How we support diversity in DEEP

[music plays]

Rachael: **So, thank you so much for coming here this afternoon. We know we've got quite a range of audience members, from people with dementia, professionals, students, family carers, so it's great to have you here with us for the next hour.**

This is the session on supporting diversity in our communities. And we'll introduce ourselves in a moment, but what you have for the afternoon are three DEEP groups, three groups that are members of the DEEP network who are gonna talk about the specific communities that they work with. And then we'll have a broader discussion about what some of the principles of increasing diversity might be and kind of good principles of practice and engagement.

But I should say before we start, that this event is part of our DEEP 10th Anniversary Festival. It's one of 21 events we're running this week to celebrate 10 years of working together to amplify the voices of people living with dementia. So, this is the end of a very busy year, a busy year, especially for Rachel, who has been running 17 DEEP events across the United Kingdom. And we're just conscious that we couldn't do it all in one space, so we've had lots of geographical events, and then this was the kind of culmination of our events for the year by having our online festival. So, we hope that you can see some of the magic that's happened in the year, but also... we're also launching I guess a lot of films and resources and tools during this week, so we really hope that you will share them as widely as you can, and with other people with dementia especially.

All of our events are recorded and they'll be available to watch after we've finished our week and we've tidied them up a little be... a little bit. So, just to remind you: you can't be seen or heard during this next hour, but you can communicate via the chat box if you'd like to, and Rachel will keep an eye on that and feed things in where she can, but don't feel obliged to use the chat box.

So, to kick us off, I'm gonna ask if we might all introduce ourselves. I'll start, 'cause I forgot to do that in my session yesterday: I'm Rachael Litherland, I work for Innovations in Dementia and have been supporting the DEEP network for 10 years; I'm down in Exeter.

Di, would you mind introducing yourself?

Di: Good afternoon, everyone. My name is Di Burbidge and I'm the Service Development Manager at Chinese Wellbeing, which is a small specialist charity in Liverpool's Chinatown.

Rachael: Thank you, Di. Rosie, and Nicola?

Nicola: Thank you.

Rosie: It is. I'm Rosie, and we work for the...

Nicola: [unclear 03:20] at MacIntyre.

Rosie: We work for MacIntyre. I'm...

Nicola: And I'm Nicola. So, we're here today together to just give you a bit of information about MacIntyre, but also hear directly from you, Rosie, aren't we?

Rosie: Oh yeah.

Nicola: Thank you for having her.

Rachael: Thank you very much. Chris?

Chris: Hi everybody. My name's Chris Maddocks. I've been a part of the DEEP network for a number of years and have been so greatly helped by everything that they've done for me and for others. I'm living with dementia, initially I was diagnosed with vascular dementia, then Parkinson's disease, then Lewy body dementia, and I am on the LGBTQ+ Dementia Advisory Board. I'm glad I put that sign up 'cause I can read it backwards. And yes, and we're here to talk to you about the advisory board and about a group called Speak Out with Dementia, which is for people who identify as living with dementia and are members of the LGBTQ+ community.

Rachael: Thank you, Chris. And John?

John: Hi everybody, I'm John Hammond, and I use pronouns he, him, and I'm here with Chris to speak about the LGBTQ+ Dementia Advisory Group, which I'm a core member, and the Speak Out with Dementia online group, which is hosted by the organisation, the charity I work for called Brighton & Hove LGBT Switchboard, and Speak Out with Dementia, we'll speak about in a while. But yeah, I work for Switchboard, it's a charity that's been supporting the LGBTQ communities since 1975.

Rachael: Wow, thank you, John.

So, before we move into hearing from these different groups, we... we've had a film created by a group in Manchester called Fabulous Forgetful Friends. They would have liked to have been here today, but can't be, so they did us the really fantastic job of making a little film that we could show.

//[music and film clip starts: 05:23]

?: I'd like to introduce the Fabulous Forgetful Friends, call to action for dementia, what we want, give me – I will.

?: Give me myself – and I will be me.

?: Give me an ear – and I will speak.

?: Be patient – and I will relax.

?: Give me music – and my heart will dance.

?: Give me joy – and I will laugh.

?: Give me a way – and I will follow.

?: Give me [unclear 06:14] – and I will share.

?: Give me inspiration – and I will excel.

?: Give me teaching – and I will learn.

?: Give me truth – and I will consider.

?: Give me compassion – and I will care.

?: Give me identity – and I will shine.

?: Give me attachment – and I will engage.

?: Give me occupation – and I will be focused.

?: Give me inclusion – and I will belong.

?: Give me comfort – and I will feel the warmth.

?: Give me love – and I will thrive.

?: There's the evidence, please do something with it now, thank you.

