

Exploring Expertise | Fetal alcohol spectrum disorder transcript

00:00:02 Speaker 1

OK, so I'm going to well, I'm just going to slowly, slowly do an introduction so that hopefully as uh, by the time we get there, I'm just very conscious. We've got a lot to cover this morning. So we want to be.

00:00:14 Speaker 1

Starting off on time. So my name's Claire. Seth. I'm one of the kinship consultants at Coram Bath. I'm just here as a host today. I'm not involved. I will be handing over to our chair. Alice.

00:00:26 Speaker 1

In a moment. But I'd also just like to say we're also joined by Ellie Johnson, who is the health consultant at Coram Bath as well today, so much more knowledgeable than I am in terms of.

00:00:42 Speaker 1

FASD from a health perspective, so Ellie, do you just want to quickly say hello?

00:00:46 Speaker 2

Yeah. Hi everybody. Umm, as Claire said, I'm uh, I'm Ellie and yeah, I'm the health consultant here and looking really looking forward to this morning's session.

00:00:57 Speaker 1

So uh, we're joined today by UM. So chairing the event today is Alice, who is I will let people introduce themselves as we go through just to save time and they'll do it much better than I can. But Alice, who is Alice Civil, who is our chair today and a trainer for the national.

00:01:17 Speaker 1

Foetal Alcohol association and by Sandy and Martin Butcher, who I will let Alice introduce, but they're going to be our main presenters today. So just so you're aware of the format for this morning.

00:01:31 Speaker 1

So if we can just ask you please just to same as any other training, if you can just have your phone on silent please lovely for our presenters to see you. If you feel comfortable with having your camera on, there are going to be there is time for a breakout.

00:01:51 Speaker 1

Session during the course of this morning's event, so it would be helpful if you've got your cameras on then to see.

00:01:56 Speaker 1

Each other, if we could ask you please to meet, meet your microphones while Sandy and Martin and Alice are presenting. Please, just to prevent that feedback. Obviously not when you're in the breakout room and talking to each other. It's really lovely for us to know who's here. So if you could please put your name.

00:02:16 Speaker 1

And your role and the organisation you work for or why? Why you're here. We're we're aware that we've hopefully got a really mixed audience, which is really exciting. So if you could put your name in the chat, that would be very help.

00:02:29 Speaker 1

And and our course, this is recorded because hopefully well in the few in short space of time after the event, it will be recorded just the quality assurance. If there are people who talk during the the presentation, that's not gonna be going anywhere else. So don't worry about.

00:02:49 Speaker 1

Sharing your thoughts and views as we go through is just for quality assurance purposes and.

00:02:55 Speaker 1

So this is the way how things are looking this morning. I'm going to hand over to Alice in a moment. Well, she'll then have presentations for about half an hour. Then you'll have 15 minutes and breakout rooms to discuss a question that Sandy and Martin will ask you to consider. So a chance to speak to each other. Hear from people.

00:03:14 Speaker 1

And different organisations and and different area.

00:03:18 Speaker 1

And and then we'll have half an hour for feedback from your breakout groups and questions and answers. So plenty of time for discussion in this morning sessions and we will aim to finish at 1:00. That's mine. And Alice's job just to try and keep us roughly roughly on track. But I will with any further ado.

00:03:37 Speaker 1

Stop sharing and hand over to Alice.

00:03:41 Speaker 3

Brilliant. Hi everyone. I'm very pleased because I have managed to want and mute myself on cue. So my name is Alice Sewell. I am the training officer at the National Organisation for FASD. Today we're going to start with the presentation and this will be delivered by Martin and Sandra Butcher.

00:04:01 Speaker 3

Sandra is the CEO of the National Organisation for FASD, and Martin is the chair of the East Hertfordshire Support Group. So to ensure that we cover everything Sandy and Martin, I will pass over to you.

00:04:16 Speaker 4

Thank you. It's lovely to see all the expertise that's here in the room as people were typing in where they're from, we're so pleased to be here going to talk about what FASD is. We're a little bit about national policy changes and how this might affect you. And then we're going to talk a bit about our families journey today. The first thing we'd ask you to do.

