

Dorset Women CIC E4_mixdown v2

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Women's health, minority backgrounds, ethnic minority, gypsy and traveller communities, disability, healthcare inequality, racial discrimination, maternity care, breast cancer, digital access, community engagement, training workshops, accessibility, mental health.

SPEAKERS

Lorraine Stanley, Dr Linda Agyemang, Anjali Mavi, Marianne Storey



Marianne Storey 00:09

Welcome to episode four of speaking of women's health, our podcast about the women's health programme that we ran in Dorset last year. And I'm really happy to be here today with my delicious co host, Anjali. Hi Anjali, hello way. And how are you doing? I'm doing very well today. Thank you. It's a dreary day outside, but we're here talking women's health, which always makes me happy.



Anjali Mavi 00:33

Yeah, same here. So glad we are again, back on action,

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Marianne Storey 00:36

and today's episode is about women who come from minority backgrounds, and it's me, that's you. You count yourself as one of those Angie maybe we'll get into that in a minute, because what we found in this women's health programme was that what came up again and again and again was the inequality experienced by women from minority backgrounds. And when I say that, what do I mean by women from minority backgrounds? I mean women from an ethnic minority background, and endorse it. Actually, our biggest ethnic minority is women from gypsy and traveller communities, and then we've got all sorts of a wonderful, rich, diverse range of other people from ethnic groups, which you can talk about far more eloquently than me, Anjali, but we're also talking about women who have disability, older women, younger women, anyone who really just doesn't fit into that majority of the kind of middle aged, general kind of white woman profile that Dorset has so so many of so that's what we were talking about today, because there are some really shocking statistics. So Anjali, you know you've already said You call yourself woman and ethnic minority. Tell us more about that. What? How does all of this resonate with you?

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Anjali Mavi 01:46

Well, each episode has a lot of information and meaning detailing, but this episode is definitely one of the very close to me, because I am from this background, and I can say there's because of lot of lack of information and support within the medical sector, we really get lost. So talking to the specialist today, I think it's very important for me to raise the raise the question, how we can get involved, why we are not giving them equal opportunities, especially not only ethnic background, the disabled woman and ethnic background that also very important because of the myth we came the different cultural background we have. So I think this is very important to understand why there is a gap and why we are not giving a full information on time.

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Marianne Storey 02:38

And I know in this episode, Lorraine talks very passionately about the ability for disabled women to actually get in and have some of these services that are available for women. But she's had personal experience, but she I know she's a huge champion for other women. You have similar so, you know, such an important topic, and I'm just so glad you're here.

A

Anjali Mavi 02:57

I can share personal experience, personal stories, because I have many stories to talk about.

M

Marianne Storey 03:03

Yeah, it must be so frustrating for you. It is

A

Anjali Mavi 03:06

indeed and see me being a person who knows the system, because because of my personal experience, I start working on it, but there are many women who come with like hope. I can help them. I think this episode will give them more hope and information to carry forward. So very important. I'm excited for myself, but for more about people I'm working who are lost in the system.

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Marianne Storey 03:31

Yeah, well, that's fantastic. So let's crack on and hear what our fabulous guests have to say this week and reassure people that there are people like them out there really trying to do something about it. We are really excited today to be doing this podcast about more minority women's voices when it comes to women's health, and I'm so pleased to have with us today, Linda from Bournemouth University and Lorraine from an organisation called swad, they will both do much better jobs than me telling you who they are. So Linda, why don't you tell us who you are, what you do and where from? That sounds like something out of blind date.

D

Dr Linda Agyemang 04:11

My name is Linda Ajman. I'm a senior lecturer in adult nursing at Bournemouth University, and I've been so passionate about women's health, particularly around black women and their health, around cancer, inequalities.

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Marianne Storey 04:29

Amazing work that you do, Linda, I know I've heard lots about the amazing things you're working on. Maybe we'll talk about them a bit more as we go through Lorraine, do you want to tell us

L Lorraine Stanley 04:40

who you are? Yeah, I'm Lorraine Stanley. I'm the founder and CEO of swad. Swad, which stands for sex, with a difference, we're not for profit training organisations specialising in the area of disability and sex, and I also do a lot of work around women's health inequalities. Interestingly. Also, in a lot of ways, related to cancer screening. So I think this could be quite a juicy episode, really well.

M Marianne Storey 05:07

Interestingly enough, correct me if I'm wrong, Anjali, but all the other episodes we've recorded so far, the inequality for needs of women from any kind of minority background, whether it's an ethnic minority or kind of economic minority, it's come up every time, hasn't it, Angela, in terms of how important that inequality is and how it affects people's access to health care. So I am also hoping this will be a very juicy episode. You know, Angela, do you want to just introduce who you are given that you've not met these two before, which I thought you must have done so just give us a bit of background about who you are. Yeah, hi everyone.