[group sings *New York, New York*]

[music and film clip end: 07:39]//

Rachael: **So, that's a group of a range of people with dementia. And I guess that's just something to say about the DEEP network is we hope it's a home for lots of different groups, lots of different people, many people with dementia are supported in their groups for a long,**

long time as their dementia changes, and we hope that that... this network can provide that safe space for that.

So, now we're gonna hear from three different groups who are all part of the DEEP network who come from perhaps a different community, and we'll talk a little about that and pull that together nearer to the end.

So, Di: Di, you're here today—

Di: Hi.

Rachael: —as part of Chinese Wellbeing, and I wondered if you wanted to say a little bit about Chinese Wellbeing. Chinese Wellbeing have been a member of the DEEP network for many years now.

Di: Yes, Rachael, I think it goes back to 2014,—

Rachael: Mm.

Di: —but very briefly: Chinese Wellbeing is a charity, we're in our 33rd year this year, and we currently provide home care and a range of services that wrap around home care, so it's not just... [we're commissioned? 09:02] to deliver home care on a task and finish basis – as everyone knows, that's how social care is today. But through the charity we raise a lot more funding to do activities, and we created the Dementia Network and the Tea House Reminiscence over the years with support from you, Rachael, at DEEP, and so we go back a long way and you have given us, and my colleagues, in the diversity subgroup of the Dementia Action Alliance, tremendous support with our groups and getting them off the ground basically.

Rachael: And so, what does it... so, Chinese Wellbeing have been involved, as you say, in quite... well, you've been the recipients of a few DEEP grants, haven't you, to... I guess the purpose of those DEEP grants in one of the stages of DEEP was to... for you to do the things you wanted to do as a group to have your voices heard, so were very

broad, and you were able to kind of run with that as a... as a group. But also in later years you have participated in your own way, I guess, in some of the kind of national pieces of work that has been possible to bring the DEEP groups together; I just wondered if you wanted to anything about that?

Di: Yes, well we started off with... in 2012, raising awareness in the community. There's a lot of social stigma and people remained hidden, families didn't talk about dementia; no one spoke about dementia. So, we started to raise awareness of signs and symptoms and we introduced the Tea House Reminiscence, which is a lovely, lovely environment where people can reminisce, get involved in activities, and every now and again we would raise awareness of dementia through sort of not... not sort of blatant ways, but very subtle ways, so people started to engage. And then it was down to you, Rachael, when we got our first round of funding from DEEP, and it was to allow people's voices to be heard, and we created some films, and you said to me, "Di, as long as people living with dementia and their voices are on those films – that'll be fine," and I remember the conversation distinctly because at the time I said, "I'm not sure, Rachael, we're gonna... we're that far yet, I'm not sure we're gonna get people on film saying 'I am... I'm... I've got dementia and it's OK to talk'," but believe you me – we managed it, and people... 'cause we didn't identify anybody in the group particularly as having dementia, and people were happy to contribute in that safer environment.

And yes, over the years we've moved on from there and the network has grown and the Dementia Network we have is for... is obviously for the Chinese: we deliver the network in Cantonese, which is the main language spoken in Liverpool, and the membership consists of people living with dementia and their family carers, plus we have several who have got memory problems, but haven't been diagnosed, and that's the issue in... across the UK since... obviously since the pandemic; the diagnosis rates in Liverpool were dropping before the pandemic. So, we

are now sort of on active campaign to go back to raising more awareness; we've just got some more funding. And the last consultation and the last DEEP exercise we did, or project, was about asking the Government what we... what we want to say to the Government. And the Forgetful Friends group, at the end of that video, said, "There's the evidence," well, quite frankly in the Chinese community, over the years that Chinese Wellbeing's been involved, we've done consultation, after consultation, after consultation – we are still waiting for things for change within Black, Asian and minority ethnic communities. And some of the comments to government: "Please listen to my needs and make more effort to communicate with me, I do not understand English." "I would like a safe place to go where people speak my language and understand my needs."

Maintaining cultural identity is so important to yourself, it is... it is you, it is what makes you the person, and therefore meeting in a group, sharing the same language, the same culture, the same food, really does help wellbeing, and that's what we're about with our groups.

Rachael: **That a fantastic example, Di. Can I just share... I'd love to share this picture which is of... kind of, as you say, the kind of in the early days, you know, that kind of worry that actually maybe people wouldn't even... you know, wouldn't be on film, wouldn't be on film talking about dementia or acknowledging they had dementia: I'd just like to share this... where we got to with the call to the Government, and this is your translated call to the Government about what your communities wanted, and the yellow cards, which I'm sure many people know, 'I want to speak please', held up loud and proud, and for me... like, and, you know, I heard you say, having been kind of in contact since 2014, you know, these take... these things take time, don't they? But I just wondered, to conclude, before we move on to the other groups, what does it mean to you to be part of the DEEP network?**

Di: It's a connection, it's a connection, because what's happening in the DEEP network, we're able to feed back to our network, and it makes members of our network feel less isolated, and feel part of something that's a bigger movement than just our network. So, it does... it does give comfort because we do... and we always feed back, and we love reading *Deep News*, and whist our members can't read the *News*, the ideas... the ideas that just come forward from the other groups, really do help inspire us, so it's... yeah, it feels that we're not on our own.