00:04:39 Speaker 4

To think about if there's somebody.

00:04:42 Speaker 4

Who you might have in mind what brought you to this course today? Is there a child, a young person, a family? Maybe that you're working with and things just aren't going as expected? If you if you have a a piece of paper, maybe jot down some thoughts as we go through, we're going to fly through things a little bit quickly, but.

00:05:02 Speaker 4

I think it always helps to.

00:05:04 Speaker 4

To hold somebody in mind while we're doing this and and we'll come back to that towards the end.

00:05:12 Speaker 4

So fair question for those of you who don't know what FASD is, it's foetal alcohol spectrum disorder and FASD results when prenatal alcohol exposure affects the.

00:05:23 Speaker 4

Developing brain and body.

00:05:25 Speaker 4

It's a spectrum. Everybody with FASD is affected differently.

00:05:29 Speaker 4

While more than 400 conditions can Co occur, FSD is, at its core a lifelong neurodevelopmental condition.

00:05:36 Speaker 4

We really want to emphasise that all people with FASD have many strengths and early diagnosis and appropriate support are essential, especially for their executive functioning. That's the common description of FASD that was agreed through a process involving more than 150 people, experts and people with lived experience across the country. Again, we could talk all day.

00:05:56 Speaker 4

About this but.

00:05:58 Speaker 4

The the strong message is that if you're pregnant or planning a pregnancy, the safest approach is not to.

00:06:03 Speaker 4

Drink alcohol at.

00:06:04 Speaker 4

All that charts on there to show that throughout the pregnancy there are different developmental things going on within the world, but what most people don't really understand is that the central nervous system and the brain is developing.

00:06:19 Speaker 4

Throughout. So that idea that FSD is spectrum, it means that.

00:06:26 Speaker 4

This old school thinking that you may have heard that people with FASD have certain facial features that's used to be called foetal alcohol syndrome. The diagnosis have changed since then, and now it's FSD with or without Sentinel facial features, and it's because it's in recognition that.

00:06:46 Speaker 4

Somebody doesn't have to have the facial features, for example.

00:06:49 Speaker 4

If Mom had morning sickness and wasn't drinking early in the pregnancy when some of those facial features might be developing but was drinking later there, there might not be any physical outward physical appearance, but the the brain could have been affected by FASD, so there's no safe time, no safe type, and no safe.

00:07:10 Speaker 4

Of alcohol pregnancy. There's new diagnostic guidelines that are in effect now across they started in Scotland but Nice and accept accepted them so that these diagnostic guidelines are now in effect across Scotland, England and Wales.

00:07:25 Speaker 4

And they say that to get a diagnosis, there has to be evidence of pervasive and long standing brain dysfunction, which is defined by severe impairment and three or more neurodevelopmental areas of assessment. And you can see the range there. It's everything from cognition to language, attention, executive function, etcetera.

00:07:44 Speaker 4

The Department of Health has said there's no mild FASD. This is another misconception that that comes from old school.

00:07:52 Speaker 4

This is really important. If somebody has a diagnosis of FASD, they need and deserve support also in the signing 156 guidelines, which, as I said, are now in effect across Scotland, England and Wales.

00:08:07 Speaker 4

And we know that Northern Ireland are taking this into account and we're not entirely sure what's going on there, but.

00:08:15 Speaker 4

This is something that comes up quite a lot. Do you have proof of an alcohol exposed pregnancy? It can be either reliable clinical observation, self report or I don't want to just square this here reports by a reliable source that includes those involved in social care.

00:08:34 Speaker 4

Medical records documenting positive blood alcohol concentrations or involvement in alcohol treatment or other social legal or medical problems related to drinking during pregnancy. When I said that the facial features are not needed for a diagnosis when those facial features are present.

00:08:51 Speaker 4

You don't necessarily need to have any of those for proofs of alcohol exposed pregnancy, so it is important to know if the child or young person does have the the Sentinel facial features and there's a role for many professionals to collect and note this and and or if there's sometimes people don't realise.

