

TRANSCRIPT

Episode 8 – Developing Lived Experience Leaders



Paul Parsons - This is Not a Consultation. I'm Paul Parsons

Caroline Latta - And I'm Caroline Latta.

Paul Parsons - Welcome to Not A Consultation.

Caroline Latta - Our podcast on all things patient and public involvement and NHS service change.

Paul Parsons - Hello, everyone. Here we are with our first podcast since Integrated Care Boards were set up across England in July.

Caroline Latta - New legislation means changes to structures, process, regulations, guidance and a lot more. And we'll be exploring what that means for service change in the coming months.

Paul Parsons - Yes, lots to talk about. And if you've got questions you want answered or topics you'd like us to cover, get in touch. As always, we're on listen@notaconsultation.com and on Twitter as [@NotConsultation](https://twitter.com/NotConsultation).

Caroline Latta - It's always lovely to hear from our listeners.

Paul Parsons - There's little better than the ping of a listener's email dropping into the inbox - always brings a smile to my face, just like this conversation did. So should we get to that, Caroline? What are we covering today?

Caroline Latta - Well, Paul, today on the show we're talking about an NHS England programme that's supporting people with disabilities, long-term conditions and other experiences of NHS services to become lived, experienced leaders.

Paul Parsons - The programme aims to develop people's knowledge, skills and confidence to become effective care leaders for personalised care. It's a fantastic initiative that starts out by giving patients and carers information about how the NHS works so that they can influence their own care and takes them to a level where they're happy to share their stories and experiences for wider benefit.

Caroline Latta - And spoiler alert! I was so taken with what we learned, that I went away and I've enrolled in the programme myself.

Paul Parsons - We invited two of the team who run the programme to come and tell us about it. And we started, as we always do, by asking our guests to introduce themselves.

Jo Fitzgerald - Hello, I'm Jo Fitzgerald and I lead the lived experience team in the personalised care group at NHS England. My lived experience is that my son, Mitchell, had one of the first personal health budgets.

Gemma Crabtree - Hi, I'm Gemma Crabtree and I'm a lived experience manager within the personalised care team at NHS England.

Paul Parsons - Very warm welcome to Not a Consultation. Can you start by telling our listeners a little bit about your work?

Jo Fitzgerald - Okay, so it probably helps to start by telling you a little bit about our team. We are the lived experience team within the personalised care group at NHS England. We're a team of six people with lived experience, either as an individual or as a family carer. And the main focus for our team is to really ensure that the voice of people with lived experience is woven into all of the work of the personalised care group. So whether that be in developing policy and strategy or in recruiting to the team, because there's really a firm commitment from everyone within the group to make sure that the voice of people with lived experience is woven throughout.

Gemma Crabtree - I think what's unique about our team is each of us having our own lived experience. So therefore, working with people with lived experience means that we already are on a level playing field. We know what it's like. So whether that be of a long-term mental, physical health condition or whether that's as a carer, it's something that we understand and therefore we can see the importance of weaving that into everything that we do.

Caroline Latta - What are the principles and purpose of the Peer Leadership Development Programme?

Jo Fitzgerald - The purpose really is to ensure that people with lived experience are equipped to contribute to conversations or discussions or workshops on a level playing field. And that was born out of our own lived experience. So my son, Mitchell, was 22 when he died. So I had 22 years of being asked to be involved in things and I remember very early on wanting to make a contribution. I felt I had something useful to say, but often found myself in situations or contexts where I didn't really understand what was going on. So I would be asked to join a steering group or I'd be asked to join a board, and I really felt on the back foot. People knew each other, they understood the language, they understood more than I did, how the health and care system works. So when I came into my role in 2015, one of the first things I wanted to do was ensure that anybody who was involved in the personalised care programme felt that they could contribute on a level

playing field. And we felt that the best way to do that was really to help people understand, because, of course, we know that the health and care system is a bit bonkers. To help them understand how it works, but also to understand how to make change happen and how to influence in a positive kind of way.