A Anjali Mavi 05:42

My name is Anjali Mavi, and I'm a radio presenter, and I work in the community. I'm founder of BPC Indian community, which is Bournemouth pool Christ Church, and here in Southampton, also, I represent Indian community, but I work with many diverse community. I've worked with NHS also, but right now my focus working with Dorset woman and talk about this amazing project they have done, and I'm co hosting with Medra and

M Marianne Storey 06:06

yes, so Anjali brings a brilliant perspective to all of this, having lived experience of many of the inequalities that we talk about, which is great. So let's kick off with a quite a general question, which I want to put to you both about, why do you think or why is it important that talking about the views, needs and inequalities for women from minority backgrounds is important at all, I hesitate to say in the current climate, but you kind of kind of read that between the lines. Why is it important to have this conversation? Linda, do you want to start

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Dr Linda Agyemang 06:44

it is very important that we continue to talk about it, because we are continuously seeing the inequalities being faced by marginalised women. For example, we heard about the Embrace report that highlighted the inequalities in maternity care faced by black women. So these issues continue to widen. We also saw reports from limb. It's all on breast cancer inequalities that are faced by black women. So all these issues around cancer and also on maternity and these are not the only issues we know about other long term health conditions that women, particularly from minority backgrounds, continue to face. So it means that these issues or these concerns continue to exist. So we need to talk about it, so that if we are not talking about it, then there's no opportunity to then do something about it, or even to reflect on whether what we are doing now is actually working or not, so I think it's important that we talk about it. And I don't

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Marianne Storey 08:05

want to put you on spot, Linda, but you mentioned two reports, so it'd be really good for our listeners who haven't heard of those reports. Perhaps that we could put a link so you could share those at some point. That would be amazing. The embrace report you talked about, and limb, yes, limp it all. Can you give us a couple of examples of the kind of things that those reports highlighted?

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Dr Linda Agyemang 08:27

So the Embrace report was published when we heard about the maternity cases in terms of black women who are about four times likely to die. We also know from limp et al study that highlighted how the likelihood of being diagnosed with breast cancer in advanced stages for black women. So these actually highlight so for example, from the report, we do know that there is the likelihood of being diagnosed with advanced breast cancer. So when we talk about advanced breast cancer, that's stage three or stage four. So that likelihood is higher for black women. And that was a gruelling report. It's something that when you read, it's very chilling, and I think that it's high time we always have these sort of conversations, or we see these reports, but it's important that we talk about it, because when we don't talk about it, then we don't know whether what we are doing now is actually working. So it's important that we are having some of these conversations and brings these things to the awareness of people who are in positions to do something about these inequalities.

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Marianne Storey 09:49

And dare I ask the question, why is it so bad? These are not small statistics you're talking about. You know, a black woman is four times more likely to die. A during or around childbirth.

D

Dr Linda Agyemang 10:02

Why? Well, there are a lot of reasons underpinning that, and one of the keys is when we listen to women's stories, for example, we did have a PPI to understand black women's needs, one of the things that they keep saying is that they are not being listened to. When people are not being listened to, these are some of the barriers or the challenges that could then lead on to missed opportunities for care. And so when this happens, then we tend to see some of these reports we see. So that's what I would say. And then, like we can definitely highlight some of the challenges as we go along, and then I can put some of these later on in the chat at some point. But one of the key things that was raised was the fact that women felt they are not being listened to, and if we are not listening to women, then there is that opportunity to make care. One other factor was whether when women do have a pre existing condition, and then if that pre existing condition is not managed. So I'm talking about women who experience maternity inequalities. One of the factors that was also mentioned was the fact that some of these women might have a pre existing condition, and so if this pre existing condition is not managed, then there is also that opportunity of that missed opportunity for care that would ensure that there is an improvement in outcomes for these women.

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Marianne Storey 11:47

So you're suggesting that they're experiencing equality in a pre existing condition, so they're already being treated differently, maybe underserved in that treatment, and then when they go on to have a child birth experience, that sort of just extrapolates

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Dr Linda Agyemang 12:01

absolutely so it's more like a smart poll, so the woman would have a pre existing, let's say, might be having diabetes, might be having a cardiovascular disease. So there are might be pre existing conditions that are not well managed, yeah. And so there is that missed opportunity to manage that, and that might have an implication on the maternal care. So if I am pregnant and I have this pre existing condition and it's not well managed, that might have an impact on my outcomes.

