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## START AUDIO

Interviewer: This is all official now. Hello, P9.

P9: Hello.

Interviewer: Thank you for coming in to speak to me today. I appreciate that. I just wanted to talk to you a bit more about feedback and what that means to you and to your organisation and the different activities and workshops that you run. First of all, would you mind, for the recording, introducing yourself and telling me a little bit about the work that you do?

P9: My name's P9. I've got 30 years experience in off and on group-work going back to the early '80s, in fact. Whenever I've had the opportunity to undertake group-work, I've tried to do it in any work field, because I'm fascinated by the group-work dynamic and how it can impact upon people, be they significant offenders or, now, in particular, in the dementia field and whether the group-work dynamic can be used to create an artificial group when natural groups within somebody's lifetime have gone away due to bereavement, loss, separation or because of dementia and cognitive loss or physical loss.

Can we artificially create something that can benefit those people? I think the answer, from what I'm getting from the experts, the CQC, a mental health organisation in Northumberland as of yesterday, the university in Newcastle and Northumbria and, to a lesser extent, Sunderland University, is yes, it's worth pursuing and trying to find better ways to improve, which is what I'm about with yourself and the tablet.

The history is that in 2012, I spoke to the head of community care at Northumbria. She indicated, yes, that group-work was certainly a thing when I was doing my training back in the '80s and...

Interviewer: Are you able to say a bit more about what you mean, I know we've talked about it in the past and I've seen what you do but are you able to say a bit more about what group-work is and what that means?

P9: Yes. Group-work, there's so much. It's about using that group-work dynamic so bringing a group together that wouldn't naturally come together and juggling and manipulating, if you want to use that word, but juggling and directing diverse personalities within the group into a coherent unit, which will then work over time together in an effective way. That is very complicated at times. There's a simplistic way of doing it but it's pretty complicated and can be quite damaging to individuals if you don't manage it very carefully. A group, how do you define a group?

Interviewer: How long is a piece of string?

P9: Yes. I can't give you the full detail but it's something that recognises itself as an entity and so rightly individuals see themselves as being part of a group. It has a purpose. It has a function, perhaps, as well that they identify. It's identified by the group leader as a group in itself. That gives a rough guide. There are other criteria as well, which I can't think of at the moment.

Interviewer: Would you say that you're the group leader of the groups that you run?

P9: That's very interesting.

Interviewer: You said a little bit about what the purpose is. The purpose is to...

P9: The purpose, in the dementia setting, is to test it out, as I say, to see whether we can actually produce an artificial group, bring it together and create a unit that will function together and benefit everybody in terms of a sense of wellbeing, a sense of self, give people a greater sense of self, have fun, make them smile, as I've described with people today and use their humour and their creativity. It's based upon playfulness and creativity but what the university told me after the CQC assessment a month ago was that I seem to be doing is unique, certainly in this region, as far as they're aware.

While a lot of people try and do what they call group-work activities, which can be bingo, icing craft or whatever, what I'm

introducing, presumably because of my background in social work and psychology, it's bringing in an emotional element. Through the written word, the poetry, it's capturing that and then feeding it back to them and going deeper and deeper.

Building up trust, I suppose, in me and the rest of the group so they can share stuff which... Certainly, I've got examples of where people like C14 in the Laughter Box, four or five weeks in, started saying that the superficial stuff, which we had worked on in the initial groups had a much greater depth to it and because of what C15... No. It was C16. Sorry, I'm giving names \_\_\_\_ [0:05:44]. C16 had said about her relationship with her father, she felt for the first time in half a century that she could talk about her own emotions relating to her relationship with her father.

What she said in the first group that we'd taken very light-heartedly about the father coming back and falling over the bins at Christmas mortally drunk, I'll show you the poetry around it, if you want, and we all had a good laugh about it, was actually deadly serious because within three years of the marriage, a rail worker he was in North Tyneside, had become a significant drunk and destroyed the lives of everybody around. Fantastic social history. That's another thing, it's capturing social history.

One of the things that, certainly, C14 said that she appreciated, and it seemed to come across from others, the older you get the more you want your life captured. One or two people, famous people, the Churchills of this world and other people are immortalised with statues and things like that. The rest of us just disappear off the face of the earth and, if we're lucky, we have a tombstone and most of us don't have that.

Thinking off the top of my head but it seems that people in their 80s and 90s would like to have something captured and a

number have turned and said, "You've just caught something in my life there". I feel responsible because maybe I'm distorting history or whatever and maybe I'm doing something they don't want captured. When they come of their own volition and solicit the situation and say, "I'm pleased to do that", then it's job done. That's one aspect of the... Does that answer the original question?

Interviewer: It's interesting what you say, as well, the other things that the group supports and I think it comes out in what you were saying there, the idea of supporting the sense of self. Can you say a bit more about that? How does it support that? What does that mean, really?

P9: Yes. Great question. You and I have a strong sense of self. You'll have a stronger sense of self than I do as I get older and I haven't got a job now, a proper job, the job that I had, thank goodness. What it did was I knew who I was and every day I would get up and got to work and write reports and I would do stuff in courts and supervise people and that was me, one sense of me...

Interviewer: You could point to that and say..?

P9: I then became a father. I became a married man. That was a very significant point. I then became a father and that became, I did all that musical stuff with my kids and so on and so forth. When the kids move away, actually, there's a great amount and certainly C22, when our daughter moved away, the eldest,

she went through quite a difficult time. She lost a major prop of 18 years.

For myself, I've lost, at this relatively early age, I've retired so I've lost my job and that status. I've lost lots of friends and colleagues and all of those related activities. By the time you get to 80, if you're lucky enough to live that long, you've also lost a partner, a house, you're in a care home, it goes on and on. Sense of self, who the hell are you? What am I? What will I become? It's quite a significant question.

People who surround you in the care home, who the heck are they? There's a poem about this. I'll show you, actually. It's horrendous. Who are the people who push you around, who make all the decisions for you? You do not, once you get dementia, make any decisions. The doctors, the next-door neighbours, your children or maybe not. There's this incredible loss of self. If we can instil that back into them, even a small 5%, then maybe that's what the CQC and everybody are saying that seems to be being done at the moment. I'll show you the mental health email. I'll send it to you.

