**Transcription – Carer 6 (paid)**

Duration: 27 minutes, 45 seconds

[First part of interview involved the completion of a demographic form with paid carer]

**Interviewer**: So yes, the next bit is sort of the interview questions. And because you participated in the PETAL therapy. We would really like to know what you thought of it.

**Carer 6**: Yeah. No problem.

**Interviewer**: Yeah, if you have any feedback for us, that would be great. So my first question is kind of a general question, what motivated you to take part in the PETAL study?

**Carer 6**: The service user I was working with had a couple of incidents in the community, um, regarding aggressive behaviour. Also, had an incident with the BT police regarding an allegation. I thought it best that we work to find out find out, why, he's doing his behavior and how we can support him in order to help him understand, how he gets into these situations and what we can do to try and alleviate these situations.

**Interviewer**: Okay that's that's good. Yeah, that sounds good. And can you describe what it was like to take part in the study?

**Carer 6**: Yeah, I found it really useful. It wasn't judgmental. It was relaxed. It was done at the service user’s pace. Yeah, sometimes we deviate from the sessions, and the person running the sessions, was able to bringing the person back in but also meeting that person's needs, you know, so there was a couple of cases where she had to read from his book, he got a book about his life and she read that, and she was able to do that, and then she's been able to refocus it through focusing back on the work that, we were supposed to be doing.

**Interviewer**: Okay, that sounds, I'm glad to hear that. And you know, I was telling you earlier about the information sheet, and you said you got that maybe a few months ago, and I sent it to you yesterday. What did you think of that sheet? Did you think it was easy to understand what the study was about?

**Carer 6**: Yeah, It's what's in the book. He had a book, you know, a book for ourselves, and a book for the service user. And it's what's in the book, explains how it is, so it's fine.

**Interviewer**: Okay, that's good. And I just want to confirm this. Was it you that did the questionnaires at the beginning with [Participant 6]? Or was that the key worker?

**Carer 6**: Oh, I don't recall, sorry I don't. I don't know. I mean, maybe I did them, because I'm not so sure if they actually interviewed the care worker. I think she went on holiday round about that time, as I remember, that would have been me. But I can't remember what they were.

**Interviewer**: Okay, yeah, there were quite a lot of questions as sort of about aggressive, challenging behaviour, about mental health.

**Carer 6**: I think it was me, thinking about it, I think it was me. But I’m not 100%.

**Interviewer**: Okay, okay, that's okay. So if it was you, do you remember finding them easy or difficult, or if you don't remember, that's okay.

**Carer 6**: I don't remember, sorry.

**Interviewer**: No, that's okay. Okay, thank you. And sort of more about the therapy itself, you already kind of answered this, but what would you say was your overall experience with the PETAL therapy?

**Carer 6**: Yeah, it was good. The only thing that I've, it was a couple of things. Is one that I think I said this to [Therapist 2], that we should have the same book as the service users. Our book was different, you know, our book was more, I mean, it didn't follow the book of the services user. It was different, you know. So it was it was a bit difficult to correlate the 2 together if that makes sense, any sort of sense. And I just thought that [Therapist 2] did bring some, she made some cards up but I just thought that we should have had all the leaflets, they should have been able to be taken out. You know the bit about all the different ABCs and the other things, the emotional behaviour, all the stuff, you know, that had red, green, yellow, 1, 2, 3, and this one, I think we should have had those resources as a separate sheet, you know, because we don't have a colour printer. It’s a bit difficult to get these. We’d have to go to the head office to get that. I don’t know why saying that, that’s not really your problem. You know the all the bits the bags, rather than just be in the book. We could have taken them way, maybe photocopied them, or something like that, you know. I think it maybe would have helped with filling in all the forms and that sort of thing. Do you understand what I mean? Rather than it being in the book. Do you know what I mean? I know it’s the first one, it’s just my observations about it.

**Interviewer**: Yeah, no, that's really useful feedback because I guess the book is kind of heavy. It's maybe not the easiest thing to carry around if you want to use it more. Oh, yeah, that's great feedback, thank you. And did you feel during the therapy, you were able to raise the issues that you were concerned with the most?

**Carer 6**: Yeah most definitely, yeah, no problem. She was open to any suggestions we had. The venue, where it was, breaks, you know, questions. Yeah, it's really, really relaxed. We were heard, we were understood. You know, as I said, it's no judgment about, you know about the way we supported the service user. We were there to learn and give our experiences and it was fine.