So the Peer Leadership Development Programme was born really to enable people to have that kind of a space to explore things and for us to use our own experiences to help them see the possibilities.

Caroline Latta - So, Jo, tell us a bit more about the practicalities of doing this leadership course. What's involved? What can people expect?

Jo Fitzgerald - So, if somebody wants to become a peer leader, they would ordinarily complete three steps. Steps one and step two are exclusively self-led learning and it's really accessible. So it's hosted on the Future Learn platform and people can access it at any time. It runs continuously and they can do it in their own time.

So broadly speaking, people can take up to four weeks. But we have seen people rush through it, they've really enjoyed it and they've rushed through it in a day. So very much fits around your particular circumstances. So you can pick it up and you can put it down. The same applies to step two. So step two is also sort of self-directed self-led learning. When we move on to step three, that's a blended learning approach. So there is again some learning on Future Learn platform, but we also have some facilitated sessions on Microsoft Teams. The commitment there is to attend one day a week for four weeks. It will be the same day each week and it runs roughly from 10am to 3pm. There is some flexibility, but we do ask people to complete 80% of the course.

Caroline Latta - So tell us a little bit more about the programme.

Gemma Crabtree - I came to the Peer Leadership Development Programme after already starting on a journey with the NHS. I was a lived experienced practitioner and I'd spent three years with Mind. I thought I knew quite a lot about the health and social care

system and then I saw this really interesting programme and thought this would be something that I could benefit from. I realised that there was more to learn about the NHS, there was a lot more to learn about personalised care. And having lived with a long-term mental health condition for my teenage and adult life, I thought that in conversations I was having with health professionals, it would equip me with knowledge, skills and confidence to be able to talk more confidently about my own condition, but also about how I might be able to help others with their own long-term conditions.

So I started the Peer Leadership Development Programme. It's a blended programme, so it was really easy for me. I was also working as a maternity nurse at the time, so I spent my night shifts doing the Peer Leadership Development Programme steps one and steps two. And step one really goes into the detail about the NHS, about personalised care, about the six components of personalised care, and these were things that I didn't know about. But what's brilliant about it is that it's illustrated throughout by people who have already been through the Peer Leadership Development Programme.

The peer leaders themselves can demonstrate how the Peer Leadership Development Programme has impacted the work that they do and has benefited them in terms of their own long-term health conditions. So, learning all of that peppered with people's experiences really help to bring it to life and then going from learning that kind of foundation of the NHS and personalised care and about how we can start working together to affect change. Step two then goes into how we might use what we've learned to be able to support others. So thinking more broadly around both strategic co-production but also peer support and self management education, and how we can use what we've learned to be able to support ourselves in our own long-term conditions.

So for me it really opened up some doors both in terms of my own knowledge, but particularly moving into step three when we have interactive facilitated sessions. Meeting lots of people with other long-term health conditions or who are carers, where that different perspective really makes you think differently about your interactions, your own interactions, but also about how you manage your own condition and learning top tips from others about how they've managed their own condition. So it really was a fantastic, illuminating experience.

Jo Fitzgerald - And the Future Learn Platform itself is really accessible, so you can comment. It's very interactive. It includes videos, so you'll hear from other people with lived experience talking about their personal stories. There is short articles. Everything is geared to people learning in small chunks, to time and in a place that works for them.

Gemma Crabtree - I think one of the things that's also so attractive about the Future Learn Platform, as Jo said, in respect of the commenting, is that you see one another's names. So when you do become part of the same cohort, when you're on step three, you've already recognised names that are taking part in the course, but also you've interacted with one another. So you do become part of quite a cohesive group. Something we haven't mentioned yet, which is vitally important, is that the course is absolutely free. So people who are signing up to the course do so free of charge.

Jo Fitzgerald - And another point that's worth mentioning, Gemma as well, is that when we move on to the step three course, where people begin to talk about their personal experience in more depth, those are closed groups, usually a minimum of 14, maximum of 18.