And the... you know, the one... the other thing that I'd like to just sort of... one other comment, was that we've done a dementia strategy in Liverpool, and the co... the community consulted... were consulted again, and have fed back: that was 2019, and I know Covid has intervened, but one of the comments was, "Refer to your dementia strategy and take action – I have no time to wait."

Rachael: Fantastic. And... you know, and as you say, that mirrors that Fabulous Forgetful Friend's comment at the end—

Di: It does.

Rachael: —[as well? 16:33], doesn't it?

Di: Yeah.

Rachael: Thank you so much, Di, we'll give you a little break, huh.

Di: Thanks, Rachael.

Rachael: And... ouu, now, Rachel, can you let Maq in and make him available as a participant? I don't know if you can hear me; I'm sure you can. We'll move to Chris, and to John, who are gonna talk about... and I'm so glad, Chris, you had this behind you, the LGBTQ+ Dementia Advisory Group and Speak Out with Dementia.

John: So, thank you so much for having us as well, it's an absolute honour, and great to hear from Di as well, so I'll hopefully follow in good footsteps

here. So, before the pandemic there were just a very, very few dementia groups for LGBTQ+ people available across the UK, and only in a couple of metropolitan areas really, and this made a lot of LGBTQ people living with dementia feel isolated, so as the Covid-19 pandemic struck, the isolation became even more apparent, and with this, some of the services that did exist, moved online, so there was finally an opportunity, I guess, for us to branch out to other locations now that we were all living in this more remote world.

The LGBTQ Dementia Advisory Group began as a steering group in summer 2020 with the aim primarily of creating an online peer support group for people living with dementia and who identify as LGBTQ+. The steering group was made up, and continues to be made up, of people living with dementia, and their partner, carers, as well as professionals, and people who work in health and social care, or researchers, and who work alongside and with people living with dementia. Some of the members of the group identify as LGBTQ, some are allies, but the predominant group make-up is LGBTQ+ people.

So, a pilot version of the peer support group ran successfully all the way from November 2020 to March ’21, and the peer support group ‘Speak Out with Dementia’ began, and so the Speak Out with Dementia peer support group runs now every week online, on Zoom, and is a safe space for LGBTQ+ people living with dementia. So, it’s a dedicated online space for people to meet every week to share their experiences, to find a community. Di talked about this, you know, to share identity and culture can be very important with people who are... and that you... that you share an affinity with, and so that group meets every week now. And in January ’21 the original steering group became the LGBTQ Dementia Advisory Group, and that group meets every month. The... there are core members who continue to meet, and again their purpose really is to raise the awareness of LGBTQ people’s needs in dementia services and in dementia care, and also to attract new members, I guess, from different walks of life from... again, from researchers, from health and

social care, people who have a passion, I guess, to help LGBTQ people living with dementia to thrive. It exists as well as a... as a networking opportunity for people who support other people affected by dementia who identify as LGBTQ, so it's a growing influence really. The Dementia Advisory Group has an ever-growing influence both nationally and internationally. So, we are approached often by organisations from overseas as well to give advice, and the advisory group also is a repository of resources. So, lgbtqdementiaadvisorygroup.net is the website, and anybody can go along and have a look and pick out some resources and things, and also watch some pre-recorded vid... webinars and things that we've done from the past.

Chris, have I done a good job, is that OK? [chuckles]

Chris: You've done an excellent job, as always, John.

John: So, I think—

Chris: I would just like to add to what you said, the fact that it was Rachel Niblock that got this group up and running in the first place – thank you, Rachel. Because she was approached by a gay man who said, "Look, there's nothing for LGBTQ+ people living with dementia," and DEEP, as they always do, grabbed the bull by the horns and started this process off, so thank you, Rachel, and DEEP, for that.

Rachael: **[unclear 21:20].—**

John: Absolutely, yeah, and I think the real... I mean there's a huge value to the Speak Out with Dementia weekly group, so Chris comes along to that group. I wonder, Chris, what you feel like the value of having the Speak Out with Dementia Group is for LGBTQ people?

