**WORK PACKAGE 1 – SESSION 7**

**Individual interview with stakeholder P11**

**21st April 2021**

Audio File Name: S9 – IDoService – Individual interview- Other stakeholders – 21 april

Duration: 00:31:17

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

**R2: = Researcher (Interviewer in bold)**

P11: = Stakeholder

**R2: Question before we begin.**

P11: Sorry. One moment, [R2]. [non-related talk]. Sorry about that, [R2].

**R2: No problem. Do you maybe have some questions?**

P11: No, I have no questions.

**R2: Okay, great.**

P11: I'll let you do the questions, and I'll do the answers.

**R2: Okay. That's perfect. Yeah, again as of last time I have to ask you, if you can just confirm you fully consent to be part of the study.**

P11: Yes.

**R2: Perfect. My first question is last time you said at (unclear 00:00:56) you are more in contact with people with moderate to severe dementia stages. Do you try to offer different kinds of activities or at least I will say attract people with early symptoms?**

P11: From my perspective, I'm obviously very new to this role. I only started in January, I only returned back to the UK and because of COVID all activities were cancelled, so I don't know what it was like before COVID. We are starting new groups up now. The thing though, anyone that we have in our system are those that are referred to us through from the Memory Service. I think a lot of people why we get people that are sort of, moderate or advanced is because they wait quite late before they go to see their GP, and before they have that assessment. There are very few people that I've spoken to that have early mild onset, and they generally don't want to take part in a dementia activity because they're still able to take part in most of the things that they would have been able to do anyway, so they don't particularly need or want a dementia branded group as such.

**R2: Are they looking for some kind of support for other things or are they more saying, okay I'm good for the moment and if I need you, I will come back later when I will need...**

P11: Yeah. We were trying to set up a walking group that's going to be open to anyone, and we're hoping that more active things people will join in rather than activity based. If it's outdoors, we're hoping that more people who are sort of earlier in the journey will join.

**R2: Are these people, so as you said, it's not very normal time with COVID19, so of course it was less contacts for you with people, but have you noticed that people with early symptoms or even mild symptoms would say, Oh I prefer to go in my community and having my normal activities, but for this thing, so these things it's more difficult for me or as I am mentioning some difficulties, potential difficulties or?**

P11: No. The few people that we've spoken to, they've not said they've had any particular difficulties. Many of the people we have are quite active, and they're part of like cycling and hiking groups that they're still a part of. I think a lot of them… a gentleman that we have, like, he just has his wife come along with him now just for that extra support, but he's still able to take part in all the same activities.

**R2: Okay, great. We mentioned doing this focus group, but difficulties, but money and cost of things, of activities and also services, so is it something very strong, something you are hearing often from people from all stages and carers too, are they complaining about costs?**

P11: People will generally say that they'll pay for an activity, and they don't mind paying a small cost, but when it actually comes down to it, and I think a lot of the time, especially for a lot of our service users, if a carer comes along, that's double the cost because it's two people. Then depending on how they get to these activities, you’re then looking at transport as well as the added costs. I don't think they mind a small amount, but a lot of people, they don't have an awful lot of money coming in, so it could be the difference between getting shopping or joining an activity for some people.

**R2: Is it some funding, or I don't know, in Greater Manchester or in Great Britain for people with not a lot of money to help them to access to these activities?**

P11: There are benefits that people can apply for if they’re eligible that we do support. But again, it's up to them, how they choose to spend that, so other than funded projects where it would then make the project free, so like obviously our service is free. We may do some activities that are at a cost. If we were to do say we were to go to the aquarium for the day, obviously we would have to pay for something like that.

**R2: Yeah. They will have to pay for the entrance and transportation?**

P11: Generally, depending on the number of people, we can support with transport, we have our own buses, but we're limited on the number of people that we can put on the buses at the moment because of COVID. But usually, we'll get discounted rates or carers go free when we do outings like that, like the local communities, like they will try and work with us, but you can't always get it completely free.

**R2: Could you maybe because I'm very new in the country, could you maybe give me an estimation of the cost, usually an activity, is it £5, £10, 15?**

P11: It varies on the activity. For example, they used to do a coffee morning here where I think it was like 50p or £1 that they would pay, and that was just to cover the cost of tea, coffee, and there would be activities. But then if you didn't include transport, entrance to, for example, somewhere like the aquarium can be quite expensive depending on which one you go, anywhere like £8 up to £20, £30, which can be a lot. We've just partnered up with Manchester United. They're doing a tour for us, a free stadium tour in May. They run their own reminiscence groups for fans that are living with dementia.