Paul Parsons - You talk about making change happen. On what kind of level?

Jo Fitzgerald - I guess the answer is on different levels. So fundamentally, I don't think it's a coincidence that a lot of our workers thrived because we're in the personalised care groups. Personalised care, in its essence, is really about making change happen at an individual level, so really sort of shifting the relationship between people and how they experience health and care services, but it also applies to what happens at a strategic level. So if you think about some of the core principles around personalised care, it's really about seeing people differently, it's about recognising different knowledge and experience, so really valuing the experience and knowledge of a clinician, but alongside people's own experience of how their health condition affects their lives. So there's something about that synthesis. So everything that applies, all those principles that apply

around personalised care at an individual level, also apply it to strategic level. There's a growing recognition of the value of bringing different voices together.

Caroline Latta - How do people go about getting involved?

Jo Fitzgerald - So how people get involved in the Peer Leadership Development Programme really is in a range of different ways. So it's really important to say that we don't see it as ours or an NHS England's initiative per se. We see ourselves as enablers and facilitators for other people to have this positive experience. So people can either join the programme themselves. So we run open sessions where people can find out more about it and they can choose to jump on the programme and then to apply for a place on the step three course. So sometimes we run what we call a generic cohort. So that might draw from people with a whole range of different lived experience. But more recently, we've been testing other ways to deliver it. So, for instance, there was a programme in NHS England around Perinatal Mental Health and they wanted to set up a strategic co-production group. So they knew that they needed to better involve people with lived experience in their programme but didn't really know how to go about it. So we said, okay, if you reach out to some women, or in some cases some men, around Perinatal Mental Health, then we will run a cohort for you and give them that underpinning knowledge and develop their knowledge, skills and confidence.

And what actually happened was a group of 14 people came through the programme who then became their strategic co-production group. So we can also offer the course to particular groups of people. And another way that we've done it is through sort of a place based approach where we've gone to an ICS. So people in a geographical area have chosen to come together as a cohort because they want to get involved in things that are happening at a regional or local level. And again, this is a really good way to equip them to do that. And more recently, we worked with Royal Brompton and Harefield, so they had some patients with lung condition or heart condition. So again, it was kind of coalescing, really, around a particular piece of work or a particular group where it made sense for people to not only learn new things, but also to build relationships. So one of the aspects of the programme really is, and I think Gemma's highlighted it when she described her

experience of being on the programme, is really about enabling people to build relationships and to build networks around a particular interest.

Gemma Crabtree - I was just going to add to that in terms of some really exciting work that we're doing at the moment in respect to some particular conditions. So we have two particular cohorts of people. One who are parents and carers of children, family members with type one diabetes, and another cohort where people have experience of cardiovascular disease or risk factors in relation to cardiovascular disease. And that really illustrates how a group of people who are going through the Peer Leadership Development Programme together are building upon the same foundation. So they have that shared learning, but they're also then able to come together as a group of people, learn from each other, but go on after the Peer Leadership Development Programme to be able to build programmes of, for example, peer support.

So we're looking at a concept in relation to cardiovascular disease where there's peer support within the community that's led by people with lived experience of cardiovascular disease who've been through the Peer Leadership Development Programme and have got that shared experience, but working hand in hand with people within the primary care network. So, for example, social prescribing link workers or health and wellbeing coaches, so that together they have got the capacity and capability to be able to offer peer support to other people coming in who need some help and respective cardiovascular disease, who may then want to go on and become peer leaders themselves.

So it sort of becomes self-propagating in that sense. And that has been a really powerful way to get interest in respect of certain conditions, specific groups of people, where they've reached a kind of end in the road in terms of what they want to do, in terms of their lived experience, and they need to be reinvigorated and want to think of new ideas that they can do together. So that's been something that we've been really interested in, is starting to become quite successful.

