



Tracy Paine in conversation with Laura Yates and Tabitha Moses

The following interview was recorded in August 2021, with the outgoing Director for the Belong organisation, Tracy Paine, the Project Facilitator for *Where The Arts Belong*, Tabitha Moses, and myself Laura Yates, Head of Participation for Bluecoat.

Where The Arts Belong is a project that brings artists and people with dementia together through a unique partnership between Bluecoat and Belong. The project has happened mostly in the villages run by Belong across the Northwest and continues to do so until December 2022.

You can see the work of the artists from the *Where The Arts Belong* project at Bluecoat between March and June 2022. In Gallery 4, *Where The Arts Belong: Making Sense Of It All* brings together the work of Brigitte Jurack, Alan Dunn, Gav Cross, Roger Hill, Francisco Carrasco, Jonathan Raisin, and Mary Prestidge. In Gallery 1, the work of Suki Chan: *Conscious*.

This project was funded by Arts Council England and the Baring Foundation. You can find out more on the Bluecoat website, www.thebluecoat.org.uk

Laura Yates: Tracy Paine is the outgoing deputy director for the Belong organisation who Bluecoat partner with on a project called *Where The Arts Belong*. Belong are a dementia care provider. Also just later life, you have space for older people to find new community in later life too. And you have grown the organisation that was originally called...

Tracy Paine: It was Cheshire Lifestyle Services originally, but was never really used. So it was always known as CLS.

Laura Yates: Well, you have grown that organisation and transformed from a very traditional care provider in Cheshire to this amazing village model inspired a bit, maybe by dementia care in Europe, some of it in Europe is very, very good, isn't it, particularly in Holland. And you've now got how many?

Tracy Paine: We have seven that are operating and people are living and working in, and we have two more that we are waiting to be completed by the contractors. And we have our site on Wirral Waters as well, which is really exciting.

Laura Yates: That is exciting actually, Birkenhead. It's called the West Float.

Tabitha Moses: Nice. And that was the original one that got Bluecoat and Belong together.

Tracy Paine: It was, yeah, it was through Peel Holdings that brought us all together. And we started to think about how we could work in collaboration, knowing that the time frame for Wirral Waters was probably a bit too ambitious, and what really, what could we do together in between that? And we realised that the new builds of Chester and Birkdale were still within the catchment area of the Bluecoat. And therefore, could we use the opportunity of working together to start to create communities through arts before the villages actually opened, and it's really important to try and get that heart of the community developing before the doors of the village is open so that everyone has a feeling of ownership and participation, and you know, it's where people belong, feel that they belong from the outset, really. I think we experienced that in our latest village, which was Belong Newcastle-under-Lyme, where we've got a Heritage Lottery grant which meant that we actually went out to local communities, to the schools, to the colleges, to the history groups, to the churches, to the museums, to bring people together between heritage and arts, if you like. And we realised that we should use that approach in all new village communities.

It certainly was very vibrant from when we first opened that village. And that's so important for the older people who choose to come and live in the villages. As you said, it's about transforming what we all know and understand of care homes, that's perhaps not what we would all aspire to in our own old age. So the Belong offer is much more around community living, supported living, independence, maximizing people's opportunities to live a good life with the amount of support and nursing care that's needed at the time in their life, and to provide a home for life. So creating that community and bringing people together as early as possible was really important to us.

So when I made connections with Bluecoat, it just seemed that this was a really good vehicle in which we could work together with people. Not knowing an awful lot about the arts myself, it's been a really good learning curve for me as well.

Laura Yates: We spent time in Crewe, which was a really amazing experience in the pilot part of the work of the project. And obviously then we've had the pandemic and some delays to the opening of the other villages, but Chester is well on its way and it's looking great. We went past it the other day, me and Tab on our way to the Grosvenor Museum. So the work itself is about exploring the place that artists might have in the enrichment of people's lives with dementia.

And I suppose the premise is that ... you can live well with dementia. And for artists as well, it's an interesting experience working with people whose consciousness is slightly different to the standard.

Tabitha Moses: Yeah. You call it a magical,

Laura Yates: it's magical. It's quite magical. And I think you can't really do anything about it once you've had your diagnosis, because unfortunately there is no cure. Organisations like Belong, and I suppose, arts organisations like Bluecoat who have an interest in exploring dementia as a happening in your life, you have to accept that there's nothing you can do other than embrace what's happening and maybe find the organisations who can help you with your journey. I know you don't like the terminology, dementia journey. Some people use that type of thing.