**R2: When you and when your team are organising activities, you're also thinking, okay, we have to be careful and to keep some activities free because for some people it can be too expensive?**

P11: Yeah. We, we try and look at both and any paid for, we try and lower the cost as much as possible by getting in touch and explaining the situation. Can they offer a reduced price, carers go free? Have they've got any complementary tickets, even free parking because we have a lot of national parks nearby, but as well as the entrance fee, you then have quite high parking charges. We always do a lot of research; we get in contact with organisations to see if we can get any sort of reduction in price.

**R2: As a charity, I suppose you have some funding from population doing donation, but do you have some funding from Greater Manchester or UK government, these kinds of things?**

P11: I wouldn't know that side of it. You would have to ask the chief executive on that one. I wouldn't be sure.

**R2: Okay. No problem. Staying on this things of cost because I think we mentioned the fact and a lot of people say it's very, very difficult to involve people from minorities or by minorities or LGBTQ plus, et cetera these kind of minorities. I suppose for some people with not a lot of money, it's probably more difficult for you to access to them because if you offer something to them, they will say, Oh, sorry, I don't have enough money.**

P11: Yeah. Yeah. That's why we try and do activities, like even just like the local like park walks that we're trying to do, obviously the free we just meet in a local park, they can come and chat with other people that are living with dementia, other carers, they can get advice and support from us. Anything we can do. We're in touch with local garden centres to see if we can get like a little community allotment going that again would be free of charge. We try… is what we generally do groups that would be regular, so sort of weekly, fortnightly, monthly, we try and have, they are at no cost at all. And then paid for, would be sort of, you know, a quarterly trip, be a bit further afield. They usually paid for at some cost. I think pre-COVID a long time ago, they used to do trips to the seaside with hotel stays, but you know, it's just not possible at the minute.

**R2: Yeah. Okay. It's several, I don't know, maybe you can't answer, but it's several Age UK entities in greater Manchester, do you have meeting together some time or?**

P11: No, so we’re all independent. We all work completely separately. We will chat now and again, so we all have different services, so not every Age UK will have a memory loss service. It depends on the funding that they get from their own local governments.

**R2: Okay. Hmm. Interesting to know. Yeah. Great. I think I will turn off-topic, but yeah, I think it was you, you talk about also to reduce costs but the location of activities, so it's better maybe to offer several kinds of locations and in nice places.**

P11: Yeah, definitely. The walking group, for example, that we're looking to start, we're starting it off quite nearby to our offices, which is in Urmston. Now, people that live in Sale, Altrincham, the likelihood is that's too far for them. They're not going to travel all the way here, so we are going to have to see how it goes, if it goes well, and it's something that's liked, we can look at expanding it to different areas. The same for the Community Hub meetings and drop-ins, we usually have three or four around different areas of Trafford.

**R2: Okay, so proximity is really something important?**

P11: Yeah, I think if it's more than sort of, I would say if it takes more than 20 minutes to get there, I think people would just write it off. If they can walk there, a short bus journey, a lot of people, they don't drive now, so they're relying on other people, they're scared to get on public transport at the minute. I think the proximity at the minute with COVID is important because people don't want to get in a taxi. They don't want to get on a bus.

**R2: Yeah. Yeah. And before COVID19 for buses or maybe tramway, it was a good option for some of them, or you would say?**

P11: Once you reach, I think it's 60, they get a free bus pass, so they can travel. I think, during non-peak times, so they can travel on buses for free.

**R2: Right. It's something most of them enjoy it, or they're not too afraid or?**

P11: I think as long as their mobility is good, and it's something that they’re used to, but you know, if you've got a wheelchair user that's on their own, they're potentially not going to want to get a bus by themselves.

**R2: Yeah. But it's good to know most of them have this free pass, so it's great. Have you observed that, I don't know, they prefer some kind of buildings, I don't know, going in a school or in the community building, to have these meetings?**

P11: I don't really, I think as long as it's a big enough space, and it's got the facilities you would need, I don't think it makes too much of a difference. We generally use like assisted living facilities where they have communal lounges or community halls, that type of thing.

**R2: Yeah. In this case, you are sure accessibility is good and all these wheelchairs, and these kinds of things. Is it easy for you to find this kind of rooms? Do you have support of communities or?**

P11: I'm not too sure. I've never been involved with finding suitable places. But I don't think there's a short supply of them, obviously at the minute due to COVID, nobody wants you there. I think pre-COVID, I don't think there were any major issues.

**R2: Okay. Good. You will say, for example, for walks in parks because yeah, the first idea could be okay, it will be better to go outside of the city. It's more beautiful and this kind of things, but in the end, it's people prefer when it's quite near of their place.**

P11: Local, yeah.