Jo Fitzgerald - I think one of the things that struck me as well about the programme, the more that we've delivered it, is its versatility and transferability, because a lot of the learning is beneficial to a wide range of people. But also, again, that's rooted in personalised care. So personalised care is a whole population. It's a universal approach

that really touches into things like shared decision-making, social prescribing. So again, that speaks to its versatility. So even though we can tailor the programme to different cohorts, a lot of fundamental learning about personalised care really resonates with a wide range of people, because there's things for everyone.

Paul Parsons - Thank you both very much. In our work on major service change, patient voice is so important. We often hear the term experts by experience. I wondered what you thought of that term? And also to ask that the journey you've described sounds much more like a personal development journey than a training course. And I wondered whether you would give us your views on that as well.

Jo Fitzgerald - So I'm aware that there are lots of different ways of describing the involvement of people with lived experiences. As you say, some people are really comfortable with the term expert by experience, other people talk about patient leaders. Just reflecting, really on our use of language, we tend to talk in terms of lived experience and our understanding of that is around the sort of experience. So, yes, we all have lived experience in some shape or form of using NHS services, but I think what distinguishes our work is the sort of lived experience that fundamentally changes you.

So you may have had a particular view of the world or you may have had a particular sense of self, or you've had a particular way of living or a role or something. That when you have the sort of experience that both Gemma and I have, and certainly when my son, Mitchell, was born, it absolutely fundamentally changed me as a person and it changed the way I saw things. And from that point onwards, I would never be the same again. And it was such a fundamental shift in my values, in the way I saw the world, and how I experienced things that that has stayed with me and has informed kind of everything that I've done since.

And with that comes different insights. So I know that I carry that with me. I know that when I interact with my colleagues that it's a particular place I come from in how I describe things and in how I see them. So there's something for me about really valuing and celebrating that particular perspective. You can only know what you know in a particular kind of way if you've directly experienced it so that it feels very powerful. In terms of the personal development rather than training programme, that's also very

intentional. We talk about peer leadership and we've called it the Peer Leadership Development Programme because of the leadership role that we see people playing. Now, interestingly, people often don't start off thinking of themselves as leaders. In fact, sometimes people baulk against the word, they just don't feel comfortable with it. Well, I'm not a leader. But actually, when you start to think about different models of leadership and you start to think about things like personal and the difference between personal and positional, power, all of that sort of stuff that Helen Bevan described so well, you begin to see leadership in all sorts of different ways and in all sorts of different people.

So what we try to encourage is people to grow, to learn, to develop, because what we often see is people want to give something back, but they don't quite know how. And it's only through a personal development journey that they begin to see the value of what they bring and feel more confident to then step into that leadership role. And we've seen people, as they grow enormously and to the point. So a really good example is one of our peer leaders who from sort of really questioning what role she could play, growing in confidence to then, becoming the first person, and I think probably the only person to have actually spoken at the NHS England Public Board, and that was her finding her voice. So I guess a lot of what this programme is about is helping people find their voice, feel confident, find their place, find other colleagues who are doing similar sort of stuff, really grasping those images of possibility and very much stepping into a leadership role.

Gemma Crabtree - I think to amplify that, Jo, particularly in my own circumstances, with a long-term mental health condition that I didn't want to talk about. It really gave me the confidence and the acceptance to want to talk about my condition, to know that it's safe to talk about that in most circumstances, but also to know when it may or may not be appropriate. So part of the Peer Leadership Development Programme, when we get to step three, is sharing our personal experiences. And that's not just in the context of storytelling, that's really thinking about what message we want to get across to people and what's really important about our personal experience. So what I have learned through my own experience of having OCD and in particular of having three young children and managing that condition when it related to them. So I had Perinatal OCD, and part of what was really important about that is going through the Peer Leadership Development Programme. I heard other people's personal experiences, we learnt really how to talk about that, to be able to have the confidence to talk about our own

experiences and how that can be conveyed to people, whether within the system or within a peer support context.