Chris: I think what people have said to me is that when you're diagnosed with dementia – you have a stigma, but if you're diagnosed with dementia and you're a member of the LGBTQ+ community, it's like having a double stigma. And I think what's most important about the Speak Out with

Dementia Group is that it's a safe... a safe place and a safe space for people to be themselves and to talk about anything that they want to talk about. And we've identified problems for example in housing and care homes for people who identify as LGBTQ+, and there's a huge need there, and most of the care homes... one of our group did a bit of an assessment and approached 10 care homes: eight of them wouldn't take people under the age of 64, so if you're below that age and, you know, some of our group are, that's a huge problem, and also those... the two homes that would consider taking him on, said that, you know, they would treat him the same as they treat everybody else, but I think that LGBTQ+ people need a bit more than that: they need to know that they'll have understanding of their sexuality as well as their dementia. And the other thing that struck me is that, you know, if a gay man regresses in their memory, they might go back to a time when it was a... it was a criminal offence to be a gay man, and they might only remember that time, and they may or may not have been arrested for being gay, so as their memory regresses, maybe they'll just go back to that time. Or similarly with a transgender person, they may go back to a time when they were the sex that they were born in, and not the sex that they are now, and I think it's particularly hard for transgender people. And I can remember one person telling me that they got ridiculed and got harassed just travelling on the bus before the doctor's meeting where they felt it was a safe place. And there's lots of examples that I can give you.

But I think the other thing that's important for LGBTQ+ people is that their family is a family of choice – it's not always their relatives. And an example of that was I heard a story about a transgender woman in a... I'm not sure if it was the hospital or a care setting, and the parents went in and just said, "This is not Jane, this is our son, John, he will not... and you'll not dress him in women's clothing, we'll dress in the men's clothing," and you know, what you do in a situation like that when they're not even getting the support from the parents? So, LGBTQ+ people – their family of choice can often be very different, 'cause it has to be people that they feel safe with and that they can trust.

Rachael: **Can I... and I wanted to just ask... you know, I know you're involved in lots of things, Chris, in the dementia world, but I wondered... I think you've said this already, but I just wondered what having a specific group around LGBTQ+ communities gives to you, and what that space gives to you?**

Chris: I think it's somewhere where I can be more myself and I can talk to people about things that matter to me. And sometimes, you know, there's still a lot of discrimination out there in this world, and it doesn't matter at the end of the day who you are or, you know, what faith you are, what religion you are, or what sexuality you are, but what I would say is – see the person and not see the dementia first, and see the person and not their sexuality first, and it's all about seeing the person, and the rest doesn't really need to be talked about openly; however, it does need to in... as Di said, you know, you have to have a community of people that gel together, that understand one another and that you can be yourselves in.

Rachael: **A really important point, thank you John, and Chris.**

John: Thank you.

Rachael: **We'll come back.**

Rosie, and Nicola: we've had lots of conversations with you over the years, and it's been wonderful.

Rosie: Oh yeah.

Rachael: **But we, you know, are kind of working, aren't we, towards kind of hopeful relationships, so it would be really great to hear what MacIntyre has been doing around your dementia work and how that kind of connects with the DEEP network?**

Nicola: So... yeah, so my name's Nicola, and I'm with Rosie today and we're just gonna... just introduce you to MacIntyre if you don't know who we are

and what we do, but importantly, Rosie, you're going to talk about your own diagnosis of dementia.

Rosie: Oh yeah

Nicola: So, if we just flick through. So, that's us, if you can see us clearer in that picture. Rosie and I have worked together for many, many years, I've been part of MacIntyre for the past 18, and Rosie, you've lived and worked at... and still live and work at MacIntyre, don't you?

Rosie: I do, yes.

Nicola: So... and it's really important that Rosie and I, we do our best to connect externally, we do some fabulous work around dementia and learning disability, because MacIntyre is a provider that supports children and young people and adults with a learning disability or a diagnosis of autism, so... and the reason I work so closely with Rosie, is I sit within our health team and one of my main focuses is how do we support a person living with a learning disability, Rosie living with Down's syndrome to live well with a diagnosis of dementia. And I've just popped... we showed these slides when we were at Dementia Congress and I've just sort of kept them to what they are, but you know, we... sadly a person with Down's syndrome is much more likely to get an early diagnosis of early-onset dementia, and we see that within MacIntyre. We are supporting people in their sort of mid-30s, 40s, living with a diagnosis, quite complicated to even get a diagnosis, but we've become much stronger as a... as a charity on how to recognise those barriers and what we need to put in place. So, we do a lot of robust health recording, so when we start to see changes within a person, we've got that evidence to be able to present to a GP to say, 'this isn't normal, this isn't right,' and you know... and we sometimes have to sort of fight our corner a little bit, but as you can see there, the numbers: one in 50 people with Down's syndrome in dementia at age 30 to 39, and they're much higher than the general population.