Tracy Paine: Yeah, I think you're right. I think having that diagnosis, certainly for the person who's living with dementia, in some respects what we hear is that that's a relief because they know what it is they're going to be living with, and they're going to then have access to support networks and services, and organisations like us, we have the opportunity where people can come for the

day and join in with our activities and access to our Admiral nurses, our dementia specialist nurses. But it's also about helping people to live well with dementia. And it's also, what we know is really important to understand the person. We're all very different, aren't we. You meet one person with dementia because we all have our own family histories, our own occupations, our personalities, our travel experiences, our family experiences. Bring all that together with your dementia as well... how you live your life is going to be very different.

And so I think it's finding those commonalities that arts brings, isn't it. And what we know is that many people living with dementia, particularly later on in their dementia, where cognitively they're struggling to manage, actually bringing in new experiences for people living with dementia is really interesting. Perhaps those perceptions that we believe: I believe I can't draw, for example, I perhaps think I'm an okay singer, but you know, I can do some dance. I'm quite good at dancing. I'd like to think I could write poetry. Maybe, as you start to shed those misconceptions of what people might think about you and how you might expose yourself by trying some of these things within your dementia, you may be even more artistic and learn new skills. And I think we've seen some fantastic poetry from people living with dementia, some amazing artwork, and just generally enjoying being part of a group that's having fun. And even if you're not fully participating, you're enjoying the moment and you enjoying watching and experiencing what's going on.

And that feeling is going to stay with you for the rest of the day. Maybe longer than that, because it's that well-being feeling that stays with you. You might not be able to remember what it was you did, but you'll remember it was a nice feeling and it was an enjoyable time and therefore more likely to participate in that again, if that experience and that opportunity was given to you.

Tabitha Moses: And study after study has demonstrated the benefits of arts engagement and the social stimulation that comes from taking part in a group activity as well as one-to-one with artists.

Laura Yates: I wonder if I could, so we're working with five artists with Belong.

I must just mention their names. There's Alan Dunn, Brigitte Jurack, there is Francisco Carasco. There has been Philip Jeck in the past. There is Mary Prestidge, Suki Chan and Jonathan Raisin and each person does a different thing, and they are all brought together by Tabitha who is the project facilitator. But I just wanted to take a little step back to you, Tracy, because you began your

career in nursing a very long time ago, but you are still very young. So you must've been pretty young when you started, but did you originally work in dementia? When did you decide to specialise?

Tracy Paine: I didn't ever decide really. I think it's one of those things that evolved through my career. I started nursing at 18. I thought I was going to be a children's nurse. And then I started to work with older people and that's where my career took me. So I worked in the community as well, looking after people which predominantly were older people in their own homes which was really interesting to see people and naturally experienced being a visitor in someone's home, which I think that then translated when I moved into managing a care home. I was a matron with a frilly hat. Yes, I'm that old. And just recognising that the care home was their home, not mine. And those values of treating people as individuals and making sure we preserve privacy and dignity, but I wanted to learn more about older people and the sort of special needs of older people really. So I did a Gerontology degree at Keele University.

Tabitha Moses: Can you, for the lay person like me, tell us what Gerontology is?

Tracy Paine: So it's the sociological aspects of growing old, of older aspects of the sociological experiences of people like myself entering into retirement, potentially. And that sort of fear of losing your persona or your reason for being. It's all those aspects. And recognising that growing older isn't just about those clinical medical problems that may have been focused on in the past, particularly in traditional geriatric care, but actually it starts to make you think about the older person and the value of the older person in the community.

So that bought for me that opened up connections with all the people, like the Royal College of Nursing or other geriatricians that, and listening to other people, it started to wider my contacts cause I'd worked very, very locally prior to that. So then I started to develop a national interest, getting involved in other organisations where I could continue to learn and then in 1995, I joined CLS care services.

I wanted to work for a larger organisation because I wanted to continue to learn and grow. And what particularly struck me about our organisation, which is now obviously rebranded as Belong, but the values remain from when I joined in 1995, that culture that always putting the customer, the older person, at the heart of everything that we do, that you have to live out those values, and if you're working for us, you've gotta be in tune with our values. Which is about every decision that's made is always with the person, the older person, and

actively listening to older people and to the people that we care for. So what was been an absolute amazing opportunity is to be very much at the forefront of the development and transformation of our organisation, of a forward thinking organisation that realised our buildings were not fit for purpose, that increasingly more and more people were living with dementia. And what we weren't happy with was that people were being moved on to mental health units or mental health care homes. And we knew that actually that was not a good option for older people. That was a very different need for people living with dementia.