00:09:11 Speaker 4

That this range of proof can be useful.

00:09:15 Speaker 4

So sometimes if the child be put being put up for either in in care or up for adoption, it's important to review the past records to see if there's any reference of a reliable source

mentioning that was not called those pregnancy, because for those 90% of cases or more where they won't have those facial features, that proof is needed to get the.

00:09:35 Speaker 4

Diagnosis. It's been shown that FASD is more common than autism recent study, where they went into schools outside of sulphur and they did what's called an active case ascertainment study. They found that.

00:09:48 Speaker 4

Between 2 to 4% of the students had FASD, and none of them had previous diagnosis, and it was considered a conservative figure because some of the people more at risk weren't actually involved in the study. It's higher in other populations. For example, children looked after. There's a study done in Peterborough that showed 27%.

00:10:11 Speaker 4

There's also a high rate in adoption and also in.

00:10:15 Speaker 4

Criminal justice system. But most of those with that vasty are misdiagnosed or undiagnosed.

00:10:21 Speaker 4

Really important to.

00:10:22 Speaker 4

Know that how it's been up to this point is not how it's going to be moving forward. All of the major public health bodies have now come on board talking about FSD. The Department of Health has said in the needs assessment that the government recognises the importance of FASD. Public Health England now had called it a public health priority.

00:10:42 Speaker 4

And oh, it continues to do work on FASD. This is maybe one of the most important changes with those new diagnostic.

00:10:48 Speaker 4

Guidelines. They say that prenatal alcohol exposure should be actively considered as a possible underlying cause for neurodevelopmental delay or unexplained departure from a typical developmental profile. What that means is.

00:11:01 Speaker 4

Rather than FASD being the last thing that people think about after there's been an ADHD diagnosis of autism diagnosis, whatever that as soon as somebody's preventing with neurodevelopmental delay, the question should be asked, was this possibly an alcohol exposed pregnancy?

00:11:18 Speaker 4

It's also important to know that since 2015 it's actually been in the guidelines for statutory guidance for looked after children's medicals that FAS at the time they called it foetal alcohol syndrome should be given attention to in those health assessments, that's old school.

00:11:39 Speaker 4

Now I should say FSD, but we know it's not being done enough and we hope that will.

00:11:45 Speaker 4

Change. There's been a nice.

00:11:47 Speaker 4

Quality standard, which is a real game changer for those who don't know quality standards are different from just guidance because NHS organisations are meant to take them fully into account when they're designing services and NHS England as a legal duty to take these into account when they're looking at their.

00:12:07 Speaker 4

All the apps.

00:12:09 Speaker 4

The Nice quality standard on FASD covers everything from how pregnant women are giving advice throughout their pregnancy, about the importance of going alcohol free and and further signposting if need be is. But they also talk about the importance of recording and alcohol exposed pregnancy.

00:12:29 Speaker 4

The kinds of referrals, including a neurodevelopmental assessment for people with FASD and a management plan, which is where a.

00:12:36 Speaker 4

Lot of you would.

00:12:37 Speaker 4

Come, come in. So basically the takeaway from this is that it's a whole new playing field right now. Never before have the official entities lined up like this for FSD. Prevention, diagnosis and support.

00:12:51 Speaker 4

Our goal as an organisation is to help ensure new services start on firm foundation based on best practise and with input from stakeholders with experience and if you're interested in

learning more about this, we did a report after nine round tables involving Commissioners and policymakers and experts and researchers and importantly, people.

00:13:11 Speaker 4

With lived experience, this time is now report is available on our website.

00:13:17 Speaker 4

So why is this an issue for the people here on the call today? You're going to need to consider how to discuss the ASD during adoption and fostering preparation and training and post adoption support as well, or the support for the families after the.

00:13:30 Speaker 4

Fact there will be.

00:13:32 Speaker 4

Children, young people and families you're trying to support, for whom? The traditional interventions.

00:13:37 Speaker 4

Are not working.

