**WORK PACKAGE 1 – SESSION 10**

**Individual interview with stakeholder P12**

**7th July 2021**

Audio File Name: S12 – IDoService – Individual Interview – Other stakeholders – 7 July

Duration: 00:55:34

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

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

P12: = Stakeholder

**R2: Yeah, great. Thanks a lot for agreeing in May but can you say again that you agree to take part and you consent in this today.**

P12: Yes, I agree I’ve read all the points and I consent to them all.

**R2: Great. Thanks. So, I prepared some questions so, I do survey projects, the idea is… I would say I’m more of a psychologist and the project is more designer. So, we are thinking about designing something to support the access to activities. So, we’ll say designer service but it’s not a service like Age UK, or something like that. But it can be a digital tool, (unclear 0:00:58), all these kinds of things. Are you okay? [laughs]**

P12: Yeah.

**R2: Great. And, yeah, it’s about activities, so social, leisure, physical activities. All kind of activities.**

P12: Yeah.

**R2: So, if you have a question, or if you need me to repeat something don’t hesitate to ask.**

P12: Okay.

**R2: So, my first question is, as a service and service provider, how do you adapt to the specific needs of people with MCI, on the onset, or even mild dementia? And, for example, are they looking for different activities, are they maybe more active, or asking to be more active and organise themselves more activities? Maybe I suppose they have more autonomy, or other specificities or preferences. Because in the literature most of the studies are more for people with quite severe dementia. To have a better idea of needs and preferences of people living with milder symptoms.**

P12: Right, okay. Well, I’ll go to the beginning, in 2014, well just at the end of 2013, our service identified that we had about half a dozen people that came through on our database, new referrals. These people had young onset dementia and MCI. So, we wrote to these people because we weren’t providing any groups or activities for that age group and people who were in the early stages of dementia. So, we had a couple of meetings with this group, and we said that if it was something that they would like us to do, we would set up a young onset dementia group. So obviously Age UK historically has been to provide services to older people, but this group of people said it was something that they would be really interested in.

So, we started up with a new onset dementia group in 2014 for people living with dementia with a diagnosis under 64, and their careers. So, we started that group back in 2014 and it’s been running for all the years since then. Just before lockdown, and it was very successful, I must say. And obviously during that period of time, people left the group because their dementia had advanced, they were no longer able to participate in the activities. Some unfortunately passed away and some went on to residential care. But we were getting new referrals, so the group was changing all the time during that period. Just before COVID, we identified that we didn’t seem to be getting many new referrals for people in that category. We were thinking how we could tailor the group again to this younger age group, and those still continuing to attend, their condition had advanced.

So, we were actively trying to get new referrals to join the group, but then COVID happened so that stopped everything because the group stopped anyway. So, since we re-opened our groups again, including the young onset dementia group, we thought we needed to look into this problem again. Just recently I identified 12 couples on our database, new referrals for this age group. We wrote to them again and a couple of weeks ago I had a meeting to see if this group of people that we’d identified wanted to attend a new young onset dementia group. Six turned up, that was three people with dementia with their carers, and it is something that they want us to pursue. So next Thursday… no, actually this Thursday, tomorrow, we’ve got a second meeting with this group to go through what we can offer and ask them what they want from this group.

So, when I did that the first time in 2014, the couple of meetings that we did have with that group, we asked them what we wanted from this group. So, i.e., what activities they would like us to put into the programme. What did they want to include, as it was their group. We’d always made sure that it was the service users that led the group, it was user led. They gave us a list of various activities. The usual things: they wanted to play bingo; music, for example they liked to have music quizzes which was actually age appropriate because obviously with them at that age, they didn’t want a quiz on music from the 50s, for example. So, it was music from the 60s and 70s, and they really enjoyed those.

So, a lot of activities that were age appropriate within the venue that we hired to run the group, but also, they wanted a lot of activities outside the group. Going on trips, and the trips were arranged from the suggestions they gave to me. We even had people wanting to do a zip wire.

**R2: Okay.**

P12: So, I went along with a couple of the members, and we did a zip wire in Wales. So, it because they were younger like you said, and because usually a lot of them were still physically active, that was another difference that we found with this group, they wanted to do activities that were quite physical.