**R2: Okay. Really local. Now I have really a different topic. It's about volunteering, is it some options for people you show maybe with early symptoms to be a volunteer and to offer some services to the people? I don't know volunteering in a football club or this kind of things?**

P11: I imagine so. I think it would depend on the organisation and exactly what they were needing to do. I can't see why not. Like, for example, if we were to start our coffee morning up again, I can't see why they would be any issue if somebody wanted to volunteer.

**R2: Some people are asking for that, some people with dementia or not that much?**

P11: Well, I've not known of anyone ask. I know a couple of people that I've spoken to that are very, very early on, you would have no idea they had a diagnosis, a few of them are still working.

**R2: Yeah. Yeah. I sort of think you are maybe not really in contact with these people, so maybe they're volunteering, but, so again, this position is quite new for you and context is really weird, but are you aware of some actions in Greater Manchester to help people to have access to volunteering or the adults or people with dementia?**

P11: To volunteering, no.

**R2: No, not that much. You at Age UK, do you have some people volunteering for activities?**

P11: Yeah, we do. We have volunteers across the whole service, so day support, reception. When we have the coffee morning, we have volunteer drivers. We have quite a lot of volunteers.

**R2: How is it working, they are just in contact with you?**

P11: Yeah, it's just like they are any other member of staff, like you wouldn't know they were, you know, they are no different, you wouldn't know that one person's a volunteer and one person's a staff member.

**R2: Okay. Do they need some specific interims for this kind of thing, for risks?**

P11: They would go through the same process that we would with regards to like police checks and references. They would go through the same process just because of the service user group that we work with.

**R2: Okay. Do they have some, I don't know, maybe not gratification, but access to some services or free coffee, or I don't know, in return of their participation?**

P11: We offer, there’s routine coffee on all the time. I think a lot of them just enjoy it. I feel like they get a sense of reward just from obviously the role they’re doing that, the service user group that they’re supporting. A lot of the people that the volunteer tend to be people that are retired themselves.

**R2: Okay. You have the feeling, this is kind of long-term volunteers. They will volunteer for long period because they really enjoy this regularity and caring status.**

P11: Yeah. They're quite regular volunteers, they'll follow the same schedule.

**R2: Okay. That's great. Yeah. I asked that because yeah, maybe volunteering is an option to participate and as you said, it can be very great and rewarding for the person to be a volunteer, but so, yeah. It’s interesting. I assumed you meant, so currently it's still a lot of activities online, but hopefully things will arrange and will go better, and it will be easier to have face-to-face meetings and these kinds of things, even as a charity it was still possible for you to have some people. But what do you think your organisation will change activities or change some things linked to COVID19, have you learned things from COVID19?**

P11: I think that we're going to continue online activities in groups even once we're able to resume in-person activities. I think, especially for carers, more than anything, if they have caring responsibilities, and they can't necessarily get out, they can't leave the person that they're caring for. Being able to join groups online has been helpful for them and also the distance as well, that's something people have enjoyed not having to travel to these meetings and groups.

**R2: I suppose it's still quite new, but are you maybe thinking to have a separate activity, for example, a support group, a remote support group and a face-to-face support group, or maybe having some people in the room, a computer where some would come?**

P11: I think separate, so we will probably resume our in-person one and then continue the online separately. Well, it's going to be trial and error, I think, to see sort of what people want. It might be that once the in-person groups resume the online groups, we don't have many people that are attending. I think it's just going to be trial and error for a while.

**R2: I suppose it will be more work for people, for you and other people to organise that as well?**

P11: Yeah, potentially more. But we essentially, we will cover the same content. I suppose there's not too much extra planning involved. It's just the extra time of the extra meeting.

**R2: What is, I will say, the state of mind of people around you? Are you really excited to think, okay, we will be able again to have more face-to-face meetings? We learned that it's positive, we learned from COVID19, we can have this kind of online activities, so quite a positive approach, or maybe people are thinking, okay, it's great, but it will be more work for me?**

P11: No, we want things to start reopening, we're excited to start seeing people again, like we're adding extra activities than what we were doing previously, so we're going to potentially have more than ever. We just want to get back to normal. I don't think we'll ever get there, new normal.

**R2: Yeah, no, exactly. For people living with dementia and their carers too, I suppose they are really looking for having more activities face-to-face, but are you feeling they still have some fears about catching COVID19?**

P11: Definitely still have fears. That's why we're looking at outdoor to begin with, so small like groups of six, which obviously is what we're allowed at the moment, small groups of six outdoors. We keep letting them know, all our staff have had the vaccinations, most of our service users have had theirs, but this is why we wanted to start outdoors in the fresh air to begin with.