Interviewer: That's fascinating stuff. Actually, we could probably talk about that for a while. Unfortunately, I will need to steer the conversation onto feedback.

P9: That was just the first point.

Interviewer: That was just the first question. That was just who are you and what are doing?

P9: Sorry. Christ. It's all lies well, you know. I'm making it all up.

Interviewer: It's absolutely fascinating and I would like to talk in more depth about it another time. Obviously, this project is around feedback and new ways to do it, not just... I would like to see it go beyond feedback. It doesn't just have to be feedback. It could, potentially, we could collect information, people's stories, look at how they develop, create ideas.

It doesn't have to be feedback but we're framing it as gathering feedback first and foremost. I guess the main thing is what does that word mean to you? What does it mean to your work? I'm talking about sense of self but you, as Horizons, what does that mean to Horizons and the work that you do?

P9: I want to make sure, if I'm going to do anything in the last few years of what would appear to be a working life, I want it to be more empirically-based, much more thorough, much more appropriate and effective. That's a bit highfaluting but I might as well go for it. I have to put all my concerns away that I could get a lot of negativity and have to cope with that and just say, "Give me stuff, which is accurate". If I'm doing stuff wrong, I want to know about it and I want to eradicate that.

Likewise, if I'm doing stuff right, I want to get that and build on it. That's probably the essence of it. It's getting things right or getting things as right as I can possibly make them to benefit in a way that we've spoken about sense of self and wellbeing and stuff like that, which is good for everybody because if it benefits them, it benefits staff in care homes, it benefits me, it benefits you and everybody's happy. It's a win-win situation for all, I think.

Interviewer: Is that what you mean when you say effective?

P9: Yes. Is there another definition of that that you could..?

Interviewer: I don't know. I'm just probing you...

P9: No, it's a good question. It's a probing question.

Interviewer: When you talk about that, I feel like that with my work. I want to be effective and everything that we do in our lab. I think the word we talk about is impact. Can I have an impact? I was just digging around to see if you would say if being effective is the same as having impact?

P9: Yes. I certainly want to have the right impact and effectiveness in the right way. Is it effective for me? Well, it is, actually, because...

Interviewer: Is it having an impact on you?

P9: It certainly has an impact on me because the group I did today, I hadn't seen them for a while and I had the joy of using the tablet and seeing that work but doing the group is just fascinating. [Care Home], as you'll see, it will be cut short for



training reasons but you should see the bubble... What am I calling it? Critical mass. Does that make sense, critical mass?

Interviewer: Yes, it does.

P9: It bubbles.

Interviewer: The tipping point?

P9: Yes. It just feels like you walk into the room now, it's gone on for six months and I walk into the room and I instantly start buzzing and I'm feeding off them and, hopefully, they're feeding off me and they're feeding off each other and that's critical mass for me, if that's the right expression.

Interviewer: No, that's the way we might talk about stuff that's shared. Even gathering feedback, at what point can you gather it to a stage where there's a critical mass and then action gets taken off the back of it, if that makes sense? There are so many ways of gathering feedback now. We're doing a slightly different thing but you can fill out a form. You put these things on... I don't know how familiar you are with Twitter and Facebook.

P9: Not at all.

Interviewer: Those things, that's a huge forum of public opinion.

P9: Absolutely. I will eventually go on that but that's about six months away, I think, for reasons, which you might understand.

Interviewer: I'm obviously happy to advise you and help with that.

P9: Please do, yes. There's no hurry until I've got certain things out of the way.

Interviewer: That's the thing, it's all about impact and effectiveness. Also, you mentioned negative things there as well so you see feedback as a way of assessing that and gathering it, what would be good feedback to you? How do you gather it? I know you're at the early stage now but we have talked before about other ways of gathering but what is it? What is it as a thing?

P9: As a thing, what is feedback? I set up... You might have seen it. I got that.

Interviewer: We've got one. We've got a \_\_\_\_ [0:14:57].

P9: It's good, isn't it? It cost me £35, that. I wiped it the other day, inadvertently in my bag. I must have knocked it. You might find it for me, actually, it might have gone into some sort of...

Interviewer: I can have a look at it later.

P9: Yes. Initially, when I was being very highfaluting and talking to the universities in 2013/14, I thought I'd better get my head around a formal way of collecting information. I called it, what the devil did I call it? Analysing framework outcome, I'm sure I probably sent it to you.

Interviewer: Yes.

P9: I sent it to Matt as well. Partly because of when I was at work, I would go to head office to see the guy who was the researcher and I would say, "I'm working in this particular field now" and, even when I was younger than you, I would say, "Let's research, let's see what I'm doing, this bollocks and the same sort of thing". He would get enthusiastic and we'd talk and talk and then I'd take it to the managers and nothing would happen.

Interviewer: Were you collecting feedback or just the framework?

P9: Just the framework. I'd say, "Look, I've spoken to head office, let's set this" and they wouldn't do it. Now I'm older and wiser and I've seen what goes on and I know that management are scared stiff of stuff like that. It could go either way for them.

Interviewer: That's very interesting to me.

P9: Ask me more about it when you want to. That's no problem at all. There is an interesting take on this, which I might have wrong. Sorry, what was the question?

Interviewer: How are you collecting it right now? What do you even see as..? Is it a recorded message? Is it a form? Is it notes? What is feedback to you and how do you get it?

P9: My own feedback is I used to do it quite formally on the computer and I can show you those sorts of things but that was too cumbersome and nobody else wanted to read it. I thought they would but nobody was interested. I thought, "I don't have to type it up". I started like this. This would be one of my typical sessions and the little lighter notes you can see there are little notes I made afterwards about whether an exercise seemed good or not. I'm able to refer back to that very simply.

Interviewer: So you're generating the feedback?

P9: I generate that feedback on my own work that way.

Interviewer: To yourself?

P9: I've given the care home managers and the staff, I've also given them training in this as well at [Care Home], the

analysing framework outcomes. I put together something, which the staff could ask residents and the staff could ask themselves. Questions such as, "Have you seen any deterioration? Is there anything wrong? Could things be improved for staff? The negative stuff, have you heard anything said or witnessed anything in the group that you would say should be changed or altered? The good things, has it had an impact?