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Anjali Mavi 12:34

Yeah, I mean, I want to ask one thing, Linda, as you said when you were interrupt giving your introduction, also like you are working for women in your black community, and now you're sharing they have some pre condition, and when they go for a pregnancy, and the problem still happen. And marine question was very strong, they have more problem during the pregnancy. So sitting in this position, do you think any changes happen since this programme started, or since you start working, because I've been hearing this from long time and now through this podcast, definitely, we would like to know, is there any solutions happen? Is your position has given any kind of satisfaction to your woman in your community, and the information has gone widely. So I would like to know that also, because we always talk about problems out there and the solution has been done or not.

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Dr Linda Agyemang 13:24

So when we heard this embrace or we saw this embrace report, it was in the news all over, which was very concerning. So my colleagues at BU so there were four of us, Abigail and vanora and Carol, we had what we call a public involvement workshop where we had this consultation with black women, essentially to identify their health priority needs. So when we had that discussion, one of the key points that the women raised was the fact that they feel that their voices were not being heard. So when we talked about these embrace reports and all that, that's one of the things that they said, that they feel that their voices are not being heard. And from that, when we heard that, or when I was introduced to the Dolce Women's Health Hub project, and I felt that was an opportunity there to facilitate improving access to care for women from marginalised communities. And so I felt, or we felt, that that was an opportunity to facilitate that. So we had some objectives that were set when we were part of the project. So one of our objectives was to map the uptake of services by women, so from different ethnic groups, different ages, the uptake of services we wanted. See what was happening. And the other objective was to identify the barriers and facilitators in assets to care. And another one, because the women had said that they felt they were not being listened to, and therefore they feel that the HCPs might benefit from some sort of training. So racial discrimination training, sort of so again, this was also part of the objective that was set. And so we felt that, in essence, this would then improve the experiences of women when we, for example, we undertake that particular training, or this training is delivered as part of the project, and we also felt that when we are able to map the uptake of services, it will help us to know which areas that we need to work more on. So that was the objective now. So within that racial discrimination training was delivered and it was attended. I wouldn't say it was a love is because of time we do know which is so precious. So the ACPs that did attend actually felt that prior to attending the programme, 50% said they didn't feel they had little or no knowledge in identifying, for example, a cultural ally. So after the training, 100% felt that they felt good, or they felt able to be able to identify a cultural ally. This means that if they put this into practice, we hope this would then improve the experiences of women who would be assessing this care. So that is what I would say in that we also I know from the project, the findings from the surveys that were organised or that were distributed, it actually also fed into the content that was created within the Women's Health Hub resource. So this is what I would say. It's still very early on, so we can't really be sure of what the impact is at this stage.

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Anjali Mavi 17:17

Thank you very much. I think you you explain it very well, and I hope it will continue, and women will get more support.

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Marianne Storey 17:23

So we go back, circle back to my original question, and come back to you, Lorraine, in terms of, you know, we've talked a lot there about women's inequality from an ethnic or racial or religious background, but obviously minority shows its face in many other different ways, and you represent a different kind of angle on this. So what would you say why it was important that we had this work stream in this health programme at all?

L

Lorraine Stanley 17:51

I mean, the key reason it's important is that it is going to be saving lives. And that may sound rather dramatic, but actually it's not I do some keynote speeches at events, and one I was at earlier this year, which is for the bash British Association for sexual health and HIV. It was their AGM, and I was at their conference, and I was talking about health inequalities facing disabled people. And in preparing for that, I uncovered a statistic that actually disabled people are the largest single minority group within the UK. I think I was looking at the stats for England particularly, and that was quite a shock to pretty much everybody at the conference. And what also seems to shock people. It's when I say that I am yet to be made aware of any GP practice in Dorset, but also in the entirety of the UK that has a hoist at the celebration event for this women's health programme initiative. I was speaking to a local GP who's part of a primary care network, which has nine practices in it, and apparently there is only one adjustable examination couch, which is in the sort of practice nurses room in one of the GP practices, every single other examination bench was one of those static ones. So when you look at people, not everybody recognises or would not identify, as the fact that they have a disability. But when you think about particularly Dorset with its ageing population, and we're very popular with people who are getting on a bit in years. Can't believe I'm over 50 at this point, but we'll let that lie. Thank you. I'll pay you later. So you know, for lots of reasons, people are unable to get up easily on one of those static benches, if you're looking at somebody like myself, who is still on the radar for a cervical screening. And you know, I since I've been indoor. Says the first time I got invited to my cervical screening appointment, it took me three years from when I got that first invitation letter to actually achieving having my cervical screening test. A lot of that was ignorance on the part of a combination of health staff, so we had the first try, and I'm using air quotes for those that are listening when I basically explained that I can't hold my legs. I have muscle problems. I can't hold my legs in the so called, oh, just relax. Position of the froggy legs flown apart. They're still trying to poke around, by the way, but it's very uncomfortable and didn't work the first time. So they're like, well, we'll have another go, and we'll get make sure we have a second person here to help you. So I had to recover from that first trial attempt because I have energy limiting conditions, which they don't see. All they know is they've got their appointment for the 20 minutes they want you to turn up, which obviously I did, and be on time, and then you go off, and they're like, Oh, well, you know, she can just make another appointment and come back. It can be weeks. Sometimes it can be months before I can go and do something like that again. So we had a second appointment there, which also failed, and I

