll be too passionate. Or I'll just appear completely withdrawn. And the outward expression is just not an accurate representation of what's going on inside.

It's not acceptable to society most of the time, so I'm always trying to find that balance—to present myself in a way that aligns with some version of normal I have in my mind. And my mask is a bit all over the place. It's very hard to manage, especially in unfamiliar environments. That's part of why unfamiliar environments are so distressing—I don't know which mask to wear.

Is this doctor going to be super personable? Is this doctor going to be super professional? Who is the right kind of persona to put forward to get through this situation as painlessly as possible?

## Topic 3 Supporting Autistic people

### Communication

**Narration:**

Reflect on Cecilia's suggestions of how to respond when a patient expresses a need for something, but they don't know what it is they need. If this happened with an Autistic patient of yours, what language could you use to keep the conversation going?

### Interoception

**Narration:**

Think about Ainslie's experience of labour when she was sent home instead of being admitted to the hospital.

If you were treating Ainslie, what could you have done differently so that she wasn't sent home while she was in active labour?

### Sensory load

**Narration:**

Consider the difficulties Kimmi faced with sensory issues in the NICU. If she was your patient, what are some accommodations you could have made for her so she could cope better?

### Sensory load

**Narration:**

What else do you think could help with an Autistic person's experience in the NICU?

## Meltdown

### **Narration:**

Reflect on Kayla's experience when they were in the maternity ward and was sobbing constantly to regulate their feelings of being overwhelmed.

If you had a patient that was presenting like Kayla, how do you think you could respond in a supportive and affirming way?

## Summary

### **Narration:**

Thank you for completing Aspect's module "Integrating lived experience insights into practice".

We hope you now have a greater understanding of Autistic people and their lived experience of pregnancy, birth, and early parenthood, along with some evidence-informed strategies to support them.

You will find a wealth of practical ideas and suggestions on the Aspect Autistic Pregnancy and Parenthood Hub.

If you would like to listen to more of Kimmi, Kayla, Cecilia or Ainslie's experiences, you can find additional clips from their interviews on the Aspect digital hub.