**R2: Yeah.**

P12: So basically, it was just about arranging whatever it was that they wanted to do. So, we did loads of activities, we used to go for pub lunches quite regularly because they wanted to be out in the open.

**R2: Yes. So, I would say, not ‘normal’ activities, but activities in the community, going to the pub and this kind of physical activities outside, these kind of new things and trips.**

P12: Yeah, and we used to write plays as well. They loved it when we used to write our own plays and members of the group were involved… some of them who wanted to be, and they didn’t have to learn their lines, I don’t think that would have worked, so we used to type out scripts. They used to read the lines from the script which was quite good because we… it was a [s.l headache 0:09:25] as well, and we had a lot of laughs because he would get the lines wrong even if it was written in front of them. Which actually made the play more interesting and more fun, actually. So, the emphasis was on fun activities which were age appropriate to this group. But the main thing was that it was user-led.

**R2: Yeah, that’s great. For these plays, was it a representation in the end of the year, something, I don’t know, open to everyone? Or was it something more regular during the weekend?**

P12: We tended to do the plays, certainly at Christmas. We always had a play at Christmas. During the summer months we used to put on a play. Sometimes it was just for the group and the group members to watch, but we also used to, and still do, there’s a hotel in Southport called the [s.l Southwardian 0:10:32] Hotel and this group always, and still do we were there the weekend just gone, they always wanted to go away for the weekend together. We used to put on a play whilst we were away at the hotel as well. The hotel booking was mainly for our group, but we did have one or two customers that were outside and nothing to do with dementia, they would also watch the play as well. I think it was quite an eye opener for people to see other people with dementia just enjoying themselves and having fun. It was a good laugh.

Another thing that we used to organise, every summer we would have a mini-Olympic games. So, we would hire a local athletic track in Salford, and we used to adapt the Olympic games to our group. So, we would have a walking relay, for example. Around the track, we’d have a team, and they’d walk a hundred metres, pass the baton over to another member of their team. We found that this young onset group was very competitive, they liked to do anything that involved competing against each other.

**R2: Oh. That’s very interesting to know because sometimes we think people with dementia, they have maybe more difficulties with memory and all these kinds of things. So, we try to avoid challenges but in them, some of them enjoy at the beginning, in friendly competition.**

P12: In my experience, since how many years is it? Seven years since 2014. Obviously, the group has changed membership along the way, but we’ve always found that everyone that attends, the group, they’re all competitive. They like to win a prize. They do like an acknowledgement for their efforts. Which is really good for people with dementia, the condition restricts them from being competitive and being good at something and winning something. So, the games that we used to have, I would order medals from the internet, the silver, bronze, gold medals, and we’d have a presentation, like they do at the Olympics, they stand on the podium. And the pride that they had, just winning that plastic medal, you wouldn’t believe. It was absolutely amazing.

**R2: That is, yeah, it would be amazing.**

P12: Certainly, a feel-good factor for those people. We had for example one gentleman, he couldn’t participate in quizzes and things like that, but he loved dancing, and he used to love archery. We bought a couple of sets of archery from Aldi, for example, which was quite safe, not like what you would get in the Olympic Games, but… he won that competition, and it was lovely for him and his family and carers to actually see him there on the podium with that gold medal. It was amazing. Because at these games as well, we’d not only invite the person with dementia and their husband and wife, but it was also opened up to family and friends as well. It was quite a big group.

We’d have it outside as well, and we’d put on the games as well as refreshments and people were able to participate in the games who wanted, some just wanted to spectate and watch other people. And it was really good to see the achievements and the pride, and to let other people, the extended family and friends, to see them do that. That was really good and positive.

**R2: Yeah, it seems amazing, a great idea.**

P12: When people came over to congratulate someone it was really nice to see. We got a lot of video footage as you’d imagine. It had always been very successful. Obviously COVID, we’ve not been able to do anything like that for the last couple of years but it’s still on the agenda and we intend to continue with that sort of thing. As I was saying before we’ve undertaken a restructure of our groups now where the previous young onset dementia group is no longer, we’ve still got one or two members who are eligible, but the idea now is for them to transfer over to these people, the new people, and then the other members of the first young onset dementia group, they are really now ex-carers because their husbands or wives have sadly passed away.