Just some of the... and it's not really a pretty slide, but some of the work that we do at MacIntyre regarding dementia: so Rosie and I have been part of our Dementia Special Interest Group for... oh, I think it's been established for about nine years, and that's a group that really pulls us as an organisation together to feel stronger, and I know... and some of our DEEP members have come to a previous Dementia Special Interest Group. I know George is on the call this afternoon, and Keith, and Wendy, you know, we love it when we have you guys pop in and just be with us for a day, it really helps us feel that we... you know, we're making a difference but we're also con... like you say, connecting externally.

We've run a very successful dementia project which really upskilled us as staff to be able to support people like yourself, Rosie, with a diagnosis of dementia, so that was a funded project. Our health recording, again, it is a standalone... a standalone sort of presentation, but we do that well, and to help a person to get a timely diagnosis of dementia, and we've got a lot of our resources on our MacIntyre website, our *Wellbeing For Life*, which we created, which has got a pathway of support, but there's a pathway of dementia support and for learning disabilities, because we don't... you know, we're starting to see much more externally around that support, but yeah, that's our main focus.

Memory cafés, family support, staff... and staff support, and these are just some of the external organisations that we link with on a weekly basis, and we would be lost without every one of them, so yeah, and obviously DEEP is on there too, so...

So, importantly, and I feel like I've whistled my way through that, but I wanted you... because we haven't got much time, I just wanted you to hear from Rosie, just a little bit... it's a very early diagnosis, so Rosie's only been diagnosed in the last few months. So, Rosie put some words on paper and she's going to share them with you now.

Rosie: OK, my name is Rosie, and I'm part of the [Health? 30:54] Dementia and Wellbeing Project, MacIntyre. And so [Meg, Rachael, and Nicky? 31:00],

we have someone else has now joined the team, Megan, she's our MacIntyre's new Admiral Nurse.

This year I was diagnosed with dementia; this was confirmed by my GP. In my mind I've not had it until now, and I've not had it before. I'm still trying to get used to it, and it is new to me. I can still live well [as well as? 31:37] leading a normal life. Even though I have Down's syndrome, it doesn't affect who I am. Even with me having dementia, it doesn't affect who I am, that's why I'm here today talking to you.

You view it different ways [underneath your? 32:01] emotions, for example maybe using a mixture of tapes which we do to relax to, by doing relaxing techniques, it helps a person to unwind. It's important for me to stay positive and to... and to focus on the things that you can still do. And you can also consider installing a specialist dementia clock, if someone is struggling to orienteer themself, the day and night-time, I find mine really helpful.

It is how you deal with it when you get the diagnosis [unclear 32:52] a person for the outcome, by talking about it, it really does help that you can feel relaxed. It is OK to feel emotional at times, and it is... [unclear 33:09] more determined to carry on within this project and with the team.

Thank you for taking this time to listen to my story. I hope that you will put... and share my journey and a chapter in my life, [unclear 33:34] to move forward.

Nicola: Thank you, Rosie.

Rachael: Thank you so much, Rosie, and Nicola. And, Rosie, that was incredibly powerful – are you OK?

Rosie: I'm fine.

Rachael: Yeah, it's kind of great to hear you saying about all the positives and how important it is to talk about it.

Rosie: Thank you.

Rachael: Thank you so much.

Rosie: OK.

Rachael: Take a moment.

Nicola: We will, thank you.

Rachael: So, I have lost Maq. Maq, are you there?

Maq: Yeah, I'm here.

Rachael: Do you want to... here you are. [chuckles] Hello. So, Maq, you're very involved in the DEEP network, you... we have talked a lot about diversity and about dementia in the South Asian Communities, and increasing diversity in the dementia field, and in the DEEP network, so I just wondered if there's anything you'd like to say?

Maq: Yeah, yeah, thank you, thank you for having me here. And the discussion that I've just heard a little bit of it, that is also an important issue within the community, you know, because homophobia – it's a big problem, no matter which way you look at it, and [with that? 35:08] certain faiths, it's a taboo subject – nobody really wants to talk about it, nobody wants to come out and admit it, and consequently what happens is that that person is discriminated against within the same community as well the community elsewhere. So, I find that it is something that needs to be... needs to be tackled and done something about. You know, I know people that are living double lives, they're even hiding the fact from their immediate family simply because, you know, they will be looked at as doing things that are not traditional, if that makes sense? You know, and consequently I think what happens is that they're either forced into marriages from opposite sex, because that isn't something that they can relate to, and I have also heard, you know, they attempted suicide, so it is... it is a big issue within the... within the community.

I haven't really come across many that have actually approached other people in the same condition so that they can actually relate to it and maybe get support, but again one of the reasons is, that they don't open up and talk about it, you know, and so it is... I'm glad that I heard a little bit about this today, and I'm going to try and explore it a bit more and maybe, you know, dig deep into it and help DEEP with it, and do something about it.