Is the feedback to indicate..? For example, one of the big questions for me early on, does it have an impact beyond the duration of the group? Does it go into the next half hour, over lunchtime, into the evening? Do they remember it even? It's amazing the shocks I've got when I've got that little tape recorder out and sat down with, what is she called? June at North Tyneside and said, "Can you tell us about the session you've just been involved in?" I'd directed quite a bit of stuff through her, the drama and she couldn't remember anything about it 15 minutes on.

It's amazing to me. In the group she seemed quite good. At least we're giving her something in the moment and then it's all gone. What we know... Does it last beyond that? You'll know about my letter I got from a carer on the 23<sup>rd</sup> December, the Christmas present I told you about?

Interviewer: Yes.

P9: That was the first indication that this is lasting way beyond and having an impact way beyond. That was good. Since then the staff up at [Care Home], you can talk to them if you get time, and I can't think of any other names, C17, I think, have come to me, unsolicited again, and said, "It's amazing, they get out

of bed earlier, they do this, they do that because they know you're coming".

Now they've got something going on. Put them in the group and say, "Do you remember what we did a two days ago or a week ago?" No, they can't remember it at all. What happens? We know with the onset of dementia, the factual brain goes, you'll know this, but the creative and emotional side remains so what they know, they now associate Horizons with a good emotional feeling so they will pursue that.

Absolutely brilliant, two weeks ago and it happened the week before, I've been going up to the place where June is in North Tyneside and staff have great problems getting them along because they couldn't remember what it was, "What's Horizons? Why are we going to this room? Why do we have to go down that corridor? We want to sit here. So-and-so's asleep, don't wake her up". All these problems and then two months in, when the experts would say that you shouldn't have a group that runs beyond eight to ten weeks because that's the normal duration of a group.

We're two months in there and I arrive early and there are two ladies in their 90s on Zimmer frames looking for me, "Where are you? Where's the group?" It was a fantastic moment, a critical mass sort of thing. This is working. I now know this is working. Suddenly, they started remembering. It's worked at [Care Home] consistently now for months and now it's working there. Don't kill a group off after ten weeks. Keep it going and just build.

Interviewer:

Yes. You want to collect feedback for all these reasons that you've just said there and that's feedback from everyone, it's fantastic. It's staff, it's family, and it's from the group itself.

P9: Yes. It's difficult to get that to happen in care homes. They have rules of their own and they don't like people asking too many questions because they know they get hammered from families. They've never given me the phone numbers at [Care Home].

Interviewer: For the families?

P9: I want to ring the families. I've met some of them and they're fantastic but, for some reason, the phone numbers have never come my way so I can't contact them directly. The form filling, because it's the staff in a care home with a management system, the pressures on them, which I entirely...

Interviewer: These are the forms you've produced?

P9: Yes. They don't often get filled in and it's quite superficial and because of the educational limitations of some of the staff for obvious reasons is, sadly, as well. They have, obviously, like me, I never read things, and they wouldn't have read them. There's sufficient there to be a positive, a slightly biased positive, a bit like me...

Interviewer: Feedback is like that.

P9: It's very subjective, isn't it?

Interviewer: There's a whole interesting thing there as well. Is that just the staff then? What about the people you're working with dementia? Is there no chance..?

P9: Now there is.

Interviewer: Now there is but you wouldn't give them forms or..?

P9: They never fill them in.

Interviewer: Have you tried that?

P9: Yes. I've asked them. All sorts of things I've asked them to do. I asked the staff to do it with them when I've gone. If I ask them, they always say, "Absolutely fantastic, 100%" because I've taken them from, "What's this group?" to two and a half hours later they're going through the ceiling. If I've done my job right, they're absolutely critical mass bubble, bubble, bubble. They're going to say anything. It's a waste of time me asking, really. I know what I'm going to get. I did, I forget which one it was, a 0 out of 5 rate and it was all 5, 5, 5.

Interviewer: If you're recording people's voices...

P9: That's important. That's the difference.



Interviewer: It might not just be, “How good was it?” or whatever your 1 to 5 scales are capturing. If it’s a more...

P9: Nuanced?

Interviewer: Yes, exactly. Good word. A more nuanced form of feedback that’s giving people a chance to express what they want, that’s probably better to get in the moment at that time with your critical mass thing.

P9: What would be good if you could, from listening to these things, when you do, if you could tell me whether my questions are leading. They might well be. I hadn’t thought about that until now, really, but particularly today, when I wasn’t discussing my boots or my bald patch, I was talking about the individual exercises. If you could tell me... I have to be as neutral as possible.

Interviewer: That’s difficult in a \_\_\_\_[0:23:54].

P9: Very. Especially if they can't remember the exercises so I have to explain them and I get dead excited about them. At least we're getting something, which isn't happening and it doesn't normally happen in other settings because people want to hide these things away.

Interviewer: It's really interesting. You are getting feedback here and there.

P9: Yes.

Interviewer: Is there any way you can respond to that? What can you do with it? Other than, obviously, it's giving you an idea if it's being effective but do you ever use that to develop what you're doing or does it give you new ideas? Has it, in the past, made you go, "I need to stop doing this" and doing something else just, for example, developing the stuff that you're doing?

P9: Absolutely. If I don't do that, I'm wasting my time. I hope I'm doing it effectively but I'd rather have the likes of yourself or the experts at the university, the academics looking at it and listening to that and saying...

Interviewer: Analysing it and seeing...

P9: Yes. Better still, and the other bit of feedback that I've neglected to mention within this particular question is, of course, the CQC and university and the mental health...

Interviewer: The feedback from them...

P9: The feedback from them has been very interesting, of course, I've mentioned it before but I suppose I've invited them in and,

again, that doesn't happen. The CQC just turn up. I was lucky that they found that bit of poetry, read it and started to cry.

Interviewer: That was just chance, really.