So, we’re obviously going to still provide a group for them. They are in their seventies, but they’re still active. We’re going to create a new ex-carers group for those people. And it’s my intention also to, on some days with the group, for those carers to come and meet the people with young onset dementia and their carers, because they’ve got valuable experience and its good for new people to hear stories and how they’ve managed in the past looking after their loved ones with young onset dementia. Because it’s a valuable resource, isn’t it, when you’ve got people how have been through that journey and they can pass advice and information onto people who have just started on that journey.

**R2: Yeah, exactly. And for this project, we have a focus group for people like Marian, and, yeah, a lot of times the discussion was about the fact that… probably something you are seeing in your practice, it’s often not easy to reach people who only have onset dementia, because you are thinking: “okay, I’m still good, I’m still able to have daily life activities. Maybe I’m going in this group, I will be with people with more advanced dementia. Oh, I don’t want maybe to see how it will be in the future.” Do you have the feeling that it’s improving, so maybe now people having early onset dementia are more open to join a group like yours? Or is it still something you have to work on?**

P12: In the main, I have found that the majority do get a lot of positive feelings and positive experiences from these groups. But you’re right what you said. We have had over the years a couple of people living with dementia and their carers who have not wanted to come to the group because of that reason because they’ve seen people deteriorate. And they don’t want to see that. It scares them too much. But the majority do find it a positive experience, but some are scared by that, yeah.

**R2: And, you said to me you have presently 12 couples. And some of them say no. So, it crossed my mind that being not interested in joining an early dementia group, what are the reasons to do that? Are they saying, I don’t have time, it’s not for me, I don’t like group activities?**

P12: Yeah. Just let me just see if I’ve, because I’m not sure if my memory… I’ll just see if… no, I’ve not got the information in front of me but going off memory, the reasons that some of them, one of them didn’t like the group experience, some people, and we know groups are not for everybody. There was one who didn’t really like the idea of going to a group. However, one of the couples who did attend the meeting, they thought they’d give it a go, but they weren’t sure whether or not they were going to enjoy it. But because the group initially now is small, there’s only three couples so six people, when they turned up for the meeting, this couple, they decided that they would attend. They were coming but they weren’t sure if they would continue to attend.

When they did attend the meeting, because it was only a small group when we were beginning with this group, they decided that yes, they will do, because they weren’t overwhelmed. So, because they started at the beginning with a small number, as people start to join the group at a later date, because they’re already there and had got used to it, I don’t think it’s going to affect them in the future because they’d been there at the onset. As the group grows, they won’t feel… it must be difficult for people to just walk into a group of 12 people even, that for some people is really difficult, isn’t it?

**R2: Yeah, exactly.**

P12: So, we’d always, some people are adamant from they off that they don’t want to attend. We do have some people who are not sure, we always try to encourage them. Just come along, there’s no pressure and if you don’t want to come back… but then we do find that once people have been once or twice, they have continued to come and really loved it.

**R2: Yeah, the first day is more difficult.**

P12: Yeah. Other reasons, well, there was another couple but unfortunately their dementia is too advanced to attend the group. There was a couple that couldn’t attend because of that reason. And another problem as well that we do encounter that was a case with another couple that we had. Their carer, husband or wife, works, and they were unable to get to the group because they had no-one to take them.

**R2: I have a question about that. But minorities, and single people, or people living having no husband or a main carer. Do you have some of them in your group, or is it more difficult for them to reach you?**

P12: We have had those people and it is difficult because everybody’s needs a re different. Depending on how it works out with the transport, occasionally we’ve had people who are able to get a taxi, they come on their own in a taxi and we are there to greet them. That has worked quite well in the past but with other people, we have a dementia worker in our team we have what we call three dementia workers, it’s their role, when we initially get a referral, the dementia worker will visit them and do an assessment. If we find that the client would like to attend the group, but they’re a bit wary, a bit scared of going for the first time, the dementia worker will go with them for the first few visits.

