**WORK PACKAGE 1 – SESSION 4 Part 1**

**Individual interview with stakeholder P4**

**24th March 2021**

Audio File Name: S4 - Part 1 - IDoService - Individual Interview- Other stakeholders - 24 march

Duration: 00:32:38

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

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

P4: = Stakeholder

**R2: That’s recording, and I’ll just put that on. So, thanks a lot because you sent me your informed consent but as last time, again I have to ask you if you still agree to take part in this study?**

P4: I do.

**R2: Perfect, great, so to begin, maybe do you have some questions about me about the study or do you want to … I think it was three weeks ago, so maybe you had other ideas since this time?**

P4: I don’t think so, no, I can’t even remember yesterday [laugh].

**R2: No problem, I had a meeting yesterday with [R1] and she said, oh okay the weekend was great, what have you done, I was like, I have no idea.**

P4: I know it’s not good, is it, it’s not.

**R2: Yes, all days are quite similar.**

P4: Yes.

**R2: Yes?**

P4: That’s fine, you carry on, am I breaking up a lot, am I freezing?

**R2: Yes, but it should be okay. So, as you know, in our study, we are interested, especially in people with mild to moderate symptoms, so maybe people with early onset dementia or early dementia or maybe MCI. So, I think in your position, you are meeting a lot of these people, so I am interested to know what do you think … we mentioned maybe the diagnosis, it’s difficult to have it online, especially with COVID-19 but sometimes people maybe will wait to have a lot of symptoms and they will maybe check with their GP at this time but it’s quite late. Maybe they have a diagnosis but thinking no activities or support groups, Age UK, for example, it’s not for me, I’m too young or these people are in too many difficulties for me, so I’m not like them, these kinds of things. Maybe you can tell me something about that?**

P4: Yes, I’ve spoken to a lot … because like I mentioned before, things have been on hold with the memory service, so when people go to their GP and the GP refers them to the memory service, I get a referral through as well. So, I make that initial contact with them before they’ve even had an assessment. So, I’m there offering support through the journey of receiving the assessment and if there is a diagnosis.

I’ve spoken to a lot of people this week that are awaiting assessments, but they actually feel that they’re okay, they think it’s because of the lockdown, because they’ve not had any stimulation and it’s the families that have picked up on it, that have made them go to the GP with regard to this memory loss. So, they’re all thinking that everything is fine, so I’ll be with them through that journey now but then there are a lot of people that I’m speaking to that have been diagnosed, so they’re early stage.

Again they don’t feel that there’s … they think that it’s all to do with the lockdown. So, it’s quite difficult to gage … obviously the lockdown has had a massive, massive impact on people whether they’ve got dementia or not but people that are being diagnosed with MCI, I then refer over to my colleague, [NAME] and she will make contact with them and she runs an online group called Blossom Out. Again that’s offering support for them and she would normally run a group, a physical group where they would do stimulating activities and exercise and just gentle stuff.

So yes, it’s definitely picking up at the moment with people but again it’s difficult because of lockdown to get things up and moving but I am promoting our day support a lot more and people are quite interested because obviously there’s nothing else for them to do at the moment.

**R2: Yes, it’s difficult, I think you said this position is quite new for you, some months, I think, this position like dementia. I’m sorry I’ve lost the exact name of your position, dementia advisor or something like that?**

P4: Yes, well it was dementia advisor, but they’ve changed it to memory loss advisor, I think it sounds a bit more friendly, isn’t it but I have worked with dementia for over 20 years, previous to coming to this role.

**R2: So, you arrived in this new role or activity during the lockdown, so it was probably quite a challenge for you too because you had to adapt to this new situation.**

P4: Yes exactly, I mean in a normal world, it would be a really interesting role to have because I’d be obviously doing home visits with people and it’s more personal, you can see how they’re living and adapt things for them and give them suggestions on how to do things a bit easier. Also running the hubs and the drop-ins, so people can just come down, get a bit of advice, arrange guest speakers to come on and give information to people and the carers as well. So, it’s quite difficult doing it all over the phone really.