**R2: Are you worried about some members maybe after one year they will have lost some skills, or maybe they will be afraid to be in a group again or this kind of things?**

P11: We've still been keeping in regular contact with all of our service users. We've still been doing our regular review calls. If there has been any like mobility issues, it's something that potentially will have been addressed already either with our falls prevention team, referrals to GP, so it should hopefully be things that have already been addressed.

**R2: Okay. That's quite, you were able to keep contact with people, so to monitor them and to be sure that okay. I think I have just one last question, in a perfect world, if you were able to try something, if you had a big budget and the boss saying, Yeah. Do that. Do you have maybe, I don't know, some ideas or something related to activities or services for people with dementia?**

P11: Oh God, I don't know because we’re doing everything at a lower cost. Honestly, like what we've been trying to do is, so like we've just sent out our bi-monthly newsletter and our most recent hub, we've put it to our service users and asked them, what is it you want? What groups would you like to have because at the end of the day, what I might like, might be different to what they would like, but essentially, I think something I like now, I'm potentially still going to want to do it later on in life, so I think a lot of people want to remain doing the same things.

**R2: Okay. It's really great to ask regularly to members what they want. Do you have some specific, some people think, Oh, I really would like this kind of things or?**

P11: They've asked for a book club of all things. They really want a book club.

**R2: Oh, interesting. But it's really, I suppose, very great for you to have these feedbacks and being able to adapt and offer activities?**

P11: Yeah. Because we could have what we think is the greatest idea in the world, put load of planning into it, risk assessment, and then everyone's like, I don't want to do that. We don't want to spend, put all our time and effort into something we think people would like, and then they don't. It's best hearing from them directly, what would you like today?

**R2: I think when we had this group meeting with [P4], your boss and my supervisor, your boss or your supervisor, I'm sorry. I forgot the name.**

P11: [NAME], I think it was.

**R2: Yeah, she said you were quite used to participate in studies and this kind of things or supporting studies. Have you, I don't know, some reports or being part of some reports about activities for people with dementia?**

P11: I'm not sure what research they've taken part in, in the past. Obviously, with me not being here. I know that they have been a part of research in the past, but I'm not too sure what that is.

**R2: Okay. Do you know if you have some annual, I don't know exactly what is the name, but when you say, okay, this here, we made that, that, that, and we made this amount of activities, and we observed that people were, it was a big number of participants for this activity?**

P11: Like a review?

**R2: Yeah, exactly.**

P11: I think generally that would happen, but with everything being cancelled due to COVID, there's not been much to report on, but we do report monthly on how many people attend our online activities.

**R2: Right. Okay. Well, it was a lot of information. Thanks a lot. I'm sorry if I ask question, or read a lot of question because I know it's very, not best timing with COVID19, but at the same time, it's very interesting for us, but as a project to have this insight from this situation, and we can improve. I don't know if you have other things maybe you want to add or to say, or you think…**

P11: I don’t think so, we're a very strange time at the minute. I'm just finding my feet here and trying to see what we can get started activity wise. We want to, have you spoken with [MY COLLEAGUE] at all? No, I don't. It could be worth, so we have an MCI, so mild cognitive impairment department within our service. They work closely with those people, encouraging annual reviews with GPs, a portion of those people then go on to develop a diagnosis of dementia. They do a different, a wide of activities. They encourage healthy lifestyle to try and reduce the risks of developing dementia.

**R2: Okay. What is the name of maybe a contact person?**

P11: I can send you [MY COLLEAGUE]'s email.

**R2: Oh, it would be great. Yeah, thanks.**

P11: Yeah, I can forward on her contact information to you.

**R2: Yeah. Yeah. I will see if she is available maybe for interviews too. That was great. Thanks a lot. Yeah, as you participate, you have the right to a voucher, £40 voucher, or you can also make a donation, it's as you prefer it.**

P11: Yeah, we have to make the donation if possible.

**R2: Okay, great.**

P11: You can do the same that you did with [P4], will be absolutely fine. Thank you.

**R2: No problem. Thanks to you and [P4], it was really, really interesting, so thanks for your support. As I said to [P4], I will probably send you, I don't know exactly when, just to let you know where we are in the project, and maybe I will contact you again when we will try to find some participants for interviews, so people living with dementia for some interviews, maybe you have some contacts.**

**P11: Yeah. Thank you. Bye.**

R2: Yeah. Thanks a lot. Have a nice day. Bye. Thanks.

**[End of Recording]**