**R2: Oh, great.**

P12: They obviously can’t do that on a permanent basis because of the workload. But we have had several clients in the past where the dementia worker has gone to pick them up, gone with them to the group, stayed with them and then when they get used to going to the group, sometimes they’d been able then to be happy to make their own way there if they’re capable of doing that. Sometimes that has been on the bus. For example, if a person with dementia is able to travel on the bus, if the dementia worker escorts them for the first few times, they would be able to do that journey unescorted. We tried different methods to get people to the group. We do encourage people to try and book on bring and ride but bring and ride is quite difficult because of the times.

It’s not like a taxi where you pick a time and they collect people and drop them off. Sometimes they can’t accommodate the times we want to get them to the group. Sometimes it works and sometimes not. So, basically, you’re saying public transport or taxis. It’s always been a big problem getting people to groups.

**R2: Yeah. And do they have access to money support from the UK government, or some funding?**

P12: Yeah. That’s something that the dementia workers will look at with the clients. The dementia workers can advise them and point them in the direction, signpost them to social services to see if they can get some sort of budget allowance for transport. That does quite often work out, and that’s why some people can afford taxis.

**R2: That’s great. And so, I think I said I’m French and I’m new to the UK system. When you are talking about a referral, it’s a GP asking to the person, okay, are you happy if I give your names and details to [s.l Age UK 0:26:21] support, or this kind of thing. How does it work? Is it social prescription or something different?**

P12: No, we’ve not really used the social prescription system at the moment. What happens with the referrals, anybody can make a referral to our service – any professional GP, memory assessment team, or social workers, or any organisation. But also, they can refer themselves. They can self-refer, so the person living with dementia if capable can refer themselves, but quite often it’s a family member or friend who can refer them directly to us.

**R2: Okay.**

P12: So, a lot of the time we rely on the memory assessment team to refer to us because the GP will not (unclear 0:27:17) … people having problems with memory they tend to go to their GP in the first instance, don’t they?

**R2: Yeah.**

P12: Then their GP will refer them to the memory assessment team. The memory assessment team will visit or do an assessment and the person will hopefully get a diagnosis. Then we rely on the memory assessment team then to make the referral to ourselves. Sometimes it’s difficult for clients when they just go and get a diagnosis, because as you can imagine they’re very confused, they’re scared. The memory assessment team can only advise them to come our service and if the person sometimes don’t want to that sort of thing initially, we have to rely on them contacting us at a later date, which sometimes they don’t. We can only get involved with people if they come to is. It’s good when the memory assessment team ask them and they say, yes, you can refer us but sometimes people at that stage don’t want to bother, because they’re in shock I suppose.

**R2: Yeah. They would need time to think about that. It’s really quite an organisation, and for these dementia workers, are they just something you implemented in Southport, or is it something more national?**

P12: Well, the dementia workers on our team, they’re just local to Age UK Salford. But I think that any dementia service, whether it be the third sector or statutory services, I would imagine that they would have someone in a similar role. The dementia worker, that’s what we call these staff that do this role. They would have a similar role in other organisations that have dementia support services I would imagine.

**R2: Yeah. Are there different… I don’t know if you have social workers in the UK, or is it kind of… it’s not ringing a bell when I’m speaking about social workers. Someone going home and asking if they need help with daily living, or money, or what is appropriate for you.**

P12: Yeah, in Salford, we have a social services department. And the dementia workers when they do an assessment with the person who’s been referred to us, one of the first questions they usually ask is do they have a social worker.

**R2: Okay.**

P12: Which the answer is usually no. Because social services don’t… if someone is referred to social services for any particular reason, once the social worker has dealt with that issue, they close the case.

**R2: Okay.**

P12: So, if a client needed something else, they’ve got to go through the whole system again. So, we tend to refer them back to the social worker for whatever it is the client we identify that the client needs. That could be age adaptations, personal budgets, booking respite care. Everything that you have to arrange for clients these days has to go through a social worker. So, a lot of our work with dementia workers is referring to the social worker for them to process whatever request it is from the client.