00:13:38 Speaker 4

These children are being further traumatised by this lack of understanding that their challenges are due to the underlying brain damage that happened by alcohol exposure before they took their first bro.

00:13:49 Speaker 4

You can change their trajectories by training up about FASD. While this is great that you're here today, you probably need more in depth training. National FASD is training, as do other groups across the country.

00:14:01 Speaker 4

So this is where now we're going to start talking a little bit about our families experience and to show you how the diagnosis mattered. First, we want to just mention this one chart because it's done from a small study at the University of Rochester and States and this shows that when.

00:14:18 Speaker 4

Times and I would argue this would be the same for anybody around the the child or young person, when they understand that the the, the.

00:14:28 Speaker 4

Issues that are occurring are happening because of brain based things understandings and neurodevelopmental condition. The appropriate preventative strategies can be put in place

that then leads to increased confidence, confidence, and greater success in managing behaviours. But if it's still the old kind of traditional.

00:14:49 Speaker 4

Approach where it's assumed that this is willful or intentional behaviour and consequent strategies are being used. Those don't work with people with FASD for lots of reasons. We can talk about later, but that leads to, you know, the parents and caregivers are feeling ineffective and they become less successful in managing behaviour.

00:15:10 Speaker 4

It becomes a kind of really negative loop, but we don't have to be in that orange zone down there. We can help families be in that Green Zone, but it means thinking a little bit differently about things.

00:15:22 Speaker 4

Right now, if you want to jump in here and just briefly talk about.

00:15:27 Speaker 4

Our family's journey.

00:15:29 Speaker 5

Yes, absolutely. We'll we'll talk talk a little bit about our our son and our family's journey. We'll use some of the detail in that, but only really in an illustrative way to make them make the the wider point.

00:15:49 Speaker 5

And you you can see here on the slide the the diagnostic journey we went to and in fact, even before this, after we'd adopted him.

00:16:03 Speaker 5

2000 and.

00:16:06 Speaker 5

Five, we had, you know, from various assessments from a variety of professionals being encouraged to concentrate on his sensory needs.

00:16:23 Speaker 5

And the answers to his problems and the answers to how to parent.

00:16:29 Speaker 5

And lying understanding and alleviating those the the sensory needs and difficulties that he had, but in fact, by the time we got to the.

00:16:43 Speaker 5

FASD diagnosis 10 years after we'd adopted him, it was it was clear that the sensory issues which he had and continues to have.

00:16:54 Speaker 5

Were secondary symptoms of of FSD and the the other conditions and and just addressing those was was hopeless.

00:17:07 Speaker 4

And also the attachment kinds of issues as an adopted child from a traumatic background, and that was also our focus.

00:17:16 Speaker 5

Yeah, just in, in, in everyday life. So a a trip to the shops which, you know, we would, you know, he was little, we would drag him along.

00:17:24 Speaker 5

You'd take little.

00:17:25 Speaker 5

Children to the shop with you cause you.

00:17:26 Speaker 5

Have to. You can't leave them at.

00:17:28 Speaker 5

The line.

00:17:29 Speaker 5

But it was.

00:17:31 Speaker 5

Something that sometimes caused a bit of frustration between Sandy and I that one of the things I would do when he's sitting in a shopping trolley was just spend ages spinning him round and round.

00:17:43 Speaker 4

I was mortified by it, but have since learned from occupational therapists that, unbeknownst to us, that was filling a need that he had, and that's that spinning, actually was helping him.

00:17:54 Speaker 5

We yeah, we we didn't understand why it worked, but we understood that it did and it helped helped him keep quiet in an environment which was overwhelming for.

00:18:03 Speaker 5

Him. So just that.

00:18:08 Speaker 5

That that way, that you're the right the right way to be in the supermarket is so different than the right way to be was was something that was really important for us to learn.

00:18:21 Speaker 2

And then we.

00:18:22 Speaker 4

Completely revised. He doesn't go to the shops now. That idea that we had to bring him around is is.

00:18:29 Speaker 4

Not something that we do anymore. At 19, Emily goes now when he it's something specific for him to buy.