And having done that, I was then able to have the confidence to speak at a very well attended event for GPs. So we had about 100 GPs across London. I was able to speak about my personal experience of Perinatal OCD and in particular, what questions GPs might want to think about asking at that critical six to eight week checkpoint, that might have helped me in talking about my own situation. As it was, I didn't disclose for many, many years, but being able to have those conversations with GPs and GPs asking, okay, what questions could we ask that would have made you feel more comfortable to disclose, that would have helped you to feel safe? And that was done in collaboration with other people with Perinatal OCD.

So that was a really powerful thing to have been able to do. And then second to that was being able to give peer support. So feeling confident to share my personal experience so that others could start to see themselves in my own journey as part of what they had been through, and then feeling able to disclose themselves or being able to discuss that with me. So some really important outcomes, really, of going through the Peer Leadership Development Programme that I wouldn't have experienced otherwise.

Paul Parsons - So, two questions, really, to help our listeners. There will be people out there thinking, programme managers thinking, oh, I'd really like to get more people involved, more people with experience with these services involved at earlier stages in our programmes, to help us set out what we're trying to achieve. And who knows, there might also be some people out there among our listeners with that lived experience themselves, who also think, I'd like to get involved. What's the best way of going about that?

Jo Fitzgerald - The best way is to reach out to us. So we do have a dedicated mailbox england.pldp@nhs.net. An alternative is to attend one of our open sessions, so there's no obligation to join, but it's an opportunity to provide more information. We're really happy to talk to people on an individual level, so we frequently do webinars, we do lunch and learns anything that enables us to share the programme and the difference that it can make. The focus for us is really about collaborative working. So a sense that we need to

move things often from a sort of them and us, in to an appreciation of the value of collaborative working and making sure that people can contribute on a level playing field. Always happy to have conversations.

Caroline Latta - Listeners who are the majority of them are working in major service change and change programmes across the country. How can they access your peer support leaders and what benefit could those leaders bring to those programmes?

Jo Fitzgerald - So one of the things we were really mindful of when we developed the programme, that there's often a so what? questions. So we've been really clear that the programme isn't the end. What we need to do is ensure that peer leaders then step into active roles. So one of the things that we have initiated over the last twelve months is a peer leadership network. If an organisation or if a particular service wants to reach out to peer leaders, then we can facilitate that.

Paul Parsons - That sounds really useful, Jo. A resource that I can see lots of the listeners getting in touch about.

Gemma, I just wanted to pick up with you. There are also opportunities like the one that you described about going and speaking to GPs in London about your experience. How do people go about that?

Gemma Crabtree - So there is a central way of coordinating all of this. So we have a person within the team who coordinates those relationships and does so really well to enable people to then approach Colin to kind of organise opportunities and, you know, things that come from in relation to the pandemic, for example. So the shielding letter that was sent out to millions of people in respect of their long-term health conditions. That went through our strategic co-production group, so that people with multiple long-term health conditions could look at that shielding letter and think, this is how we would receive it and this is how it would land with us. And therefore this is the wording that we would like to see in it and this would really appeal to us and we would be able to

understand this. So that was essentially coordinated and proved to be a really effective way of managing that shielding letter.

And there are lots of opportunities that come in all the time and sometimes it's simply the name of a service. So I'm thinking about developing a service and we want to have a name that will appeal to a lot of people. What do you think the name should be? And having a conversation between us around what the name of that service could be. So there are so many opportunities that might be short-lived, one or two sessions with our strategic co-production group to other opportunities that can go over several months. So it really gives people the opportunity to be able to get involved with those sorts of things depending on their own time commitments and area of interest.

Paul Parsons - It sounds like there is an awful lot of opportunities out there. So I'm just wondering, you've been going for a while, how many peer leaders have gone through the development programme and what does the future look like?