So we felt that we could meet that. We actually developed a couple of dementia 'units' at the time, but it was about breaking the big care home into smaller, more family sized households and units, as we came to know, and we developed our Belong model. Because of that, we trialed it and we knew that that type of environment and the practice was the right way forward. And really moving forward, the Belong villages with the households, we really believe, and we know that now because we've been operating them for some time is that if we get it right for the person with dementia, we get it right for everyone. We can provide a home for life. We can provide nursing care if it's needed, but mostly it's about person centred care. It's knowing the individual and understanding their background and their history and their past and their interests and meeting those. And again, coming back to the arts really, it is that release from, and taking people away from what can be a very medical model of care to actually back to that social value on the individual, and everyone has a place in a community and has interests and has things to offer. And we're always learning from people, aren't we, as you'll have experienced Tabitha with the people you met.

And I, I must say, I can see how those values might come from the top of Belong, but they really lived out on the ground and in the everyday lives of the people, the whole community, people who are living there and the people who work in there and you've got a real sense of family within the households and beyond the house holds as well.

Laura Yates: And the household model, Tracy, and people might not be familiar with, I've been in lots of other types of care homes, and it's the first time I've experienced that model. I've read about it because there's a place in Holland. That's quite inspirational called Hogeweyk, and people live there in social groups and households and there it's around profession. Cause that must be important in Holland. I've got to say, I did go to a care home in Holland that wasn't Hogeweyk, and they're not great at it all the time. Like that had 400

residents, the one I went to, and anyway, that's another story, but it wasn't like Hogeweyk, but it's a really inspirational model for memory loss support because the interesting thing about memory loss for me is that you can regress back to childhood and young adult life, and it is sort of magical to be an artistic human being, as I am, for me, I also want to see people feeling, not feeling afraid, so to use the arts as a way of exploring your brain with dementia, to me is quite interesting. And actually that late stage, that's when people are living in the households, isn't it, when they're in quite late stage.

Tracy Paine: I think with *Belong*, we talk about home for life, but it is, you know, we provide a service to people in their own homes, through *Belong at Home*. And people come in for the experience days and use the village because we're really very supportive for people living with dementia. The hairdresser has trained in how to support people with dementia. A typical hair salon in town is often quite busy and noisy and it's not right for the person with dementia. So people might just use our villages to get their hair done and have a coffee, and it feels more secure and supportive in that way. But there does come a time for a lot of people where, wherever they are living and their environment just doesn't make sense to them anymore, that they may have stopped recognising loved ones, be looking for something else and a constant reassurance of who they are and in the right place at the right time. So that the households then provide that 24 hour support care until the end of life really. So, during that time, we talk about being dementia detectives, because actually we need to try and understand, as you said, where is that person living or at that moment in time? Where are they in their life journey, their lifespan. And as you say, it could be that they're thinking they are somewhere else. Very often the households can feel like if you've been a nurse, it might feel like you're at work. We had a lady who was a midwife and it was important to her that she was still looking at babies. We would use dolls or, or bring people's babies in. And it is recreating that place where she felt at home.

Another lady, when she saw a computer felt that it was her office and where she worked. So it can feel very different to very different people. And it's trying to get in with that person and understand where they are in time. And exploring that again, through activity, offering occupational activity to people which could be gardening as well, maintenance, whatever it is, that's right for that individual. And that requires a lot of insight from the staff. So dementia, so training and development in dementia care is really important and it's back down to person centered care and the use of life plans. So let's start by trying to understand the person before they come to us.

We use a document called, *This Is Me*, which we try and ideally you or I would want to write our own. Perhaps we should be writing that now, what's going to be important to us. But then if the person is no longer able to say that, then we will be looking to families to try and give us a picture of someone before they move in so that we can understand sometimes the reasons behind certain people's behaviors. And then we would develop the life plans and we make sure that we incorporate activities that are meaningful for that individual and their interests. But as we've said, they could be new interests. Somebody joined a choir or been doing the singing or the pottery, and they've absolutely loved it. So let's do more of that, because we've seen a difference in the person, their frustrations, their emotions, we've understood their feelings a bit more through that.

Tabitha Moses: What you were saying before about not just enjoying activities and being there, but taking part in the life of the household and the village and people gardening and I love that ethos, making a contribution and people are encouraged to help fold the laundry, or cook. The kitchen is part of the house, isn't it, where people can come and help cook, wash the dishes, all those things that go along with being a useful member of the family.

Tracy Paine: Yeah. That was key to us. So the household... I've had the opportunity to visit Hogeweyk as well as lots of other facilities around the world but our original dementia strategy was written in 1997 and it was looking at the CADE model, which was an Australian model. And so, having had the opportunity to go and look at some other small households, the idea is that you're trying to create more of a family size.