said it would be really helpful. All they need, right for a lot of people, is to have a set of leg supports or stirrups on the examination couch in the GP practice. And the amount of people that that would help would be phenomenal. So if you have something like me, fibromyalgia, MS, Parkinson's, anything that involves your muscle power, including if you have a spinal cord injury and you're not able to maintain that position, would make it accessible. So they referred me to a local Cottage Hospital, because they're like, Oh yeah, they'll have the leg supports. Went in and it's like, there's no leg support. So we had another try, and unfortunately, that wasn't very successful. Then it was like a gynaecology consultant appointment where I was expecting. You know, they do have the leg supports in a hospital situation, in guy knee type related departments, which is fantastic, but it turned out that was like a little chat about stuff. And that was another time I went out and I came back, no screening appointment. With the added insult, I might add that the consultant turned around to me and says, because I was trying to do double bubble of getting my coil replaced at the same time. And he's like, Well, why are you thinking of getting a coil? And I said, I just thought I had a moment, right? And I thought I can run over this guy in my wheelchair. I can be very grown up and mature and not punch him. And I said, for the same reason, any other woman of childbearing age who does not want to get pregnant would want an integer on device to stop getting pregnant. So then it's like, I'm recovering to that appointment. Have to go back then. So that's why it took three years. Now in that timeframe, the whole purpose of cervical screening is to detect early changes. So if there had been early changes that were then let to life three years, possibly I could have developed more symptoms. There might have had to be an operation. It would have been much less traumatic in that situation to catch it early. But you know, I've had, I've spoken to hundreds, if not 1000s of people, mostly women, about accessibility in both sexual health clinics and GP practices. And people have told me like there was one lady who has skin condition and she is deaf, and they took a biopsy from her cervix without actually telling her, because their head between legs, and they knew she was deaf because she had problems actually going into the clinic. And so can you imagine, if you're there, getting examined, and the first thing you know about a sample is when you're being cut. You know, it doesn't bear thinking about, but also we're talking about women when you hear that somebody has basically been told to keep their fingers crossed and let's hope there's nothing going wrong, because their physicality has made it a little bit challenging for the medic to see what's going on in their body. I mean, would a man be told in a similar examination for a cancer. Well, let's keep our fingers crossed. Is that really where we are in this day and age? So for all of those reasons, I get involved with initiatives like this women's health podcast because it's really important. And I know I'm not the only disabled woman in Dorset, but I swear to goodness, you'd think I was this is like a call to action as well. It's like, if you've got a long term health condition, for goodness sake, if you possibly can all lend your voice and get involved with this sort of initiative, because it's really important. This is the health.

M

Marianne Storey 25:00

Service, right? This is a health service. How is it going so wrong for people with a health condition to access healthcare? I mean, it just doesn't make any sense to me. I mean, you know, Linda talked about what sounds to me overt, racism in women, not being listened to. You know, it's bad enough just being a woman, but being a black woman, being a disabled woman, it's like you're sort of doubly not listened to. Is that or do you say that that's the case?

L

Lorraine Stanley 25:28

Yeah, and there is a lot of intersectionality. So it's like for some women, it will be a double, triple whammy situation. And I think I can echo what Linda was saying about the not being listened to. I've got to a stage in life where I've given up being quiet about things. I've stepped into my power. I'm not waiting around anymore for somebody else to do something. I'm like, Hang on one sweet second here.

M

Marianne Storey 25:55

Why has it taken so long for someone like you

L

Lorraine Stanley 25:59

to speak up? There have been others that have spoken up, and it's something that I am in the process of looking into, is how we can combine our voices, but with the lived experience that I have with health issues, everything is a battle. Being a woman in business is an extra battle with disability, because quite often events where you would normally be attending to get the word out about your business or product or whatever, you can't even get in the room, right? So At that celebration event, you guys were fantastic, because you made sure it was a fully wheelchair accessible venue with a wheelchair accessible loo, because, you know, women need to go to the loo, just like men. Even though we might be a wheelchair user, we still need to go to the loo. So going to a day long event or whatever, where there isn't an accessible loo, that means you don't go.