P9: That was chance. They asked to see me and then, knowing they're going to talk to me, they're going to sit in the group. That's proper feedback. Don't just talk to me because I'll lie to you and tell you it's brilliant and tell you whatever. Come and sit in and you must sit in and stay for the whole duration. The CQC agreed to do that so they got two and a quarter hours. They questioned me, as I probably mentioned, on the theoretical basis behind it and then they gave the thumbs up and said they want to promote it. That's great.

Last week, I invited in the mental health people from Northumberland and they agreed to send members of staff every week for six weeks. I had to say, "Hang on a minute, I've got Interviewer \_\_\_\_ [0:26:17], that's enough". What that's doing... We've got the CQC, we've got the university, I invited them up and they eventually came and gave the thumbs up. In terms of feedback, I'm getting the most incredibly intensive supervision from everybody around.

The only proviso, and I got a letter yesterday from the mental health authorities in Northumberland saying, again, I'll send it to you, a big thumbs up, very interested. They want to send every week for six weeks. I said, "No, that's disrupting the group completely".

Interviewer: Am I going to be disrupting the group?

P9: Your presence will but I can live with that. It'll be great because you'll bring so much more because you're going to bring that...

Interviewer: Is this going to disrupt it?

P9: Yes, but I can live with that as well and work around that. It will take time but it will certainly shift the emphasis to an extent that it doesn't really matter because we're six months in so I know what's going on in that group.

Interviewer: We need to be careful about that anyway. If it's going to be disruptive...

P9: Don't worry. It's delightful. It's great. The need for the feedback overrides...

Interviewer: I want to see the feedback from your participants and see what they say. It must be hard for you because you're working with them, you're talking about having the critical mass and they just go, "We loved it, we loved it, we loved it" but are there examples of feedback you've had from the people in the group...

P9: Which is..?

Interviewer: You've anticipated my question. I wasn't really going to say that right now but are there examples where you got..? If you can think of an example..? I'm also very interested in negative feedback because, and you said that earlier when we talked about your other work, there are people who are afraid of feedback. The idea behind this is to make it widely available and no voices get excluded. Has there been negative feedback that you've had?

P9: No.

Interviewer: They love it, don't they?

P9: It's frustrating. They love it but it's also frustrating because it's not developing it. Maybe, as the three professors at the university in January said, "We know that you've arrived at a critical mass". They didn't say that because they don't use big words like that. They're not intelligent like me. They're just professors. It seems that they're happy, although, at that stage they hadn't actually witnessed it but now they've confirmed it, that I'm doing something, which isn't being done. It's unique in the area because it hasn't got that emotional...

I don't know whether I mentioned that. Activities, bingo, but what I'm doing is group-work with the emotional content. I want to make that clear. It's that emotional content, which is the important thing. We go high, happy, \_\_\_\_ [0:29:01], run around or equivalent of because, obviously, we don't. We get all energised through icebreakers, many of which you'll recognise, and then we bring them down. It's a flow like that, I suppose, over the duration of the group. For two and a half

hours, you get the opportunity to do that. You'll see some tears. We always get tears from various people.

Interviewer: Are people leaving the group or not? That quite a long time, isn't it?

P9: It's a hell of a long time.

Interviewer: For me, I'm knackered.

P9: You're 98 and you're 97, C17 and C18, respectively, and when we say we're going to reduce the groups because the management are insisting two hours long, they say, "We want longer not shorter".

Interviewer: That's feedback, isn't it?

P9: That's fantastic feedback. I love that.

Interviewer: That's good positive feedback from the people that you're supporting and helping and trying to engage with. That's feedback. Unanimously, they just tell you that they love it, you've never had anyone..? You said you had tears but I guess that's because you're working in an emotional space and you're trying to get there.

P9: Yes. Emotional space, I like that.

Interviewer: I'm meant to take notes, not you.

P9: Emotional space, I like that. That's a good way of putting it because I am.

Interviewer: That's what you mean by tears, you don't mean tears of..?

P9: Frustration or something? How's this? C19, up at [Care Home], we put her in the group. I don't know anything about their backgrounds more than what's presenting and the staff sometimes tell me a little bit. I don't want to know. I work with what I've got in front of me unless there are risks or anything like that. C19, a Liverpudlian lass who met Paul McCartney, great little stories but stuck on those stories and doesn't go anywhere else.

I put her in to see, the staff asked me to, and a couple of sessions went well. I can show you this report, which I wrote for the mental health services, the same people who have been on my door recently. She does two and half hours and, in the last three minutes, she explodes in anger and flies out the door with me in the way. It was amazing. She does the same the next week. I think, "Christ, what have I done?"

Interviewer: At the end?

P9: The last three minutes. What's going on? I asked the staff and they said , "She does that and she does it regularly", which is good for my sense of self-preservation. "She does it regularly, she's always fighting with other people, it's amazing that you've kept her in the group so long". The mistake that I made was, because I knew she was coming in and she had problems, I built the group around her.

Everything for, perhaps, a third of the session was directed through her all the time. It was about her family life in Liverpool. It was about her father being torpedoed and getting medals off the king. We did lots of exercises around that. I do think, what I call warm fluffies as opposed to warm fuzzies, which you might know about. What's his name? David...

Interviewer: Is it a drama thing?

P9: No. The way I use it... Ask me about the fuzzies sometime.

Interviewer: The warm fuzzies?

P9: Ask me about the fuzzies sometime but the warm fluffies, as I call them mistakenly, is the very last thing I do in a group is I get everybody to praise everybody else as best they can. Psychologically, it's the biggest buzz. You can imagine if everybody in here came in and told you how wonderful you are. It's like a leaving do.

It means nothing but if you are 94 and you've got arthritis so you can't raise your arm but you manage, like everybody else can do that but you manage to do that yourself and say,



“Okay, that’s a hand sign, we’re looking for hand signs” and, at the end, somebody picks you out and says, “I thought it was absolutely brilliant the way you did that”.

That’s a psychological lift way beyond what we can conceive. She did so little but so much so to have that done to everybody by everybody about all of their little inputs. It raises the critical mass so that they \_\_\_\_[0:33:38]. It’s absolutely the wrong time for me to ask them whether they thought the group was good but I always do that at the end with each group. Sorry. What was the context?