There's always the viability, the staffing, which is why at the moment it's 12 bedrooms. We think any more than that's too big, but the intention is that they're open plan. As you say, when people's memory is failing, then a corridor based environment is really distressing, especially if you've ever stayed in a hotel. It's how am I going to find my way back to my room? Imagine feeling like that all the time. Where am I? Where should I be? That's quite distressing, isn't it? So that open plan where everyone can see one another, that reassurance that I talked about before, about yes, it's, you're in the right place with the right people.

But having that kitchen at the heart of the household is absolutely key because that's, what's in our own homes, isn't it? And having somebody at home, that feeling of *mum's at home in the kitchen* makes you feel settled straight away doesn't it, compared with living in a care home where you can't see anybody,

you can't see the staff dress, should I be doing, where should I be? So that household kitchen in the core where all the food is cooked and baked and the smells is very different to a lot of things that I've seen across the world. People often may do a bit of tea and coffee and baking, but actually to be cooking a meal, it's almost like Christmas day, every day.

Laura Yates: Isn't that lovely.

Tabitha Moses: One thing you said about that support, that Belong offer from Belong at Home for people still living in their other homes, because once they move into Belong it's still their own home, that transition they can make to having more and more support, just reminds me of some feedback we had from Crewe where one of the household leads was telling me that, in our time at Crewe, during the time that the artists were there, we saw one of the Belong, he ended up being a resident, he started out as an Experience Day customer, and we were there for that whole transition from experience day customer to becoming a resident. And at times it was difficult for him and his wife cause it was such a big transition in their life and speak for the family as well as for the person living with dementia. But the household lead, she thought it was one of the best transitions she'd seen. And she thought that the arts really played a big part in that, that the opportunities that he had every week, there was something going on. There were some familiar faces, some artists who were there every week and some brand new, exciting, unfamiliar activities to get involved with. And she thought that continuity really helped his transition and there was less anxiety and less confusion on his part, which she said then contributed to the whole atmosphere in the household.

Tracy Paine: Yeah, absolutely. So starting with that experience days, cause this is about relationships, isn't it. Trust. And so certainly by people coming in for short periods of time and starting to experience the village, the environment, the people, knowing the faces being welcomed. It's also about the relationship with the partner – there is quite a lot of people who are still married and that feeling for the wife of, almost passing their husband on to someone else, and that guilt that comes with that, what losing your role as a wife, where does she fit in? And obviously the Admiral nurse is very key in working together with partnerships and families, but as you say, when we start to introduce that the person moves into a household, maybe just for some respite, but eventually long term care, that transition is definitely much smoother for both, for the family and the person moving in. But it's how do you then continue to maintain that relationship between the husband and wife, whilst they're living in different houses. And how does the wife still feel valued and can contribute? And so the

arts was one of those examples where families were getting involved as well, and it gave a sense of purpose for those individuals.

And actually, I know one lady who was in participating with a mother, she actually came to work for us as well as a volunteer. And certainly through the pandemic, she's found a way to be involved in Belong as well. So I think it's about relationships, sense of purpose, not just for the individual, but for their family as well. And the more we can include and involve the family, when it's safe and we're out of a pandemic, but absolutely.

Laura Yates: I was just trying to give you a bit of context as to what I was trying to say.

Tabitha Moses: I would add that it's not only the arts, which you know, can encompass everything in the whole wide world, but I would say it's the approach of the artists and their experience, the particular role in society more widely and in relationships and in communities like Belong to Mary Prestidge, our dance artist, was talking about the role of the artist as someone who opens new ways of thinking and being in relationship to each other and in relationship to oneself as well.

And I think that's something that the people who were working on the ground every day, the staff at Belong, don't have either the knowledge, experience, time or requirement to do. And that's where the artist can come in, whatever their art form is. It can be just holding that space to slow down and just come and be present in that moment.

Tracy Paine: Yeah, I agree. I think that's crucial. And I think we expect an awful lot of our staff and having that support from someone who's specialised in those areas, who can give people time is key to the future of arts in care homes and facilities like ours. And I think it's a really interesting subject that we need to look at, and I think the pandemic... we've talked about the experiences of actually almost medicalising care again, because of the need to keep people safe. But we need to start to move out of that and start to develop that absolute well-being and reason for living that people, particularly in care homes, have been treated very differently than the rest of society and still are being, and we need to make sure that they feel just as valued as you and I and have access to the same arts, interests, music, occupation, as everyone else.

Tabitha Moses: It's in the UN convention of human rights, isn't it. An access to a creative life. It's important to remember that, isn't it? I think we, as a society

need to notice and value our care workers who are doing a very important job, and our artists as well. And this project can hopefully make a small move towards that.