A

Anjali Mavi 26:58

I would say, I'm sorry, but I am little angry, actually, after listening your story. And I feel like, if I see from the financial point of view, also, if they are giving you so many appointments that is also costing them every hour to GP or receptionist logistics, the GP everything, why can't they just think about to having your right equipment and logistics in one place, which might cost them less than what three years cost must be. So if they will put some right people in the right place for fundamental logistically, that might be a question can be answered like, this is the health sector, and they need to be serious about it, and having said that, your example actually scares me, and I think this podcast might be a very big eye opener for many people like me, just want to add I have a daughter who's 17 now who has a special need, and one of her special needs is her sensory issue. And once she will be going for any such test, I don't know how we gonna manage it, because if they're doing a cervical test, which they will put things on her vagina, near favourite word is there. So how she will manage because she has a sensory issue, even she scratched, she cry, she see blood. She cry, so do. The health system has a setup for women or girls like them.

L Lorraine Stanley 28:28

There are little pockets, little jewels dotted around the UK and obviously within Dorset as well. So for somebody like your daughter, who's got sensory issues, and I am autistic myself, so I have some understanding of what that can be like. There are some resources to do with that on like a fully subtitled or BSL sign language interpreters, little videos on good practice and to talk you through and walk you through what is actually going to happen at a screening test. So one of the things that I do is, when I find a little gem like that, I publicise it as much as possible. It goes on my list of gems. So then when somebody rings me and says, you know, I'm worried about this procedure, have you got any resources? I can go yes, and then I send them about five different website links, but it's staff themselves having the time and the intention and wish to find out more, to be as accessible as possible. Sometimes that's missing, so attitude goes a long way.

 29:39

Yeah, absolutely. We

M Marianne Storey 29:41

recorded a podcast recently about gynaecology, and we were lucky to have Daniel Webster with us, who is the Clinical Director for obstetrics and gynaecology for University Hospitals Dorset. And he was talking about an initiative which has a very unpleasant sounding name of Gert, which apparently stands for get it right first time, G, I, R, F, T, which is, I believe, a national programme which is trying to get it well, as it says on the tin, to get it right first time, so that women like you don't and I think it is a very specifically women's health programme. And he mentioned that, and it's a shame we can't go back and kind of bring it back into this conversation. But to me, what it sounds like is the importance of having voices like yours and yours Linda on programmes like this thing that he's now working on, get it right first time, so that the clinicians really understand what it's like when you don't get it right the first time. And not only the trauma, as you described around to the patient, to you, your human being, but to the system. You know, the expense of having not got it right first time with you. I mean, heaven forbid, had anything terrible happened as a result of you wasting such a long time, but even just the cost of all the appointments, as Angela has pointed out, you know, it's just crazy, isn't it?

L Lorraine Stanley 31:03

And part of that being in a semi rural and rural community in Dorset as well, is things like having an accessible, mobile Breast Screening Unit, which I don't believe there is at the moment. No, no, I'm happy to be corrected on that one, though.

M

Marianne Storey 31:19

I mean, we could spend this whole podcast talking about, you know, our frustrations around these things. But the point, if I could bring us back to this women's health programme that we were involved in, was to try and tackle some of this stuff. And it was all of the things we've discussed. Was the reason why we made sure that minority, marginalised voices was a very specific workstream in and of itself, within this programme. And Linda, you've already mentioned some of the work that you did in that workstream was about training. And presumably the training was because you wanted to address this issue of women not being listened to. And was the training about specifically, just women from ethnic minorities, or was it about inequality generally? And what did the training involve, and who did you give it to?

D

Dr Linda Agyemang 32:09

That's a very important question. I can't really remember the name of the person we gave it to to provide the training on top of my head, but it would have been, as you said, because when you talk about women from marginalised groups, it's not just about racial marginalisation, and it's from a lot of women from many communities that do experience this. And for some women, as Laurene said, they've got intersectionalities as well. So which means there are added layers for some of these women. Unfortunately, the training was geared towards racial discrimination. So that was what was about. The training for healthcare professionals to develop that understanding and awareness of how racial discrimination can impact on the experiences of patients or service users women that want to access care services. So it was also born as a result of, as I said, the PPI workshop that we did. So this is one of the things that did come up. So when this Women's Health Hub project was introduced to me, and because I've also worked with fanora, as I said, Then during the discussion around what work streams, we might want to also focus on as part of the Women's Health Project, this in terms of the racial discrimination training for ACPs was included as part of our objectives. So there was limited time, as we know, from the inception of even when I was introduced to it, up until when the project had to then be finalised. It was limited time, but so ongoing. These are some of the things that we need to look at women from other marginalised groups. What sort of training can we do for ACPs to improve these women's experiences as well. So it's if, perhaps, maybe, as we go along, you might want to ask, what are some of the things that we think we need to do more for this project? And this is one thing that I was going to say definitely, because we we couldn't within the time frame that we were working on the project. We couldn't address all the the training needs regarding women from other marginalised communities.