00:18:36 Speaker 5

Bedtimes, an absolute nightmare. Again, you know you, you you want the child to lay still to relax, to, to go to sleep and that's.

00:18:45 Speaker 5

It's impossible for him that Sandy said. He's 19.

00:18:49 Speaker 5

Now his bedtime process is a long one. It moves through him looking at his tablet and listening to music to when he's ready to sleep. You know, this this incredibly loud blasting of music in total darkness? Yeah, with black out.

00:19:09 Speaker 5

Curtains on the windows and a very intense physical rocking. He sits up in bed and rocks and rocks and rocks. And you know the the amount of time we spent trying to stop him do that.

00:19:24 Speaker 5

To help him relax even you know, cuddling him tightly was was it must have been a nightmare for him and.

00:19:35 Speaker 5

Again, it's. It's a a lesson about.

00:19:39 Speaker 5

You know, so other.

00:19:40 Speaker 5

Kids, this will be completely different, but but it's a lesson in, you know, just accepting the differences and changing your approach to accept those differences to make his life easier and and and to allow him to to live his best life.

00:19:55 Speaker 5

Yeah, this was a really difficult one. I mean, I toileting, I I spent ages. I was, Sandy was working in London a lot in his early years. I was working from home, mostly quite close to primary school and.

00:20:15 Speaker 5

I it was a governor in a classroom volunteer at the primary school, partly so.

00:20:19 Speaker 5

That the school would.

00:20:21 Speaker 5

Partly because I wanted to do.

00:20:22 Speaker 5

That partly because it.

00:20:24 Speaker 5

Created an atmosphere of goodwill with the.

00:20:26 Speaker 5

School. But I I would.

00:20:28 Speaker 5

Go in there were there were years when I would go in almost every single day.

00:20:34 Speaker 5

Because he had sold himself in a quite dramatic way and needed change of clothes needed to be looked after was quite distressed and.

00:20:46 Speaker 5

Yeah, that, that's again symptomatic of the the the real problems. And then in the end.

00:20:53 Speaker 5

There was, you know, a physical reason for it, which we didn't understand until he was in his teens, and we finally got to a specialist who worked it out and and worked with us. But that's again FASD related. It's one. It's one of the.

00:21:12 Speaker 5

Parts of his body that was.

00:21:13 Speaker 5

Physically damaged when?

00:21:18 Speaker 5

When he was in utero and these, these kind of needs can be, you know, very, very varied and it's it's it can be very hard to get to the bottom of it, but again.

00:21:34 Speaker 4

Another example is every night giving him a bath for years, you know, put your head back so we can rinse the shampoo out.

00:21:43 Speaker 5

The battle.

00:21:44 Speaker 4

And who knew that he has fused vertebrae in his neck and he actually can't put his head back? Talk about some maternal guilt there. So with FSD, as we said, there's there's more than 400 conditions that Co occur. And the importance of the diagnosis is that you can start to look at things differently and they're all you have to understand the cause.

00:22:03 Speaker 4

Of the.

00:22:04 Speaker 4

The the challenge and understand that a lot of this is about also how they're understanding what's happening to them and able to it. It's all about brain processing and not understanding making linking cause.

00:22:16 Speaker 4

And effect and.

00:22:17 Speaker 4

Link it's it's just a real model as parents and those for people supporting their parents too. It's why the traditional parenting stuff just doesn't.

00:22:25 Speaker 4

Really work for people with FSD.

00:22:28 Speaker 3

Sandy Martin. Sorry to interrupt. We've got about 10 minutes left of the presentation before moving on to the question, if that's.

00:22:33 Speaker 2

OK.

00:22:34 Speaker 5

Yeah, yeah, we're actually doing quite well. We're we're getting through the slides.

00:22:40 Speaker 4

Don't start shouting now, Martin. Keep going.

00:22:44 Speaker 5

Yeah, you breathed on it. We still get this, this is and and doctor Raja Mukherjee in in Daniel sorry has explained that at some point with talkers heightened sensory.