**R2: Yes exactly, it’s not that great but it is a very exciting position and before that, I think you said you were in a day care centre?**

P4: Yes, I was one of the coordinators in the day support which is specifically for people with dementia but that’s a mixture of early onset and people that have obviously waited and are further down the line, so they’re more advanced, which is difficult for them to join a group like that, I think. But we were, in the past, in a position where we could have up to 30 people attending on a daily basis, so you could group people that were the same level of dementia so that people could work together in a group and converse.

But obviously it’s been reduced now to 12 people, so it’s quite difficult and everybody has to sit on their own individual table, so it’s just trying to gear things to stimulate them, the right activities.

**R2: It’s more difficult now to stimulate them and I don’t know, it was maybe when I was a student, we talked a lot about the fact, for example, in nursing homes, it was really important for people with quite advanced dementia to be in contact with older adults without difficulties and these kinds of things, this kind of inclusion. But in the centre, a lot of older adults without memory loss complained a lot about that because they said, okay it’s really frightening for me to see that and I’m afraid maybe one day I will have the same difficulties.**

**What is the thing because I suppose when you have a diagnosis of dementia, you are also afraid what will arrive in the end, so probably some people are interested in having more information, but others are maybe afraid of that situation?**

P4: Yes definitely, because obviously you can’t pick and choose which people at the moment come on the same day, so you’ve got varying degrees of advancement in the dementia and I find that people that do have the insight, they obviously can see somebody that’s more advanced, that’s walking around the room, talking to themselves in the reflection and because they’re still quite in denial, they get quite angry with them.

So, they’re trying to mask they’re scared obviously because they can see what could possibly happen in the future but also, they don’t have the patience as well, with them because it is quite difficult. It’s just a case of guiding them and just explaining to them that this lady has got a condition and we’re just helping her and letting the family have a little bit of a rest. So, then they’re okay with that.

**R2: Okay, yes if someone can sit with them and explain a little bit of the situation.**

P4: Yes, it’s just a bit of reassurance.

**R2: Great, our project is about meaningful activities, some of them will be in groups and it would be interesting to know how it’s possible to adapt to a situation?**

P4: Yes, do you mean with social distancing or just –

**R2: Yes, maybe stigmatisation and being with people with the same disease but in a more advanced stage but I have a question about the COVID-19 situation and the (unclear 00:12:16) because we have a lot of hope for this summer, but I suppose you are already thinking maybe in the future, in my activity, probably I have to adapt or change things.**

**So, last time you said that for some people, you had a feeling their mental health really declined this time. So, I would like to know, what are your fears when you’re allowed activities again, I don’t know, maybe people will have lost a lot of skills or they will be afraid to come back and also, on a more positive aspect, how do you think the new service will adapt to a situation like that?**

P4: Right, okay, yes, when people have returned, when it reopened again in July, there was a massive, massive decline in the majority of people, obviously their families as well because they’ve not had that break. So, the families are really eager for them to come back, even though the worrying side of catching COVID and things like that. But it was just about getting them back into the routine, so we’ve kept as much routine as possible, just to ease them back into the day support setting.

So, we’ve given them their drinks when they arrive and just tried to make as fun as possible because it’s a more intimate group because it’s a smaller group as well. But there are people that have commented, that still have quite a lot of insight saying, oh it’s not the same as it was here. So, then I sit with them and explain, because of the pandemic, we have to keep our distance, we can’t have a Friday disco like we used to. So, once I explain that to them, then they’re like, oh yes, so they remember and then they’re okay with it, but it is a lot of explanation you have to do about it because they have forgotten about the pandemic.

So, moving forward now, because we will be able to hopefully meet in small groups, I’m trying to arrange some walks, with the carers and the service users, obviously I will have to hand-pick mobility-wise and how far advanced they are but we’re going to plan on doing some walks, we’ve got a big minibus there which I can drive. So, people that haven’t got access to transport, we can provide the transport and we’ll take them places for nice walks, a bit of fresh air, we’re also planning … we’re in discussions with Manchester United at the moment as well, because they have a reminiscence group.

So, we’re going to go down there in a couple of weeks, just to have a look at what happens and then we’re going to arrange, again with the minibus, to go up to Manchester United on quite a few sessions and that will be the same with the people from the MCI group as well. So, it will be like the history of Manchester United and things like that, so some people will be interested, some people won’t and then as soon as is possible, we’ll be getting the hubs back up and running again in the community, so people have somewhere to go to and speak and meet others and share experiences.