M

Marianne Storey 34:44

I mean, do you think training would help Lorraine? Is that one of the answers? Do you think? I mean, there

L Lorraine Stanley 34:50

has been a slight shift, which I'm happy to report. I do a lot of stealth infiltration of various networks into Dorset, and at one recent one, I made a connection with somebody from mid Dorset primary care network. So I'm really happy to say that they were also shocked at some of the stuff that I was saying, and welcomed me. And we're going to be doing a little bit of co working to get this message out there, to educate GP practices than any health clinics really, on what they need to be thinking of and what a difference that it can make. So, you know, there are, generally speaking, the NHS is good people. Do you know what I mean? I'm not an NHS basher.

M Marianne Storey 35:36

Certainly would be our experience of working on this programme. I would wholeheartedly agree with you

L Lorraine Stanley 35:41

about that. Yeah, you know, they have literally saved my life in the past. So you know, it's not bashing, it's the fact that I want everybody in my particular sphere, I'm dealing with people that have got disabilities and stuff. I want every woman with a disability and long term health condition to have the same level of access to good health and life that any other woman has, and it is a bit of enlightened self interest. Because, you know, if I can help make things better for everyone, I'm making things better for me. You know, I'm not, like, totally altruistic or anything, but yeah, that that's what I would like to see, and it's finding the gems who, at that moment in time, are in a position where they can take up the baton and help us get the improvements that that's really crucial. I think

A Anjali Mavi 36:32

I totally agree with you, and I hope the training workshops, more activities can be, you know, provide for local people, yeah,

L

Lorraine Stanley 36:43

something that happened recently. I was in having a health appointment for a particular reason, and the screen saver this was in, I think it was Poole hospital. The screensaver on the doctor's screen was actually promoting the Oliver McGowan mandatory training. And I'm one of the CO trainers for that particular scheme. And Oliver was a young man who had a mild learning disability and was also autistic. And very sadly, the people involved in his health care did not listen to him or his family, and he was re prescribed some anti psychotic drugs, which he shouldn't have been prescribed, and he'd already had a bad reaction to previously and very sadly, he died as a result of that. And his family did a lot of campaigning to get it into UK law that this mandatory training had to happen. So for me to be in that position as a I'm a disabled person with autism who also does training and is involved in women's health, to be in that appointment and know that the NHS in Dorset has invested time and money in putting on that training is really, really good news, because it's not happening everywhere, even though it should be. So there are some really good bits and pieces here and there.

M

Marianne Storey 37:59

Well, I mean, I think this programme itself is an example of how the NHS endorse it. I mean, you know, everyone that we worked with was so passionate about improving these things for women, of all the subjects we've talked about, but this one very much included in that, you know, there are people, Linda, aren't there, who really do want to tackle this problems, which sort of leads me to the next my last question, really, which is, what needs to happen next? I mean, what are you both working on that's still championing this, this cause, and you know, what's the next priority? What's the big thing that we need to address coming up?

L

Lorraine Stanley 38:36

So what I'm doing at the moment is I'm updating my ebook that I wrote a few years ago, which is aimed at GP practices and such sexual health clinics, but I'm going to be getting more of like first person case studies included in that book. So that's a project that I'm doing at the moment, but also I'm in the process of booking in a set of drop in clinics across Dorset, where I will be inviting anybody who has an interest or lived experience with disability and long term health conditions to actually invigorate them and say, Look, this work needs doing. Have you got any capacity? This is what you can do for those of you who can't actually see what we're doing, because this is like an audio thing. I'm actually joining this conversation from my bed. I do most of my work from my bed, because I can't sit or stand for any length of time or I will pass out. So I have my computer screen suspended above my head, and that means that I can work, and I can do a lot of disability activism, and so, you know, that's the important thing, is to get the message out there. So there's two very clear things that I'm doing. One is make sure that I do the updated book, because that's going to be a lot more widespread this time around, and then do the involvement consult. Session thingies around Dorset,

M

Marianne Storey 40:02

brilliant, always the activist Lorraine, amazing. Linda. What's next for you?