Interviewer: I can't remember her name, the Liverpudlian lady, rushing out?

P9: Yes. Thank you.

Interviewer: You’ve restructured what you’re doing based on a kind of a feedback?

P9: Feedback from staff, yes.

Interviewer: From her behaviour...

P9: The reason she went out?

Interviewer: I suppose you made the connection by speaking to the staff so you know that she does do that normally. It's not really a reflection...

P9: What's interesting, I had made a mistake. I think I can defend myself on it, not defend but I think I understand what happened. That was why I wrote a report for the home and they sent it to the mental health people because I wanted it to be known what had happened and, if any, feedback that I would get from the mental health organisation.

In fact, I'll send you a copy of the email I sent yesterday. Interviewer, mental health email, send. In terms of feedback, I wrote an email to mental health saying thank you for the positive feedback and then later, about midnight, I then wrote another one saying, "If you've got criticisms, let me know". Again, it's looking for feedback.

The mistake I made here was, when I did the warm fluffies, I went round and I kept her till last because I wanted her to get the biggest praise and make it really significant. The biggest round of applause she's ever had because she'd contributed to some really important things and I wanted to boost her and help her. I worked around the room and she thought, she was sitting there thinking...

Interviewer: She thought she was being left out?

P9: Part of the problem is she's paranoid. By the time we got round there, what had happened was that critical mass meant that Enid, here, had gone off at a tangent into some vocal flurries, which I'd been trying to develop over the weeks and,

suddenly, she was doing some \_\_\_\_ [0:35:51], “Everybody just do that for a second. Great. Fantastic”. My mistake was Enid had eyesight problems. She’s gone completely blind in this eye, it’s horrific, over the last few months.

At the time she was going down, I didn’t know. She had hearing difficulties, which I did know about but I didn’t realise that she would respond so negatively to the fact that we were saying, “Can everybody do that?” She said, “What? What do you want me to do?” I moved from here to sit next to her and explain. I thought if I just explained it gently to her, she’d get it.

She just couldn’t get it and the frustration became so much. Just before it got round to her and the warm fluffies hit her and she went, “Yay, I’m wonderful”, she bolted out the room and went storming... It’s so sad. Yes, it’s interesting. I won’t show you that report, by the way, it’s confidential.

Interviewer: It’s fine. Don’t worry about that. I like to think that was feedback she was giving you.

P9: It was great. It was bad feedback. The other thing is that five minutes later she had forgotten that whole incident. I went and spoke to her and I said, “Are you okay?” She said, “Of course, I am. What group? What happened?” It’s terribly sad.

Interviewer: Maybe because you’re still developing what you’re doing, you are very open and you encourage negative feedback and you want to hear about that.

P9: Ironically, I don’t get much.

Interviewer: You can't give me an example. Can you give me an example of good feedback, maybe not from the CQC but from your participants?

P9: I've got loads written down, bits and pieces. You give up asking in the end because you know you're going to get it.

Interviewer: It's not helpful but...

P9: It's great. I get eye contact. At the end of every session, I always do the warm fluffies and Laura always says, "It's you, you bring the ideas, you bring your personality". It happened again today. That's feedback, isn't it? I don't bother writing that down.

Interviewer: You probably do with the important things. I speak to a lot of charities who are under pressure to gather feedback about what they do but it's all in here for so many people, they work with individuals. At some point, not all of it, obviously, bits of it are going to come out, "So-and-so said this" but it's not on tape or even on a form. It may just be that they remembered that.

P9: I half transcribed but I might have lost it on here, you might be able to find it for me.

Interviewer: I'll certainly have a look.

P9: Laura, I interviewed her on that. June, I did, but she couldn't remember 15 minutes later. That was another reason why I... What we could do is you could say to me, "I'm going to give you two weeks, every group you do, you've got to note down all the positive feedback and it's got to be unsolicited". I'll just give you a couple of sheets of that, what people just say without me saying...

Interviewer: We could do that. I'm happy to do that.

P9: That would be interesting, wouldn't it? You decide which period you want it to be over, not too onerous. You'd have to buy me...

Interviewer: I don't want you to change what you do for me.

P9: No.

Interviewer: If it's helpful for you.

P9: Yes. That's a good idea.

Interviewer: We could certainly do that. Hopefully, we'll be using this at the same time. That's great. It's so nice that you're getting the

positive feedback. Presumably, some people would even forget that quite soon after as well.

P9: Probably. You'll see what the memory state of people is when you come on Thursday.

Interviewer: Although it might seem useless to you because it's unanimously good, has it ever prompted you to change something in what you do? Has it given you ideas?

P9: Today, going through this, you've got it recorded there actually, with C21. I went through the four icebreakers. I then went back over it with him and said, "Which one would you prioritised?" He'd selected one, which he said was particularly good or hinted at that so I went back to it but he said, "No, it was all very bland or they were all good". Again, they've got cognitive losses so they're not able to analyse...

Interviewer: Critically?

P9: No. I don't think so and they wouldn't necessarily want to so it's a complex equation. Certainly, yes, I would have loved C21 to have said, "That exercise, I've done it too many times or somebody couldn't..." Today, my criticism of it but I would love it to come from them, was that C20 didn't get it. Now, C20, I think in two months has gone really downhill. There were some quite worrying things, which I'll feedback to the manager, not the one that I spoke to you about before but the good manager, tomorrow and say that I was a little bit concerned.

Interviewer: There is a tension there around if everyone says everything's great, how can you, actually, turn that into action?

P9: Yes. It's a problem.

Interviewer: It's a difficulty, there.

P9: Yes. It's a huge one, isn't it? You just don't see it.

Interviewer: I think you're doing what you can to make sure that you're reflecting on it properly.

P9: Absolutely. Do advise me if you think of other\_\_\_\_[0:41:36].

Interviewer: I will.

P9: Thank you.

Interviewer: We talked a little bit about encouraging negative feedback, which you're not really getting. If you did get negative feedback, can you think about how you would act on it?

P9: I just wouldn't talk to that person ever again. You're in my group, \_\_\_\_.

Interviewer: They get fired from the group.