Rachael: **Yeah, that's all that action,—**

Maq: [chuckles]

Rachael: **—and doing action even on this call.**

Maq: Yeah, [unclear 36:55].

Rachael: **So,—**

Maq: The subject of diversity: I believe that the word 'diversity' is a diverse word anyway, and you know, you don't have to have dementia, you don't have to have physical disability to be inclusive or included in things, but if you have... what you need is like... and for instance, I mean, I know yourself and Chris, of course, you know, I can relate to you, I can talk to you, I can... I feel safe, and I know that I have been listened to, I've been heard, and I make an effort, as it were, and the peer support that I've had through people living with the dementia, has been immense, and that's been the backbone of my recovery.

As far as DEEP is concerned: I was diagnosed in 2010, as yourself and [Nicola knows? 38:00], and it was 2011 that I was introduced to Beth Johnson's *[sic]* Foundation, and then later on – DEEP, so in a sense I've known DEEP ever since it started, and I've had the honour of meeting yourself and Rachel Niblock and numerous occasions, and I think you've seen the transition in me since I joined. And you know, I can safely say that if it wasn't for DEEP, I would not be sitting here talking

to everybody because that's what DEEP did for me. Thank you very much DEEP.

Rachael: **Thank you, Maq. I just wonder maybe for all of you, you know, does dementia overcome some differences? You know, I mean, we talked a lot about special places to be and how safe they are and where you can... I think it was you, Chris, that said you can be yourself, but I wonder, you know, particularly again kind of starting with you, Maq, that, you know, you're a member of a community group, you know, a group based in the community of Stoke-on-Trent with people from... with all kinds of differences, but actually the thing that connects you is dementia.**

Maq: I feel in the experience that I've had, and, you know, this lockdown, to me was a blessing in disguise, because that's when I was introduced to Zoom, and that opened doors for many things, and over the last couple of years or so, maybe a little longer, I met over three thousand people and the majority of them were connected with the... well, all were connected with dementia, either they were carers, living with it, professionals, all sorts, and there are people that I might not ever meet, but we have connected in the manner that I've got friends for life, and forever discussing things on social media, you know, talking to people, I've had lots of calls from people and that.

But my main concern is, but what I've been trying to do is, to get South Asian people to join, and this is where I'm struggling, because again it's a taboo subject within some cultures and customs, and they don't talk about it. I've tried, I've tried, I speak the languages, I speak 14 different dialects and languages, and I've tried everything, and even the GPs, I mean the majority of GPs are bilingual, and they've tried, but it's difficult to convince them to actually come out. The group that I am a founder member of is predominantly [unclear 40:56] community, they'll all White, and they'll all British, there's only me and because of me being there, you know, I've had Alzheimer's Society quote "a lucky find here", because, huh, they... everybody wants me, because I've opened up and

spoken about it. But yeah, it needs... it needs to be addressed and I think... I think and we're doing things about it, I think DEEP has done quite a bit because they've introduced me to some of the people that... Afro-Caribbean, and I know a couple of doctors, psychologists, psychiatrists from Asian community and they've become part of DEEP and they've been introduced to DEEP by myself, and I think... I think we'll get somewhere.

Peer support is the most important thing I believe, and that's the best way to connect with people, and DEEP had provided that platform for us, and I think to a certain extent we've built the community within a community, within the DEEP community, and that community of people living with dementia, you know, they're not living quality life, they're living good quality of life because of that group I think.

Rachael: **Thank you, Maq. I think that's really interesting and maybe connects with what you were saying, Di, about the time it can take for people to connect, I guess... I guess, you know, the history of Chinese Wellbeing is very longstanding in Liverpool, isn't it, so that community has built up of Chinese people over many, many, many years and then dementia is something that is coming into the mix. And I guess from your experience, Maq, that actually the South Asian community perhaps is perhaps more dispersed, that they're... it's harder to identify where people currently are.**

But I wondered if you had any tips, Di, if there's anything kind of that, you know... or maybe just to kind of situate, you know, what has happened in Liverpool with Chinese Wellbeing?

Di: Well, I think you're right – it's a very long journey. You... you know, we started in 2012 till just appointed a dementia champion for a couple of hours a week to start raising awareness. Then we introduced the Tea House Reminiscence and it's been just sort of talking about dementia in a gentle way and just, you know, fun quizzes, if you can call them that, just to start education, that... a process of understanding and breaking

down some of the taboos and some of the myths around dementia. And it's just... it was just that constant sort of talking about it, and gradually... gradually, gradually, because we're a care provider, also providing care to people living in their own homes with dementia, family members and other people started to approach us. They started to recognise that maybe they have a... you know, they needed to sort of talk to somebody about some of the early stage, early signs, and it's just evolved, but it's... it comes and it goes with us because nobody will fund it, nobody in the general mainstream, you don't get funding specifically to support people outside of mainstream, and so it's a case of we work very hard to get grant money for projects, and that's what we've been doing for the last 12 years, and despite having the dementia strategy for Liverpool that has been developed by what was the CCG, and the City Council, we're still waiting for some of those recommendations to be implemented for people from Black, Asian, and minority ethnic communities – we're still waiting.