**R2: Okay.**

P12: As far as I know, the are social workers all across the UK, certainly in England, would have a similar system.

**R2: Yeah, that’s great. I’m asking that because I’m… I was in Luxembourg; I think we have social workers but not… I think it’s interesting, these dementia workers being a kind of transition, and giving information, maybe having contact with Age UK or other services. Yeah, great.**

P12: Our dementia worker role is quite a large role that they have, they have a lot of tasks, if you will, to do on behalf of the clients. The client as you imagine doesn’t know where to go for different issues. It’s the job of our dementia worker to provide information, advice, signposting on behalf of the client. That is the big role of the dementia worker. Including giving the client emotional support which is another big thing for people. They need a lot of emotional support as you can imagine.

**R2: Yeah, absolutely. And we’ll talk a little bit about that. So, currently with COVID, things are getting better now, but how have you adapted your activities, and how have people adapted to the situation? I suppose it was traumatic for some of them, but maybe you found a solution, or online activities, these things?**

P12: When we first went into lockdown, when was that? March 2020, we obviously had to stop the groups because we ran groups… well we do now again but Monday, Tuesday, Wednesday, Thursday, Friday, we used to have different groups running on different days. So, obviously all that stopped in March 2020. Initially one of the first things we did, all the clients in the database, we tend to have 350 cases, we had to divide all of those clients between the staff team. We all had roughly about 30 clients that we had to contact through phone. That was one of the first things we did, to contact all these people to see what help they needed during the pandemic. So, for example, have they got family or friends who could do their shopping? So initially we were concentrating on the practical issues of the pandemic, the shopping and were they able to get their medication. Things like that.

We weren’t able to physically do anything. But we were able to refer them to, for example, a shopping service, we have a shopping service, and we were able to refer things like that. So, we concentrated first on the practical issues, and then we started up activities on Zoom. So, our staff had sessions on Zoom which they would do Wednesday, Thursday, Friday we had Zoom sessions morning and afternoon on three days a week for people. And they’re still running, actually. So, we made these phone calls regularly. We had to look at the clients on the list and after the initial contact we had to identify which of these people needed weekly calls, fortnightly calls, monthly calls, and that depended on what support they already had in place. We still do the calls but obviously not as many as we did because we’ve opened the groups again.

We opened the groups back in November. So, we’ve been running from November to the present. But we had to change the way in which we did them because of the guidance on social distancing, PPE, etc. So, we had to look for new venues, it was quite a big job because we could only use a venue which had a robust cleaning schedule in place.

**R2: Okay.**

P12: We had to look at all that. We had to purchase PPE, we had to write risk assessments, we had to do health screenings for clients the day before they attended groups, we had to do the temperatures on arrival, we had to have a protocol in place in case someone had a temperature or were showing symptoms. It was quite a big task.

**R2: Yeah. I suppose it was… quite a lot of things to do so it was probably very difficult for your service, to be able to… it was an overload and a lot of things to do. Have you had external help, or maybe…?**

P12: No, not really. It was for me, and [P8] as managers, to write up risk assessments for every area and work instructions for staff, to make sure staff knew what they had to do, what they could do, what they couldn’t do about masks, about wearing masks and cleaning. It was a lot of work initially but now it’s second nature. We did get advice form Public Health, because everything we did… we had to do a recovery plan and we had to write everything down. That was presented to Public Health, who had to ratify that before we could implement it. It all went through quite smoothly, this was back in October, and like I said we resumed the groups in November. Since then, it worked really well.

One of the things that we did have to change, we used to have groups of more than 15 people. Obviously because of the social distancing and government guidance that we could only have up to 15 people in at one time, instead of having on a Tuesday and Monday groups, which up to 30 people, we had to split them into two groups. We had a group in the morning, and the other half in the afternoon. We’re still doing that. I know that it’s going to change in the near future, but we still have to do that at the moment. So that was a challenge as well, it was more staff time because instead of doing one group each day we had to do two, so we would be there for the full day.