D

Dr Linda Agyemang 40:08

I think that one of the things that as Wayne was talking that struck me was the fact that we need to work in close partnership with the people whom we are trying to improve the assets for. So we know that the way the world is moving now, everything is going digital. Now. How ready are the community that are already being marginalised? How ready have they been prepared to embrace this. So I think we need to work closely with them so that it doesn't become an added barrier. So we need to work closely with them to understand what would work best for them as we enter into a digital care access age. Because this is what I'm seeing. This is when you read anything. This is what is happening. Maybe, if not, I know it's ongoing, but in maybe 345, years to come, how ready have we prepared these communities, these women who are already being marginalised, to be to improve access to the digital care space. I mean, we can only do that by working with them.

M

Marianne Storey 41:24

How do you do that, Linda? I mean, I know you are very experienced in this field, so maybe you can help us understand so

D

Dr Linda Agyemang 41:29

we need to go to the communities. It's interesting, because I can share my experience as a black woman and working with black people. So sorry, Lorraine, if I'm not able to address other women from other backgrounds, because when we talk to the women, what they say is that researchers, those that are in position to enact changes, they need to come to where we are. So when you say, how can this work? Where are these women? Where can we find them who are the bridge builders? Who do these people trust? If there are issues with trust that is also impeding Access to Care Services, who do these people trust? How can we embrace and involve all of them to understand what it is that would work for them if we are bringing something up, these people are already marginalised, so we need to think about how it's going to work for them. We can only do that by working closely with them. We need to go to where they are, listen to their concerns and work with them, take them on board. So it's good that we have this website, which is a first step, but we need to have some sort of ongoing monitoring, and we do that by listening to what the women are saying and incorporating that as part of feedback to improve on whatever the structures that we do have in place and any other service that we think that we are digitalizing it, because that's what I'm seeing, that this is what is going forward now, as we see,

A

Anjali Mavi 43:12

I think I echo with Linda, and I also believe in this marine I mean, I think this programme, and especially this podcast, which we are Recording now will be a definitely one of the channel, where people can connect and see what the support is available. But having said that, maybe extension, maybe you get funding Marine, or maybe one a day, but I think we discuss some kind of networking where we can call all the community leaders from different, diverse community, and then we can share this podcast information, or more people we can invite. And then there can be a bridge, and they know this is the information available, and each leader might get aborted. You get trained, maybe if there's any possibility or any funding available. And then they can pass the information, because, I can say from Indian community, from digital point of view, the population of Indian community in Dorset are very working class people. I have done the survey. So most of the people are either working in JB Morgan pool hospital or in Barclays. They are very digitalized people, like they know to access having on the, you know, AI or digital world. So passing the information to them will be easier. But then there will be a some of the minority community. They don't have access of digital world yet, some old home people and, you know, Marine. I was just thinking in this very fascinating word come across to me when I was looking one picture, one disabled lady was holding a crash and there was a phrase, she doesn't use smartphone. So the word comes to my mind is she's also disabled. She's social media disabled also because she doesn't know how to use smartphone. So how she will get excess of health information, which is going towards app and everything? Thing. So I think we really need to find right people who can definitely become a bridge and give the information to all the diverse community and the women who are into minority actually.

M

Marianne Storey 45:13

I mean, I think that answers the question really nicely. In terms of my question was, what's next? It sounds to me like what needs to be next is that we need a network of trusted people who I kind of hate, generalising like this, you know, like minority communities trust in order that whatever information we have that could reduce their inequality of experience and lengthen their lives, their healthy lives, and give them equal health opportunity that we can use that somehow, that seems to be the next step in terms of dealing with a very big and very entrenched problem in our society.

L

Lorraine Stanley 45:54

The good news is that there are some building blocks that already endorse. The Community Action Network Dorset have got a trusted voices project for want of better expression, and that can help. And they've also recently, I can't remember what the buzzword board is, basically for people that are ethnically diverse, minorities in the area where they're taking actually control and taking the lead on making connections and pushing forward projects that mean something to them. So, you know, similar to the NHS, there is some good work going on. It's just getting the word out in a variety of ways so that everybody has a chance to know about it.