My concern would be within another couple of years we're asked to go back and consult once again with the community, and there are so many consultations that have taken place; we know now what is needed. There's more culturally-appropriate- language-appropriate services, and peer support – I agree. Peer support: once you start getting a group of people together and they realise, they're talking openly about it, is giving a tremendous relief particularly for carers, family carers, the relief that comes with just talking. We've got many sort of... many quotes and feedback from carers who just say that we come to the group, they talk with people who are going through a similar thing, and it relieves them for that... for those two hours they're with us, with their friends and other people sharing, it does relieve the anxiety that can come with having a caring role.

And for people living with dementia: we're doing things they enjoy, we're doing things that... we're speaking the same language and we're doing culturally-appropriate activities, and it makes them... it improves

wellbeing and it makes people feel connected, I think is what I'm trying to say.

Rachael: **Thank you, Di. I seem to [nod? 46:41]... so, I think there was a... the thing around funding, that kind of just sparked a little bit of interest I think from John, and Chris, but I'm also thinking from MacIntyre's perspective as well, you know, that kind of... it's almost like that kind of energy that... to give some focus to projects does require some things to be in place and to have some funding, some money behind it, but also that energy, that kind of... that willingness to go down this that perhaps... so I wonder if John, and Chris, and Nicola and Rosie want to say anything at this point, if it sparked anything in you? John?**

John: I think a really important thing about any projects as well, and I agree with Di – the funding can be very, very difficult to get for any [minoritised? 47:29] communities. But the thing about projects is they should be created, led, designed by people from the communities, so you know, sometimes some of the authorities, or the statutory services, or... you know, try and design projects or initiatives for different communities, actually without any of the consultation or discussion with those communities whatsoever, and they're bound to fail, and so actually there should be a lot more empowerment I think to... the communities... the communities know best. You know, like... you know, we work alongside people every day, we live with the experience every day, and so, you know, really empowering people. And also, I guess, funding that isn't just, you know, six-month-to-six-month, or year-to-year where you're constantly then going back through whole process of, 'can I survive another year providing support to a... you know, a particular community?' for example. So, longer-term sustainable initiatives where, you know, funding is really... put its mouth, you know, and it walks the walk and not just does the talk, I guess, so I think that just made me think about that, that all services absolutely should be designed the communities – by and for.

Rachael: **Thanks, John. MacIntyre: what... how does this kind of resonate with you?**

Nicola: Yeah, I mean when we were... when we had our dementia project which was funded by the Department of Health, one of the first things we did was set up a steering group, a working group, for people that draw on our support, and we were guided by them. They were called Keep Going…….Don't Stop! group, and I have so many wonderful memories from working with that group, and it allowed us to really make sure that our steps forward were the... were comfortable and we weren't just sitting a desk in the head office thinking, 'this will work,' you know, it's that whole collaboration and that... and like, you know, I've just heard absolutely hearing from the people that are living with dementia, or living with a learning disability, planning for their future as well, so... yeah, yeah. And the good thing is that, you know, we were... we were very successful in the work that we did under that umbrella and that just now sits within our health agenda, so we are really still working closely on that even... we haven't got the funding and we are always thinking of ways to be creative and how we can sustain that at MacIntyre, so... yeah. [chuckles]

Rachael: **Thank you, and I guess what you... what you've just said about communities knowing best – that's sits really powerfully for me, as I guess what we stand for in DEEP is that the voices are there, the experiences are there, it's available, our role in supporting DEEP is to try and get maximum impact and to connect you to each other so you feel safer, more together, stronger, more powerful, but it's the same principle, isn't it, is that actually you all know best, you know best about your dementia, you know best about your communities, but it requires that... some of that infrastructure behind you to help you espec... maybe especially if you're coming from a more diverse perspective? I don't know, I mean perhaps because it's... you know, you've each in different ways used words like 'coming out' and 'safety' and 'security' and kind of 'being**

myself', which perhaps... was it you, Chris, that said about that kind of double experience of stigma?

So yeah, just as we're coming to a close, I'm wondering if you have any advice, or hopes, for what happens next for your group or for your... for diversity and growth within the DEEP network? Chris?

Chris: Sorry, I'm just lowering my hand. Thank you. I think that the key thing that's come through to me is 'nothing about us without us', and it's so important to get people living with dementia involved in all sorts of things, and including research, get us involved from the very beginning, and I think that is starting to happen. And it's the same with our group, you know, we haven't had any funding whatsoever, and we depend on the time and the kindness of individuals to do these things, and I know that people in the DEEP groups all do this. And I have made a lot of friends that I wouldn't have made if I hadn't had dementia, so that's the plus side to it.