P9: They get fired from the group.

Interviewer: You do encourage it so would it mean you completely stop doing something?

P9: C16, you'll meet her. She's wonderful. She's wheelchair bound. She's absolutely great. She's a lady of few words but, when she says something, she's got gravitas. She's hilarious. 'Tipperary'. Did I tell you about this?

Interviewer: The song?

P9: The song 'Tipperary'. Everyone knows it. I know it now and if ever you want to break a mood, shift the atmosphere...

Interviewer: 'Tipperary'?

P9: Yes. You just do the rhythm, you do, "One, two, three, one, two, three, one, two, three. Now, let's do one, two, three, four, one, two, three, four, can anybody think of a song? It's a long way to Tipperary".



That's good. Most people can join in but then some people will lead and some people will be mumbling away because they don't actually know the song or they don't feel confident singing. What you want, as it is here, is to be as dramatic as possible. My poetry, when I feed it back, I will act it out if I can, not as well as you'd do but I'll do a little bit seriously and get a laugh out of it.

With 'Tipperary' I discovered, to my utter amazement, this is genius, this, that if you put boom-booms in and if you start the conversation by saying, "Look, you've all sung that but when I was conducting at the Sage last night doing 'Tipperary', there was something more. What's missing?" You get them all going, "What's missing?" You go, "The boom-booms are missing". What? The boom-booms are missing, what do you mean? "It's a long way to Tipperary, it's a long way to go, boom-boom".

When you reach that stage, you divide them up and you've got your lead singers and you've got your backing singers. The backing singers and I go, "Boom-boom". They love it because it's physical and it's loud and it's dramatic and they can do it and they only have to say, "Boom-boom". Doing that, I tried it out a couple of times and it seemed to work. I was working on 'Sing a song of sixpence, a pocketful of rye'. You have breaks and you act out the, "Oh". We'll do it tomorrow. I think it's hilarious. They probably don't. "Tweet, tweet, tweet, all the blackbirds sing". Anyway...

Interviewer: I know 'Blackbird' by The Beatles.

P9: "Blackbirds singing in the dead of night". We should do the same thing and do that one.

Interviewer: We'll do that.

P9: I digress. So we do it. C16 was in the SAS, very proud of herself, three stripes. Three stripes, she'll tell you a story about that and cornflakes but we'll leave that until Thursday. She said, "You can't sing that" with her gravitas. "Why not?" She said, "It's disrespectful to the soldiers, they would not have sung it that way in the First World War or the Second World War". I went, "You're absolutely right, C16".

I've never done it with her group. What I'm doing is sacrificing half of the rest of the group because they don't get as involved and they can't because I'm taking the mickey out of something, which is sacred to C16. That's a really good point. That was a great learning curve for me, that one.

Interviewer: That was negative.

P9: That was negative, yes.

Interviewer: You're happy to respond, you can almost respond to it within a session.

P9: Yes. I prioritise that song in other settings.

Interviewer: You still use it elsewhere?

P9: I'll use it elsewhere. Yes.

Interviewer: That is interesting. You can actually use the feedback you're getting to tailor to specific groups as well. You must be keeping track of that?

P9: I'm multi-tasking, aren't I?

Interviewer: You're multi-tasking.

P9: Hugely.

Interviewer: The action that you're taking is, essentially, responding and...

P9: Hopefully, yes.

Interviewer: Cool. That's the kind of thing that may get captured here as well.

P9: That would be great.

Interviewer: If you could see that there then you've got it on record and things like that.

P9: In fact, when I interview C16 with her permission, I'll raise that with her so that you can have a record of it for clarification. Very often they forget. There is an example today with C21 where I wanted this recorded because I'd written it down and I spoke about it at the conference last November or December at Northumbria in one of the workshops and it caused a bit of a ripple.

It was this thing about the Alzheimer's Society are very much into their Memory Day and reminiscence and there's a movement among the creative people around, like Equal Arts, to say, one of their directors said, "This is nonsense, they just produce a lovely glossy thing, Memory Day and this is what we do, we do memories, we get cups from the 1950s and we talk about the war". I do that as well but what they taught me is that you go beyond that you bring it into the present.

I was at this conference and this workshop and had it written in front of me from the day before, C21, at Laughter Box, had said, "My wife, C22, tells me that I live in the past". He said, "I can't help that because my past was there before". I think it's a great quote. I don't understand it yet but it's a great quote. "Coming to the Laughter Box makes me feel in the present". It's great.

Interviewer: You want that recorded.

P9: Yes. I got him to do that but when I said, "C21", I didn't want to put words in his mouth so I stopped half way through, I said, "C21, some months ago you said... What did you put in the end about being in this space and being in the present?" I

mentioned about his wife. He couldn't remember. I had to say, then, "Is this what you said? What did you mean by it?" I'll return to it. It is difficult when people have no memory.

Interviewer: It's a really challenging area as well.

P9: Absolutely fascinating.

Interviewer: Hopefully we get some recordings that will start building that up so, I don't know, maybe play it back to the people that left the recordings at some point.

P9: We could do.

Interviewer: Is that something you would do?

P9: I would be happy to do that with them. That's amazing. So they have a memory of it.

Interviewer: Maybe it could become... I should stick to the feedback for now but when we think about stuff that could go... It's quite simple what it does, it's meant to be feedback about activities but if, because it is nuanced feedback, it might have applications in other things.

P9: Let's think about that. How could we help them through listening to their own voice back? One of the whole intentions of the thing is to give them a voice as well. That literally is giving them a voice, isn't it? Yes.

Interviewer: Could you say more about what you mean by that? You don't have to.

P9: Giving them a voice?

Interviewer: What does that mean to you?

P9: What does that mean to me?

Interviewer: Sorry, if these seem like annoying niggling questions.

P9: No, not at all. It's a major one. It's part of when people say, like you said at the start, "What's this group-work about?" It's many different layers and one of the layers is about giving a voice. It's about, again, as dementia sets in, as separation and confidence levels goes down and you become isolated, you lose any power in society or even any power in your family or even any power over your own life.