A

Anjali Mavi 46:36

Mereen, you said it's very important to have a trust and then Lauren did mention there are some people now in NHS who we can say champion or a voice over people who can connect people. But I feel like with my experience, especially during the covid time, it might change, but still, for health reason, people have their opinion about NHS, and if we have some particular people who they one diverse community, or any minority community, or any woman group, anyone who they trust they believe that person more often what NHS is providing. So if it is going like I can example you Lauren, some of the people might thinking what Lauren is saying is right, what my GP saying is not right, you know. So I think we need people like that who can be a spoke person, and they can say, yes, what information is coming from NHS? Is it right? And it will help you. So I think this is also one of the thing I feel Maureen, we need to promote, like having a people or speaker from minority community, or women who can vouch for NHS

M

Marianne Storey 47:44

Dorset race equality. Council used to have community champions. Do you know if they still do?

A

Anjali Mavi 47:50

Yeah, they still do. Okay, I'm a member. I'm both kind of a trust member with them.

M


Marianne Storey 47:55

Yes, you are one of such community champions. Lorraine, the Community Action Network, trusted voices. Does that include people from other minorities, not just ethnic, racial minorities? Does it include disabled people with disabilities, or older people, younger people,


L

Lorraine Stanley 48:12


basically anybody who has been involved in sort of community work or campaigning or have lived experience? So it's open to anybody. And then they've recently done this initiative, which is supporting people that are from minority ethnic groups, etc. So that's a good, actually quite a good, central repository for information. And I think there's also Dorset Community Action, which is covers the rest of Dorset. So between even those two organisations, people can get a lot of information.

 Marianne Storey 48:45

Yeah. I mean, it's a vast subject, isn't it? I feel like we could slash should do a podcast just on this subject. You know, the issues faced by women from minority backgrounds, so perhaps we'll hold that thought also,

 Lorraine Stanley 49:04

that would be fantastic, and it's also keeping the information there for the future. So what I love about podcasts and interviews and the like and even blogs, actually, is that information can sit there, and somebody, maybe in eight years time, 10 years time, we'll do a search, and they'll have a particular question, and then they will come across this little gem which will hopefully help them point them in the right direction.

 Marianne Storey 49:30

Yeah, it's such an important subject, which just leads us to say thank you both for being here today, giving up your time. I know you're both very busy people. It's been a really interesting conversation, and can't wait to get it out there into the world, for other people to see what goes on behind the scenes with projects like this, and to either, you know, really, what's important for me is to understand that so many people are trying so hard to try and tackle some of these problems. You know, I think that's the key message.

 Anjali Mavi 49:59

And. I think podcasts like this where they're sharing their own experience, like Laura and Alinda, yeah, that that really enhance and connect the right people to the right time. So thank you to both of you. Really enjoyed talking to you.

 50:13

You're welcome. It's been a blast. Wow.

 Anjali Mavi 50:17

What amazing discussion. Marin, what? Do you say? I'm emotional.

M

Marianne Storey 50:22

I'm not surprised. That was such a shocking but inspiring conversation to be part of, wasn't it? And some of those things that Lorraine was talking about is almost unbelievable, absolutely.

A

Anjali Mavi 50:35

And I think the thing which is still in my mind is about how difficult to get the equipment in the right time for especially for the disabled woman, and the way she has explained her story, I hope that can give hope. She is doing things in a right way, and she's helping other women what she has gone through.

M

Marianne Storey 50:56

I know she is, she's, she's a very passionate advocate, but it's also reassuring, I guess, to hear all the amazing things, you know, the research and stuff that Linda's involved with. And I mean, you know, does it give you hope, actually? Does it give you hope that things are being addressed and that things will improve?

A

Anjali Mavi 51:12

See, if you think about what she was saying, there was nothing good years back, like if you talk two decades ago, time, there was nothing. But now some things are there to address her problem. I think one day it will be available for everyone so that that hope is there. Things are not getting there exactly what we expecting, but the things are going ahead.

M

Marianne Storey 51:36

We're going in the right direction. I guess we are going in the right direction right now, and I know that you and I will continue to champion this cause Absolutely. You know people can look to you in particular, as a real champion. So what a brilliant episode. Great one today. Angie, it's great to see you again.

A

Anjali Mavi 51:54

Want to add something before you say final, bye, yes, good. I'm 100% sure when this episode will be shared with everyone, with life for everyone, I think there's gonna be a good hit in our minority and ethnic minority community, because definitely, that's a need, that's a voice they're looking for, and I'm glad I can be part of that thing.

M

Marianne Storey 52:14

Well, I'm just really pleased to hear you say that that's Thank you. So go away from today's episode with a warm glow and a sense of hope. Fantastic. So make sure you listen, subscribe in all the usual places, and don't forget to check out the Women's Health website. And we'll put the link to that in the show notes, along with all the other relevant resources talked about today. You can find links there, and we look forward to next time Episode Five, when we're talking about women and mental health.

A

Anjali Mavi 52:42

Goodbye, everyone and keep listening. You.