And the other thing is, you know, I've heard so many times, "Oh, you've got dementia, you can't learn new things:" actually, we can, and we proved that during lockdown when we had our... you know, our craft groups and things like this. So, we need to join together, it doesn't matter what our backgrounds are and where we come from, we need to be one voice, and that's what DEEP represents.

Rachael: **Thank you, Chris. Anybody else? Want to say anything about kind of, yeah, hopes for the future or how we can do more? What needs to happen in your community for more to happen, perhaps?**

I mean Rosie, and Nicola, I wonder what the... kind of the plans are for dementia work in MacIntyre? And Rosie, I don't know if this feels OK to ask you a direct question, but I was... I wondered if you felt differently because you've been so involved in the dementia work at MacIntyre, if that made you feel more positive or hopeful?

Rosie: I think it has, yes.

Rachael: **Yeah, I think that really came across in your presentation, Rosie, that although this is a lot for you to take on board, it's... you've got lots of hope for kind of what life will be like for you.**

Rosie: OK, it really has.

Rachael: **Thanks. Maq?**

Maq: Yeah, just quickly. I think, you know, this Zoom has been brilliant, there's no doubt about it, we've connected with people, but I think face-to-face is much more important if you're just newly diagnosed, because, you know, the first thing that happens when somebody's diagnosed, they go into a lockdown, and it... that coming out, the initial coming out is the problem and admitting the fact that you've got a condition, and then being round people that have actually gone through it, or are going through it, and that's support, initial support, face-to-face support, is more important than anything, so if there's anything that we can do on that side – I think that'll be a step forward.

Rachael: **Yeah, and perhaps more so... and just wondering, Di, in your experiences during the real lockdowns, you know the pandemic lockdowns, how that affected your... the support and services that you could run in the Chinese Wellbeing?**

Di: Well, we had to quickly adapt, and many of our elders have never... have never used Zoom, or tablets, or devices, and we spent three to six months working at it. I'm pleased to say that with help from our team who go out to sort of do people's houses, just set themselves up, we... our arts and craft group, and our singing group, are all online and we do a Love to Move group online and it's become, strangely enough, the most popular 'cause people are still afraid to come out, face-to-face, they feel with infection rates, they're just still... there's that anxiety, and so amazingly over two years, you know, the arts and crafts and singing online has become very popular.

I mean our hopes for the future are to... we've just recently been in receipt of a health and wellbeing grant by the NHS: had we not had that grant in September, we'd have been seriously looking at how we continue dementia support services, other than our home care. And in the 18 months we've got, we're hoping we prove... we prove the value of a small community-based organisation who understands its community very well. We have two trained nurses who are dementia champions, they're experienced in dementia care, and we just want to prove, [to help? 56:34], that at the end of our 18 months, we were a high-value project, and we hope that somebody will look and think, 'yes, this has to continue because it's a valuable service.' And bear in mind that the people from Black, Asian, and minority communities, the rate of dementia is higher than in the general White population and it's expected to increase substantially more over the next sort of... to 20... 2020... 2050 rather, and so yeah, we just... we feel we've got 18 months in which to really, really evaluate and prove that we... you know, that it... if you like, allowing the community, using community assets to actually raise awareness, and also we're raising awareness of good brain health, so we're actually reaching the community in a very different way in terms of raising awareness of the... of how to look after your brain, what good brain health looks like. And the biggest thing that comes out on every consultation is, "Can we please have more information that is... in an accessible format so that we can understand?" and it's very little information, and they're available in different languages, and so we're working on that.

Rachael: **Thank you, Di. I think that brings us to the end of our session. I think the... it's been the most wonderful session, thank you so much, everybody, and you've had some really positive comments in the chat box, lots of people really think that was a great session. And I guess, so I'm just thinking, there's two things that are standing out for me that I would hope we all take away which we know [unclear 58:37] nothing about us without us, but I think you've really demonstrated how wide we need to think about that.**

And then just what you were saying there, Di, about community assets: you know, you've created safe and secure groups where people can be themselves, and how fantastic is that, and that's what we hope in the whole of the DEEP network, but actually what an asset that is to each other and to communities, so kind of long may we all be putting this energy in. But also I think, you know, just to kind of ask our audience to carry some of that energy with them because actually we can't do this ourselves, all our selves.

So, thank you so much to all our speakers, to Rosie, and to Nicola, and to Chris, and to John, and to Di, and to Maq, thank you so much for being our audience, we'll say goodbye now and hope you can join us for more wonderful sessions that we have during this week. Thank you so much for coming.

[music plays]

[End of Film]