If we can get people communicating dynamically in a group, which they wouldn't have done before because you know the standard thing where they sit in chairs reading newspapers and watching children's TV, they have no voice. If they do,

they're not listened to because the workers are not highly educated, not highly skilled. Some of them are but the majority, I suppose we know in the care sector, don't have a privilege so they're feeding them but they're not engaging.

I'll tell you about that about feedback as well. They say something and what tends to happen, and I'm sure I've been guilty of this, you're rushing off somewhere else or I'm about to start the group and somebody says something quite profound. "Oh dear, don't worry, you're just going through one of your stages, you're just feeling bad, you got out of the wrong side of the bed". A classic and yet there's something there.

They're not being listened to. There's no reflective listening going on. There's no open-ended questioning going on or no real counselling going on and the person scoots off.

Eventually, you close down. Can the group be used to give them a voice? Is it a political voice? Probably not. I'd love to but I can't go into politics with this. That would be unfair partly because Laura, who you'll meet, who's my big star in the group. She's still got a little bit there and she's dead supportive. You'll love her. She's great. A really nice woman. She is of one particular persuasion...

Interviewer: Politically?

P9: Politically, yes, because she was a minister's daughter. She was brought up in a nice environment and quite a privileged life and I could see a million ways I could help her understand in a different way and that could be quite good intellectually for her to think... Then I thought, no, it's not fair. You leave her where she is and go with her reality. Interestingly, having sown

a seed, last week, about a month or so afterwards, I think the group I might have been talking about politics.

If that's true, because what you want is for people to come out the group and interact as well with staff in different ways, which is why I've been doing basic staff training, not to get them to run groups but to understand what goes on in the group and putting it all together. She was saying negative things about the Tories, which I thought was great. Then I think, "Don't go there, don't go there, I want to say..."

Interviewer: You didn't even... You brought up the topic but you didn't happen to say..?

P9: There's a poem somewhere where I've got a line in about the government and I apologised for that but it's there.

Interviewer: That's interesting.

P9: It's all good fun.

Interviewer: It's this idea of giving a voice that I'm interested in, what feedback, what it should do. You're talking about giving people a voice in the group setting, who is the audience for the voice that they're being given? Is it just the other members of the group?



P9: That's number one. If people are listening to you, your sense of self and your confidence levels go up so if it doesn't go anywhere out the room... There should be a confidentiality thing but that's difficult when people don't understand basic things because of their illness. If I come across anything that concerns me, I would feed it back and I have done that. That's difficult.

There hasn't been anything absolutely... There has been one thing in terms of feedback but that was a member of staff. It's giving them a voice in terms of reminiscing about events that are important to them but not just reminiscing, we're capturing it and putting it into poetic form and getting that published. It's that thing of, "My life is being immortalised here and I'm about to die but, at least, someone will have a poem that my grandchildren can go to". There's all of that going on.

It's giving them a voice, not politically, a voice about their life. It's giving them a voice to their family and speaking to the grandchildren. A grandchild comes along and sees Granny in the care home and will go off and play in the corner, I would imagine, on one of those things because you can't communicate with Granny because she's mad, because Daddy says she's mad. Do you know what I mean?

Interviewer: It's communication?

P9: It's communication to family, "Hang on, Granny's done this poem with this strange bloke and the rest of the group and it's about certain events and she's contributed to this, that's my Granny". That's important. It's important for communication, for understanding, for greater understanding of the dementia field

in terms of education and the schools project I was talking about.

Interviewer: You talked to Matt about that. That's what I was thinking about as well. It might just be communicating knowledge about what it is. You're doing staff training with people so that they can put it in perspective. All the stuff you explained to me earlier, the sense of the self, the things that get taken away. I don't think people are thinking about all that when they see an individual with dementia, they're just at work and they want them to have food.

P9: Absolutely. Why should they? They have tasks, which I couldn't do, the physically tasks, that are very important, arguably more important than mine because they keep people alive. I'm not doing that but we do...

Interviewer: I think both are...

P9: Both. One would hope so, yes.

Interviewer: The family stuff sounds really good, actually. There's communicating with staff, even wider beyond that, if you had feedback, you might not need to call it feedback, I guess we could call it their voices. Would it go beyond that to the wider institutions that you've talked about, like the CQC? I guess it's something I don't know that much about. Who are the authorities that sit over..?

P9: Do you mean if it was a negative thing about the home or something like that?

Interviewer: It doesn't need to be negative. Even simpler than that, for you to communicate what you're doing more clearly, could you use feedback for that? I don't know. Do you apply for funding and things?

P9: I have. I'm waiting for the university to, hopefully, come up with something, which is what they said. Stupidly, I was sitting back and relying upon them. I need to contact them.

Interviewer: Is there not other funding bodies that you would..?

P9: If you knew of any, I would go for them. I don't know if you go for one... The uni are looking for it and, presumably, they know what they're doing. I don't know about funding.

Interviewer: You don't have to get involved in funding applications?

P9: I need to.

Interviewer: Yes, you will but you don't know much about it at the moment?

P9: It's a very long process and very hit and miss but I did go to the Arts Council and I filled in their little form and they were supposed to get back to me in five days and they haven't. It's now been about a month so I'm a little bit concerned about that. Tomorrow I'll be ringing them. That's one of the jobs I've got to do.

Interviewer: Are the Arts Council here in Newcastle?

P9: It used to be. I would have gone and knocked on their door but they moved to Manchester.

Interviewer: Did they?

P9: Yes. They've got this new thing.

Interviewer: Do they not have an office here?

P9: They used to behind the station.

Interviewer: That's not there anymore?

P9: I don't think so, no. It's Manchester. They might have something here, a satellite thing. I raised money through them for \_\_\_\_ [0:57:21] back in the day in 2005.

Interviewer: I guess I'm just thinking around can feedback play a role in that process because if you're applying for funding, I guess, you have to evidence what to do. I don't know. It's something that you're doing in the future?

P9: Yes. I think I'll be proactive tomorrow.

Interviewer: That's nearly been an hour.

P9: Yes. Don't worry but I'm worried about your time now. This is fascinating because it's making me realise that it's very difficult to talk to anybody about all this who doesn't know what we're talking about. We have a mutual interest so we understand each other so it's really useful for me. You're making me realise little bits and pieces.