00:23:02 Speaker 5

You know, he smells more intensely his. His senses are are heightened in at sometimes, in some ways. He doesn't like it. He doesn't like my breath after I've had coffee in the morning. And let's be fair it, you know, not necessarily the nicest smell, but at some point.

00:23:21 Speaker 5

I gave him his breakfast. When?

00:23:27 Speaker 5

I'd had a cup.

00:23:28 Speaker 5

Of coffee and he wouldn't eat it and.

00:23:31 Speaker 5

He still to this day.

00:23:34 Speaker 5

He won't eat food if he thinks I've breathed on it.

00:23:38 Speaker 4

Yeah. And I just said that that imprinted on him as a very negative traumatic experience. Yeah. And So what do you do as a family? Do you try?

00:23:46 Speaker 4

To force him.

00:23:48 Speaker 4

Or do you just accept that and and move on? And obviously, if I'm not there, he will take food from Martin, but the the the sensory issues around food are massive.

00:23:58 Speaker 4

And the idea that we could all sit around, I come from this big Italian American family.

00:24:04 Speaker 4

All of us sitting around the table eating food was a joyful experience. Usually when my brothers were behaving. But the, you know, that is not the case for our son with FSD. For him, sitting around the table listening to people's knives and forks, scraping on plates, smelling things that he doesn't like. And you know, it's just it, it's not enjoyable. So he.

00:24:24 Speaker 4

And and many, many people as young with FSD tend to eat alone, for our sunny has plastic plates and forks. And yeah, it impacts all levels of things. As you can see on here, there's lots.

00:24:36 Speaker 4

Of different ways.

00:24:39 Speaker 4

School. Martin, you're the school governor. Do you want to have a?

00:24:43 Speaker 4

Chat about that real quickly.

00:24:44 Speaker 5

Yeah, I mean.

00:24:46 Speaker 5

As with many kids with FASD, things got worse the older he got. You know, the the the younger end of primary school.

00:24:54 Speaker 5

More play based learning was OK, but he diverged.

00:25:02 Speaker 5

From his peers, you know the gap got bigger and bigger and bigger. There were, you know, some really there were, there were, there were negative years with teachers who just, you know.

00:25:15 Speaker 5

Both didn't. Didn't get him and didn't care to get him his year three teacher not only didn't know about FASD, but during year.

00:25:23 Speaker 5

Three was when he got his ADHD diagnosis and.

00:25:28 Speaker 5

She was a teacher more than 30 years of experience on the point of retirement, who said that he was the first child with ADHD she'd ever come across to. That not so good. On the positive side, his year six teacher.

00:25:44 Speaker 5

Who'd grown up living in the grounds of a residential special school where her father was the head, persuaded us to let him go on.

00:25:52 Speaker 5

The end of year AP GL Adventure Holiday with his class. When we thought he couldn't possibly cope with it and she worked so hard to guide him through that.

00:26:06 Speaker 5

You know a kid.

00:26:07 Speaker 5

Who basically had no real friends, certainly amongst the boys in his in his year because they were all into football and he wasn't.

00:26:16 Speaker 5

Suddenly became a bit.

00:26:17 Speaker 5

Of a class hero.

00:26:19 Speaker 5

And and more friendly with them because.

00:26:22 Speaker 5

All the all the boys were frightened to go up the tower 50 foot tall tower to the zip wire and go down it and Tolka was up there like a rat up a drain pipe and down the zip wire. And like I want to do it again, I want to do it again so he had an overwhelmingly positive experience because of good a good teacher.

00:26:43 Speaker 5

Giving the right support.

00:26:44 Speaker 4

And I think it's really important to note that for a lot of kids with faith stay and primary, they can be supported.

00:26:50 Speaker 4

And quite often they're discouraged from seeking HCP's for those children, but the question needs to be asked, what do you expect is going to happen in secondary school and our son's case? He was able to move quite quickly in the beginning of year 8 into specialist provision because we had the HCP in place.

00:27:09 Speaker 4

We had all the assessments of speech and language and thorough speech and language assessment. The neurodevelopmental assessments, all the sensory integration assessments.