**R2: So, currently you are looking for maybe more social distanced activities and it’s now a good time of the year to do that.**

P4: Absolutely, definitely, so obviously going for a nice walk is at the top of the list because you can keep your distance and you’re in the fresh air.

**R2: Yes, it’s perfect, its physical activity, you’re with other people, it’s stimulating, so yes, it’s perfect.**

P4: Yes, so we’re just trying to find as much as possible now, so we can plan ahead and get things booked in really.

**R2: I think it was [P6] in your focus group, she said, okay probably we will keep some zoom sessions online, even if other activities are going well, are you planning maybe the same, thinking okay, zoom sessions are not perfect for everyone but for some people it’s interesting?**

P4: Yes, I mean at the moment, I think there’s about eight people that come to the hub on zoom, the other people would normally … there’s usually about 30-odd people that would come to the community hubs, but they just don’t feel comfortable using zoom or they don’t have access to it, but we are going to continue, as well as the community ones, we’re going to continue the online ones and possibly look at doing a bit of one-to-one with people as well.

So, it isn’t the group environment because not everybody wants to be in a group, it would be kind of like a drop-in, but we’d do it on a one-to-one basis on zoom. So, they’ve got that bit of personal time as well to ask personal questions and things like that, so they feel that instead of doing it over the phone, they’ve got a face to speak to. We are, going forward, planning more day trips out, go to the seaside, again take the minibus, I’m going to be doing a lot of bus driving, I think. But yes, we’re currently in meetings at the moment, planning ahead and getting more people involved. So yes, it’s brightening up a little bit.

**R2: Yes, it’s great and you just mentioned that indeed, for some people they are not really people interested in group activities, so maybe they are social but maybe one-to-one or very small groups, in this case, you have this one-to-one session, in a perfect world, face-to-face, currently more by phone or online. But have you said, I don’t know, some activities that are good for these people, maybe more (unclear 00:19:58) because okay it’s a group but they have more space around them, maybe some activities for these –**

P4: For individual people?

**R2: Yes exactly, individual people, thanks.**

P4: Well, what I’ve been doing during lockdown, I mean if they’ve got access to computers, I’ve emailed over but I’ve also sent out in the post, activity packs for them to do. So, that’s wordsearches, art, I’ve sent them a little bit of coloured pencils in the post, the really nice art for them to do. It has been difficult because they’ve said, oh we’ve been doing jigsaws, but we’ve run out of them and we can’t buy them anywhere. It has been quite difficult to get hold of jigsaw puzzles for people and we’ve lent jigsaw puzzles out, dropped them off at people’s houses, just to try and keep them stimulated but it is quite limited as to what you can do, activity-wise.

**R2: Yes, it’s not the best indeed and I have now quite a different question about community participation and minorities, how is it for you to have access to minorities, BAME minorities, or Asian, Pakistani because I know in other focus groups, they said it was quite difficult to reach them. So, I don’t know if you have the same problem?**

P4: Yes, I have got quite a few that I’ve spoken to and usually I find within their own community, they want to look after their loved ones themselves and they feel that there would be a language barrier, an activity barrier. So, I’ve actually been speaking to a group called Together Dementia, I don’t know if you’ve heard of them?

**R2: Yes.**

P4: So, they’ve got a specific group for South Asian people and their carers. So, they’re multilingual and they reminisce about things and that’s geared towards their own community. So, I have put quite a few referrals through for people for that as well which is good, it’s more welcoming for them, as opposed to walking into our day support, for example, with music from the sixties playing. They’re not going to be familiar with that, so yes, I’ve been working quite closely with them recently as well.

**R2: Okay, yes interesting because with dementia, your late memories from childhood and these kinds of things but not living in the UK at this time, it’s not really for them.**

P4: Yes, it’s really difficult, so I think this group that’s been set up is really, really good. They do cookery as well and they’re hoping to invite me to one of the groups, just so that I can see … obviously if I’m referring people there as well, I can see how it’s all working and everything, so that will be good.

**R2: Yes quite, and do you have … I don’t know, because Educate is a charity?**

P4: Yes.