Interviewer: Brilliant. I'm super glad if it's useful for you.

P9: Will you be transcribing this at some stage?

Interviewer: I won't, personally, but I'll send it to someone who transcribes it.

P9: Really? Could I have a copy of that?

Interviewer: I think so.

P9: That would be brilliant. Go on.

Interviewer: I'm happy for you to have it. I don't see why you can't have it.

P9: It's me. You can't give it to me? It's you.

Interviewer: I know. It's a stupid thing to say. Yes.

P9: You can't have a chocolate \_\_\_\_ [0:58:39].

Interviewer: Yes, you can.

P9: Because I think the uni will be asking me to do lots of writing for them. I hope they do now. I've been writing since I spoke to the first person, the head of Northumbria in 2011, and I've got bits of paper everywhere and I've been putting it together. This process I'm going through with you now is making it much clearer.

Interviewer: I'm happy to talk to you about it any time you like.

P9: You'll be bored sick.

Interviewer: No.

P9: You just want the chocolates, don't you?

Interviewer: Yes. You brought chocolates.

P9: I brought chocolates. I could be anybody, couldn't I?

Interviewer: This will all get transcribed and you know.

P9: \_\_\_\_[0:59:11] stick around, 20 years \_\_\_\_.

Interviewer: Would you need that soon?

P9: No. The sooner the better.

Interviewer: When?

P9: The sooner the better.

P9: I thought you said Sunday. "No, Sunday. Tomorrow". Just because, basically, I'm interviewing... That's what I do so I'll

be doing interviews this week and next week and then I'll send them off for transcription and then I'm going to California for two weeks.

P9: You're going to California?

Interviewer: I didn't tell you that.

P9: Can I come with you?

Interviewer: Yes. I'll need to check. I'm going to California a week on Friday. Did I not tell you about that?

P9: No.

Interviewer: I'll tell you about it later.

P9: \_\_\_\_[0:59:50].

Interviewer: I love feedback. It might not be until after then, that's the only thing.

P9: That's brilliant.



Interviewer: Anyway... I think we, actually, got on to an interesting space when we were talking about feedback. Talking about engaging others outside of the group, the families, maybe with staff members and things. Can you use the feedback that you get to engage a wider community of people? I think that's what I was getting to.

P9: Yes. If people want it, yes. If people want that, if they want anything in this, I'm more than happy for that. It needs to be out there because the hope is I've got maybe two years before I collapse and stop working or whatever. Say if I did, let's say I get dementia, I might already, I would want all this, ideally, to be passed on to some other people who are younger and fitter and more intelligent than me to spread it out and to take into account the negative side, which is the risk side of groups and make sure that in care homes, they're training people that have not been trained up to do groups, which are dangerous.

That worries me. The care homes are trying to get this... They want the kudos, through me, of bringing me in and seeing what I do and then nicking all the ideas because they think they can do it. Some of them might be able to but then they put people in groups and it just wouldn't work at all. That sounds like I'm being precious, however, I've seen it up at [Care Home] House. I won't mention too much detail but I might have already.

A member of staff, who's now gone, because she clearly could not... She didn't have the emotional self-control, the empathy to be running a group. She had a very strong position in that place but she made a few mistakes, which I reported and then she made a major mistake, not in my presence, and then she got sacked. Thank God, I was on the right lines and sussed

her out. That's the care home making a mistake putting somebody into a job they shouldn't be doing.

At other care homes, they're saying, "We'll take you on, we'd love to, once every month". No. Critical mass, you know? How do they remember a month for a start? It takes you two months to get them remembering, in any case, and getting the emotional buzz. They don't want that. They want to be on the cutting edge, as the manager said the other day, "We'll book you for three weeks time", she said. Excuse me? It's difficult but I can understand.

Interviewer: That's almost creating a body of evidence for what you've done, what's working and communicating that to other people as well.

P9: \_\_\_\_[1:02:45].

Interviewer: That's what I was asking you about. Finally...

P9: Finally?

Interviewer: Well, not really finally. I don't know. Are there ways that this might help you? I'm thinking of our participants. Maybe I'm not, actually, maybe I'm thinking of everyone but communication should be two-way, right? Yes, you want to spread the word about what you're doing but there are loops in there that should become a dialogue, shouldn't it?

P9: Yes.

Interviewer: Yes. Maybe this is quite abstract but can you say the ways that the feedback that you collect would then support a dialogue around how you're doing what you're doing, how you might change what you're doing, how you might develop it?

P9: Absolutely. That's the whole idea. That's the bottom line.

Interviewer: Practically, how would you see that happening? Is it just C16 says something to you, you say something to her family, does anything go back the other way?

P9: It's difficult getting in touch with the families. Having been a carer...

Interviewer: Maybe the families is the wrong one to pick on but just the flows of where they feedback goes.

P9: It can go anywhere it wants.

Interviewer: It doesn't even need to be beyond the group, it could be in the group.

P9: There's no restriction as long as it's safe and people are in agreement to have it shared and it serves the purpose of

helping both the family and staff and, obviously, the residents. I don't have any restrictions on that, maybe I should. There's, obviously, this element of confidentiality but if it's a well-known family story that we're working on, it can be developed. Does that answer the question?

Interviewer: Excellent. Yes.

P9: Good.

Interviewer: I should have said finally now, because that is over an hour, is there anything that you would like to add about feedback generally or thoughts that you've had while we've been talking or avenues that we didn't go down that we could have gone down?

P9: You've given me a lot of food for thought so do you want a meal? Did you see that cool link there? It wasn't very good, actually. No, I don't think so. I'll go away and think more and email you if I come up with anything. When we're in California. Are we taking a few mates as well? The university are paying for it.

Interviewer: Take an entourage.

P9: What about stretch limos? I fancy a stretch limo.

Interviewer: That's how I travel everywhere.

P9: Feedback would be great with stretch limo. A few guys, a few lasses, that would be great.

Interviewer: That's great. P9, that's been fantastic. I'm going to stop the recording now. Thank you so much.

END AUDIO

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