**R2: Yeah. And what has been the reaction of participants, for example, I’m sure they are happy to come back and have face-to-face activities again, but some of them, are they okay asking to keep to online activities too? Or online groups? Maybe they had some WhatsApp groups, or these kinds of things?**

P12: The majority of clients unfortunately weren’t able to access the online stuff, not being techno minded. Not being able to actually navigate their way around a tablet and things like that. So, the Zooms were for mainly, we found the Zooms, initially the person with dementia was able to participate along with the carer but it was the carer who was actually getting the Zoom set up and accessing the activity. The person with dementia was there as well on the screen. What we did find as time went on, the person with dementia has deteriorated because they’ve not been having any outside contact with people and their condition deteriorated. We’ve found that now to the present day, it’s mainly now that carers are accessing the Zooms because the person with dementia, they’re not able to identify what ‘s on the screen or even look at the screen because of the deterioration.

**R2: Do you think, are you… it’s difficult to answer, but do you think it’s… if again we have these restrictions, is it possible to manage better, or do you think all the restrictions, staying at home, it was really bad for people with dementia, and in the future, it will be better to give more possibilities to meet people. Would it be possible in the future to cope better?**

P12: Well, when we first got the COVID, it was no option, really. There was no vaccine, so people had to isolate because obviously if they caught COVID they potentially could have gone into hospital and not recovered from it. It’s been a very difficult time not being able to get out and their condition has deteriorated. But at the time there was no other option. Now of course, because people have had the vaccines and are able to get out and about again and do what they were doing before basically because they’ve got the protection, the vaccines, haven’t they?

**R2: Do they think they are confident with the vaccine, and thinking, okay I have my vaccine, I will stay very careful but now I can come back in these activities face to face, or maybe some of them are still afraid? Because for one year and a half there was not a lot of group activities, or face-to-face activities.**

P12: Well, we found initially in November when we reopened the groups that some people didn’t come back initially because of that very reason. Of course, they didn’t have the vaccines then anyway. So, we did find that people didn’t come back to the groups. But as we went along, even just before the vaccines, when they realised all the procedures that we’d put into place and they were sitting two metres away from people, wearing masks, the staff each time someone even went to the toilet, the staff would put on full PPE, clean down the toilets. Obviously, the health screening before people attended, the temperatures, people gained confidence because they saw we were doing so much to avoid anyone... the transmission of the virus within our groups. Certainly, once people had the vaccines, we found that they were quite willing to come back and do things as they were before.

**R2: That’s really great. That’s good. My last question, it’s a really amazing discussion, thanks a lot for sharing all this information with me. Do you have some people with dementia volunteering with you, helping in the organisation of activities? As you said, your group especially as an early onset dementia group, is really user-led. Are some of the members, or other people, more involved in the organisation in volunteering?**

P12: Well, yeah. Not at the moment now because we’re in that transition between the first young onset group and now we’re having a new one. And obviously the COVID, we’ve not been using volunteers anyway with or without dementia over this period. But, prior to the COVID, we did have some of our people with onset dementia who did volunteer who helped to organise activities and they used to run different sessions. We identified that we had members in the group who had various skills. One lady for example she was very artistic, and she used to make her own cards, birthday cards, Christmas cards. So, when it was Easter or Christmas, we would buy cards and various things to make the cards, the little motifs and things like that, and she would lead the session.

**R2: Oh, great.**

P12: The staff would assist her because she had the skills and the ideas. So, she actually ran the sessions and “card making with [NAME]” we used to call it. And then we had another lady who was really good at planting pots, making little pots of plants. So, we collected pots and get some compost, and buy some plants. She would show the rest of the group how to make the pots for outside in the garden. And they’d all take those home. So, any skills that any of the group actually had, if they were willing to share and to run a group. With the staff, but they would be the lead on it. We always gave them the opportunity to do that. This lady was really good at painting, she did a lot of art and made some pictures and we put them on display in the community art centre in Eccles. And some of them were sold and the proceeds went to the group.

**R2: Oh, great.**

P12: So, we’re certainly empowering the clients as best we can.