00:27:18 Speaker 4

And once it was clear that he was never going to pass the English or the Mass GCSE, he said. Well, what's the point of him sitting in a room for three years in a school where nobody here thinks he's going to pass it? And I know it's a challenging situation out there, but, you know, families are fighting for those ECP's. There's a reason.

00:27:38 Speaker 4

There's a reason why.

00:27:40 Speaker 5

So at that point, again about, you know, having all the reports in place that didn't happen by accident, that happened because the school senko and and her team.

00:27:50 Speaker 5

Put a huge amount of effort in over a year and got in all kinds of specialists to come and assess him in different in, in different ways and it's so that they could put better supports in place for them in the secondary school, but also in the end.

00:28:07 Speaker 5

So that he was, you know, they had a mountain of evidence to put to the panel when he.

00:28:11 Speaker 5

Needed to move.

00:28:13 Speaker 4

And I think it's it's fair to say that you know Martin and I are confident advocates for our child and we're both familiar with how to to do that in an effective way. But there's not every family out there that has the time, space or ability to advocate in the way.

00:28:33 Speaker 4

That we do, and they might be expressing their need in ways.

00:28:36 Speaker 4

It's that you know it. It's easier to just say no or send them on parenting courses or having them, you know, denying their their requests. But if you just think back, ask that question that you're supposed to be asking with the signed guidelines, what's going on with this mirror about months delay? Is it possible? Is an alcohol exposed?

00:28:56 Speaker 4

Pregnancy that can change how things are done, and even in our son's case, when he had the ADHD and the autism diagnosis and he he didn't get the right support, even still we weren't giving him the right support until we understood that.

00:29:09 Speaker 4

Sun has organic brain damage. His brain did not develop the way it should have done. Different parts of the brain aren't talking to each other in the way that it should. They should do. He can't process the incoming information. He can't control his impulses. You know, there's a lot of reasons for the things that were.

00:29:26 Speaker 4

Happening and I think it's very important that we just rethink.

00:29:30 Speaker 4

How we're supporting different people?

00:29:32 Speaker 5

Why this all matters so much is that.

00:29:38 Speaker 5

You know, as as a doctors are going through the different processes of deciding whether to adopt and getting the training for for adoption and when they're looking at a child to be to children, to be matched with.

00:29:54 Speaker 5

It's it's.

00:29:55 Speaker 5

Absolutely vital for them as a as a family to be, to understand everything they can about their, about that the the child.

00:30:05 Speaker 5

Who? Who will?

00:30:07 Speaker 5

Come into their family, be part of their family. It's vital for the child, for the progress and it's vital for them and their mental health to be to, to and and and and to create a a functioning family and it.

00:30:22 Speaker 5

Took us.

00:30:23 Speaker 5

So many and that that and I I know.

00:30:27 Speaker 5

You know, it's it's also vital for fosters to understand. I understand. They quite often have less.

00:30:32 Speaker 5

Preparation time and, you know child can arrive on the doorstep overnight and.

00:30:36 Speaker 4

Compares the whole range of people supporting programming.

00:30:38 Speaker 5

Yeah, and yeah, for for us, we went through years of making mistakes and learning things and making more mistakes and learning more things until we understood that our son couldn't change. So we had to change and everything around him.

00:30:56 Speaker 5

Had to be different and we had to live our lives differently and.

00:31:01 Speaker 5

For, you know, families preparing to bring a child with FSD into their lives, they can start off where we've ended up.

00:31:09 Speaker 4

And it's possible that you know the the the young people are already in the systems, it's just getting them the right kind of support. I want to just quickly point out some resources that are out there, obviously Prevention's best. I don't know if anybody on the call is working with maternity teams or people, you know, but there's we have a whole new suite of resources.

00:31:29 Speaker 4

For maternity teams at National Pasty, it's really important that people with FASD understand their own diagnosis.