Gemma Crabtree - We're really proud of our peer leaders, as you can tell. We've got 225 peer leaders at the moment who've been through the Peer Leadership Development Programme. We've got a public facing commitment to develop 500 peer leaders by 2024, and we're not afraid of that target. So we feel very confident that we will be able to develop that number of peer leaders. In fact, over the next several months, we've got around 50 to 60 peer leaders who will be going through the Peer Leadership Development Programme. So that's really buoying for us and great to see that that enthusiasm continues.

Jo Fitzgerald - And as well as developing peer leaders, we're also working on a programme around peer leader facilitators. We now have a step four programme that's about peer leader facilitators who play that bridging role between peer leaders and the health and care system. One of our ambitions for the future is to really build capacity and capability within the health and care system to enable this kind of work to flourish.

Paul Parsons - We love a metric, at Not a Consultation. What is the feedback that you get? How do people feel about the programme?

Jo Fitzgerald - Off the top of my head, some of the most helpful feedback is around people's expectations. So whether it's met their expectations and 98% of people tell us it's either met or exceeded their expectations. Future Learn do reach out to people and if you look on the Future Learn platform, you'll see that our step one course has 4.7 out of 5 stars, and our step two course has 4.8 stars out of 5. Also, we're in the top quarter percentile, I think, of courses in our particular subject area, and 97% of people say that they have learned something new.

Paul Parsons - Those are some pretty amazing stats. Thank you very much. What did you think of it, Caroline?

Caroline Latta - Well, what a really interesting programme. I mean, helping people find their voice, feel confident and find their place in helping to make NHS services better. I think for me, it really cannot be underestimated how important personal experience is in helping to make improvements to health services.

Paul Parsons - Yes. In service change, it's so important to be able to hear from people with lived experiences of the service. I know we talk about that a lot, but having people who are willing to come forward, who have the confidence and the strength to stand up and tell us what their experiences are, how we can do better and how it affects them and their families, that's really important. That's usable information that we all want in our service change programmes.

Caroline Latta - Definitely, Paul. And of course, here at Not A Consultation, we're concerned with all things service change, aren't we? So it seems to me that having a pool of people who are trained in peer leadership would be so very valuable. Particularly to the new Integrated Care Boards who are planning service changes. I'm thinking about some

of those programmes we've helped with options development and imagining how rich the conversations would be with the input of peer leaders and helping, particularly in the options development phase, and getting some of those options for change really spot on, because they're able to bring that lived experience into the conversation.

Paul Parsons - You're absolutely right. And thinking about that in terms of planning your activity, then involving the Peer Leadership Development Programme early on, or encouraging local people with experience of the services to go through the programme and develop those skills as leaders, would be a huge advantage to any programme.

Caroline Latta - And finally, a big shout out to Jo and Gemma. I really loved how they've used their own lived experiences from their own lives to ensure that anyone involved in the programme can contribute on that level playing field to help people to understand that bonkers NHS as they describe it, and in particular, some of the language that we use. I mean, we're all guilty of it, aren't we? using NHS speakers shorthand and we forget how this can really exclude people.

Paul Parsons - Yeah, jargon is a barrier to anyone. So I'm really glad that the programme is taking that into account and it's not going to do the systems any harm, the programmes any harm at all, to have those experiences reflected back at them in really plain, simple, easy to understand language. And that brings us to the end of the episode for today.

Caroline Latta - Thanks to Jo Fitzgerald and Gemma Crabtree for joining us to talk about the Peer Leadership Development Programme. Take a look at it on [Future Learn.com](https://www.futurelearn.com) website or email the team on england.pldp@nhs.net. And of course, we'll put a link on the episode page of the Not A Consultation website.

Paul Parsons - We'd love to know what you think about the episode. Join the conversation by following us on Twitter @NotConsultation or emailing us at listen@notaconsultation.com.

Caroline Latta - So that's it for this episode. There's loads more learning in our other episodes. All available on our website www.notaconsultation.com.

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Caroline Latta - Thanks for listening and remember, this is not a consultation, it's a podcast.