**R2: So, you can decide on your own, you don’t have, I don’t know, someone above saying, okay you need more BAME communities or that kind of thing. So, you can decide what you want to do?**

P4: Yes, well –

**R2: More or less?**

P4: Yes, we obviously would try and get any person, it doesn’t matter to us but it’s about the person feeling comfortable. So, we would always offer them a trial day which isn’t a full day, just to see how they feel, if they feel comfortable because there’s nothing worse than … it’s an anxious time anyway, going to a new group and meeting new people when you’ve been in your own environment for so long. But then if there’s a language barrier, if you’re not enjoying the activities that are on offer, then it’s not going to work, so we always let people have that try anyway.

**R2: Yes exactly, it’s great, so I have a more research background but the last two years, I think I said about that but when I was in Luxembourg, I worked in a public centre with dementia. We had to inform families and a lot of people about dementia and what it is but it’s a public dementia centre, so it was funded by the government and they said because Luxembourg is very multicultural.**

**So, in this case, it’s more Portuguese people or maybe French speaking, etc, but it was a lot of people from Luxembourg, and it was very difficult for us to reach French speaking or French people or Portuguese people. I think we tried and maybe it was not a good approach, as you say, maybe it will be good to try other things. So, it’s why I’m asking about these aspects.**

P4: Yes and making them feel more comfortable and at ease as well.

**R2: Exactly, quite. Good, I’m sorry because I’m going quite quickly across the topics.**

P4: It’s fine, honestly, don’t worry.

**R2: Great, during the focus group, you mentioned some strategies, so you talked about a lady, she was at home with her husband but her husband usually, or in the past, used a computer but it was more difficult because she has less time to watch TV and these kinds of things. You mentioned you gave her a strategy and it worked very well, so they adapt to that, I think it’s really great and have you seen that people have some specific strategies or maybe you have some strategies to give to them to be more autonomous at home or have more activities outside, these kinds of things?**

P4: Yes, I’ve been dealing with a gentleman and his wife. His wife has got dementia and what happened was, his daughter contacted me because they were so worried about the pandemic, they wouldn’t even let her come to the front door. So, she was worried about if they were eating, if they were drinking enough, if they were exercising. So, I rang him, and he wasn’t very forthcoming to start with, but I persisted, and I rang him every single week, just general, hi, hello, how are you.

I managed to persuade him to start going out for a walk with his wife, that it was safe for him to do that and now, he actually rings me up and tells me how many steps they’ve done every week. So, I’ve checked in, oh what are you having for your tea and what are you having for you lunch, so I can then let the daughter know that they are okay. So, it’s all about the way you try and persuade somebody to do something.

**R2: Yes, it’s great, it’s very funny that he called you and said, okay we made this distance or this number … and remind me, I saw, for example, on your Twitter account, Age UK’s Twitter account that you have this, not competition but people are doing things and they send you pictures of their prediction or something, some knitting, or these kinds of things. So, you maybe saw that during lockdown, people having more communication by pictures or what they produce, this kind of things?**

P4: Yes, again it’s all the activities as well, so they’ll make things, they’re making giant pom-pom wreaths at the minute, all different colours and then we will post that on our Facebook account just to show that people are still being busy and are keeping active.

**R2: Great and do you think they enjoy some challenges, so maybe they were challenging themselves?**

P4: Yes definitely, obviously again because we’ve been quite limited with activities, we’ve got jigsaws, we have got specific jigsaws for people with dementia as well. So, they’re really, really good especially if people have never done a jigsaw before which a lot of them haven’t. We’ve given them the jigsaw and they’ve said, no I can’t do that, I can’t do it and we’ve said, look just try and then we’ve may assisted a little bit with the corner bits to get them started and then they’ve done it. They’re just like, I can’t believe I’ve done that, so we’ll take a picture of them with the jigsaw and make a big fuss of them, so that they feel that they’ve achieved something that’s good.

**R2: Yes, it’s really great, it’s really important for them, so good. I will try to keep it short because I think I heard your phone ringing; I know you’re very busy.**

P4: It’s fine.

**R2: I have a question, in a perfect world, if you have a lot of money or time or maybe not COVID-19, what do you think will improve the participation, the wellbeing of people living with dementia but also the participation in meaningful activities?**

P4: What do I think, sorry [R2]?

**R2: Yes, what can be helpful for you, I don’t know, maybe do you have some ideas about a new group you would like to develop or maybe you are aware of –**

**[End of Recording]**