**R2: Yeah, it’s really amazing what you are doing to give them pride. That’s really great.**

P12: Obviously, the volunteering with the people with dementia we’ve always done that in the past, and it is my intention to continue to do that with the new group. If anybody has any skills that we can utilise and if they’re willing to get involved in helping the staff to facilitate a group, we’re all for that. It’s better for us too, we get a rest.

**R2: Yeah, exactly [laughs]. It’s really great. So, I think I have no more questions, but do you want to speak about something, do you have an idea maybe of something you would like to do in the future, or you would like to do but you would need more of a budget or something changing in Greater Manchester?**

P12: Only that we’re starting the new young onset dementia group, we’re in the process of getting that up and running. We have another meeting tomorrow. I’m quite excited about starting all that again and seeing what challenges they give me for organising any activities and events. A lot of them, because they’ve got the diagnosis and they want to help other people, they’d like us to organise events where we can raise awareness. In the past, we’ve had, you know where you go to the supermarket and you put up a stand and you have leaflets and give out leaflets to people to raise awareness of the condition, and to let people know if they’re experiencing memory problems that if they go to their GP as soon as possible, they can get a diagnosis to find out one way or the other. It’s hard for people to do that, some people may be in denial. We used to do these awareness sessions and some of the people with dementia, they wanted to be actively involved with helping. So obviously I’m hoping to start all that again with our new group.

**R2: That’s great.**

P12: Let me just share one story. We had a young guy in our other group, he’s sadly passed away now. He was only 55 when he passed way but he did a marathon. I’m just asking my partner because we used to always run, now we’re getting older, but we’ve done marathons in the past. We had this member, and he was born in 1963. So, in 2015 he would have been how old? 51 he would have been, we used to go running every weekend at the park runs and we took this gentleman with us. Obviously, it was out of work time, but he used to come running with us and he decided he wanted to do a marathon.

**R2: Okay.**

P12: He’d never done a marathon before, he’d always been physically active, cycling and rock climbing but he wanted to do a marathon. We used to do training runs with him, and in 2015 we got him into the Manchester Marathon. My partner ran with him, but he wasn’t sure if he would be able to do the whole distance at that point as he was injured. So, I also went on my bike to follow him around because he wouldn’t have been able to run on his own, he’d have gone on the wrong path.

**R2: Yeah.**

P12: He decided that he wanted to be sponsored. He raised about £1,500 in total for the service. He completed the marathon, and his family, his wife and two children were there at the finish line. That, it brought tears to your eyes. I was saying to you before about the acknowledgement, the achievement, even when you’ve got dementia, there’s no limits.

**R2: Yeah.**

P12: If they want to do it, they can do it. We facilitated a lot of things like that with different individuals but that was the greatest. Getting him round that marathon. That was incredible.

**R2: Yeah, that’s great. Just hearing this story, I was having tears in my eyes.**

P12: Honestly, if you had been… it’s emotional for anybody, I’ve done it myself to get over that finish line. But someone with dementia, who couldn’t do things like, he couldn’t even hold down a job, he was a successful businessman and then when he got the diagnosis the only job that he could find was collecting shopping trolleys on the supermarket car park. Then unfortunately, because the spatial awareness that you get with young onset dementia, they had to dismiss him from that position because he was crashing the trolleys into cars. It was awful, being a successful businessman traveling the country being a salesman, then you can’t get a job collecting trolleys. It’s horrendous. To give him a purpose, to help him complete that marathon, it was so emotional and amazing for him and his family. It was really good. You have to look at what they can do as opposed to what they can’t do, don’t you?

**R2: Exactly, it’s something individual.**

P12: For us, as Age UK staff, to identify. Like I said, we do things in the group which is in our job role. But we also tend to do a lot outside that remit as well. It’s certainly worth it and it gives you so much satisfaction, because I’ll never forget that day.

**R2: Yeah, that’s really great. Well, that was really a very nice discussion, thanks again…**

P12: You’re welcome.

**R2: … for taking this time and it’s really… thanks a lot. I will send you an email again because, to say thank you for your participation. You can have a £20 voucher or donation if you prefer. You can just write and explain that, and you can think about that.**

P12: Okay. Thanks very much [R2], nice to meet you. Thank you.

**R2: Me too, bye-bye.**

**[End of document]**