00:31:36 Speaker 4

Just and we've been working over the last couple of years to develop me and my FSD resources. This was originally done through a grant with our partner seashell from the Department of Health and Social Care and we've since had other grants from contact and

pairs and others and COVID related grants. But we have, we're trying to build a community and.

00:31:56 Speaker 4

Makes the loneliness, because most people with FASD don't know someone else with that.

00:32:01 Speaker 4

So if you are supporting people who have kids with FASD, there's there's materials out there that can help them. There's it's also best always to listen to people with FASD. There's been new FASD manifesto, and if you, this would be my starting point is what, what do the people with FASD want? They want to be listened to.

00:32:22 Speaker 4

They want to be treated with the same respect as others. They want people to give them time and to be patient and kind and speak slowly to them and understand that their brains are different and that sometimes they don't get things and to help them shine brighter and to follow through on the commitments that you make not to try to help them, but do help them.

00:32:40 Speaker 4

Trying to do it in a positive way, keeping things upbeat, understanding the difficulties of lifelong, you know.

00:32:46 Speaker 4

Somebody when they.

00:32:47 Speaker 4

Leave care, for example. They're going to need a really solid management plan in place because they're quite vulnerable out there. If you most people that they see are functioning socially and emotionally at a level about half their actual age and their profiles are really spiky.

00:33:02 Speaker 4

So you could have somebody who's speaking really fluently to you, but who has a receptive score or receptive language score quite low. You need to make sure that you you understand FASD and put in place those supports and don't give up on people.

00:33:16 Speaker 4

It's effects awareness months. We're really excited about it. We believe if we get things right, you know it can make a positive impact.

00:33:25 Speaker 4

Just to give you, I know that we're at the end here. Alice. I'm just wrapping up visual of our website. We have a whole section of our website that deals with.

00:33:36 Speaker 4

That provides information for social care workers and for educators. If you want more information, we have lots of training, including e-learning that some local areas book.

00:33:49 Speaker 4

You know 100.

00:33:51 Speaker 4

Licences so that people across their service can get it. We have different sister sites, the ME and my FSD, alcohol, pregnancy, etcetera.

00:34:02 Speaker 4

But as we go into the discussion period now, we want to go back to that initial slide and say if you, if you did have someone in mind during this talk.

00:34:13 Speaker 4

How might the information that we've talked about here quick as it is and I really apologise, it's you know normally we give all day long.

00:34:21 Speaker 4

Trainings about FASD. So we've thrown a lot of information, but taking that idea that.

00:34:27 Speaker 4

You know, are there people out there who are clearly struggling that even with support that you think should be helping them?

00:34:34 Speaker 4

Are they? Are they still spiralling? Are they just?

00:34:37

You know you.

00:34:38 Speaker 4

Might think it's non compliance, but is it possible there was an alcohol exposed pregnancy? And is it possible that this child and young person is showing and maybe not very convenient ways if they're not getting support that they need in the right way? So how might the information that you've.

00:34:54 Speaker 4

Listen to here today impact how you might approach supporting that person in the future. That's the question we hope that you can discuss in the breakout rooms and somebody else will come on and tell you how those breakout rooms are going to.

00:35:10 Speaker 1

So how many the information that we provided help impact how you might approach supporting that person you held in mind in the future? Thank you so much. Alice, Sandy and Martin, we can just see from the huge number of comments and reflections that we've got in the chat that this has been incredibly thought provoking and very, very helpful. So thank you.

00:35:30 Speaker 1

All for your time today, I think it's been said in the chat earlier we will send out a copy of the slide.

00:35:36 Speaker 1

It's so all of that brilliant information that Sunday has been able to signpost us to will be sent out to you.

00:35:45 Speaker 4

Say a huge thanks to Coram Bath for your leadership on this. You've been out there for years ahead of other organisations and with the resources and the trainings you provided and it really makes a difference in the community. So thank you and thank you to all of.

00:35:57 Speaker 1

You as well, I think lots of mutual learning today, which has been absolutely fantastic. So thank you all very much for coming.

00:36:04 Speaker 1

And for your time. And thank you again to Alice, Sandy and Martin, thank you very much everybody.