**Interviewer**: Okay, that's that's great. [Background noise of people talking] Is everything okay?

**Carer 6**: [to someone else] I am just on the meeting in the office so..

**Interviewer**: That's fair enough. And was there anything that made it easier or harder to attend the sessions? Because obviously, you know, in terms of timing, or

**Carer 6**: No, no. it was done at the time to suit the service user. We just arranged it for the same day every week for the 14 weeks. And it was it was fine, you know. I mean, there's a couple of occasions where I had to, I was late because I had to go and due to staff sickness and they started the session without me. Because then like, I’ve been to another place, I had to take somebody out or something. So yeah, there's a couple of occasions, I mean. [Therapist 2] was always on time, you know [Participant 6], Sorry used his name. Sorry about that. It was a bit getting him focused and let him know that the session is starting, and so once he was in, he was in there, you know, [unintelligible] [Therapist 2] couldn’t get him to participate if he needed a break, so we took a break, and there was no problems with that. And the only thing was that we had to have it in our laundry room because the office is a bit small. It wasn't a private space, but that was the only place that we had available really was. The door was locked and not locked, but the door was shut and it was kept private from other people. Other support workers and service users in in the house.

**Interviewer**: Okay, I see, I see. And did you ever have to miss a session?

**Carer 6**: No, no, there's I mean, I was like about 10 minutes late or 5 minutes late. And as I said it was because people were sick and I had to go deal with their support. Apart from that, no, I didn’t miss any sessions.

**Interviewer**: Okay, that's good. And what would you say, what did you find the most helpful from the therapy?

**Carer 6**: I found that you know the actual stuff about having, you know, different ways of getting what sort of emotional state the service user was in and what he needed to do in order to communicate this, to talk to other people. How you could communicate that, you know, suggestions about different ways, you know whether it's smiley face, whether you know colour of temperature, whether giving somebody a card and such. So there was different way of how he was able to, could be used within future that we could, you know, even use this or stuff to help. He has trouble communicating and understanding what he has to say and then frustration. So using words or pictures or colours could help people understand how he's feeling at that particular time, and also he's not, he's not forthcoming with his emotions. He will just say, I'm happy when that's not really the case. It just seems like his base sort of thing. It’s what he says all the time basically. So I thought it was useful, that you can you are happy. But you can show someone a card with a miserable face, a red face or a red colour or something like that then you can show how you really feel. Sometimes you can say these things to make people happy when you're not feeling that way inside. So I thought that was useful.

**Interviewer**: Umhm, yeah, I yeah, I think I understand what you mean. Almost a bit like wanting to please other people.

**Carer 6**: Yeah exactly.

**Interviewer**: Yu mentioned that you like some of the, you know the exercises about emotions and things. Do you think you would ever use those after you finish the therapy with him?

**Carer 6**: Yeah, I think I think it. Yeah. I mean, I think, even if it doesn't the service user doesn’t want to use this. I think you can use it elsewhere. I think it’s transferable, if that’s the right word, to other people, to other situations, you know. Yeah, I think it's I think it's a useful sort of tool to have and a resource to have. You know to be able to, it might not work for this person, but it might work for somebody else, you know. So I think it's good.

**Interviewer**: Yeah, yeah, that's great. Obviously, cause you work with other people as well.

**Carer 6**: Exactly.

**Interviewer**: Yeah, do you think the sessions made a difference in how you handle [Participant 6]'s aggressive challenging behaviour?

**Carer 6**: Yeah, I think so. I mean, from a personal point of view. I mean, I think it would be better if it wasn't me, because I don't support him all the time. I think it'd be better if it was his key worker. But due to holidays and sickness, it was not possible, do you know what I mean. But you know I think it is useful. I think it would be good to sort of roll it out to everybody somehow. I don't know how you do it. I'm not an expert in these things, but I think it would be good to have a course on it, and you know, obviously the individual I mean, I don't know. You can't give it individual to everybody, can you. But I think if you, once you have done the study and work through that and got all the feedback and all the data from it. Then I think if you could if it was rolled out to support workers in general.

**Interviewer**: Yeah. I mean, I think we are hoping that once it's finished, hopefully, at least in the NHS it will be rolled out, and then we'll see. But that's great. Do you think [Participant 6]'s actual frequency of challenging behaviour changed, or the frequency or intensity?

**Carer 6**: Um, that is a good question. I mean, I think it's a bit. It's a bit soon to know this, because it's not every day that this happens. It’s when he gets frustrated in the community. And I mean he did display some of it during the therapy when he didn't get immediately what he wanted, and we had to explain, and we can't always get what you want immediately, and that was a whole reason for his behaviour. So he needs to when people need to understand him. But he also needs to understand that the world doesn't revolve around one particular individual. So you have to, when you got a learning disability, sometimes you yourself have to be patient when dealing with people, and see from their points of view, which I think we tried to do it in the sessions that sometimes he has to wait, you know, and for the most time, I would say 90% of the time, he was okay with that and he waited. But whether he'd be able to do that outside you know what I mean, that is that is to be tested really.

**Interviewer**: Yeah, because you did just finish. Not too long ago, so.

**Carer 6**: Yeah, you will have to see.

**Interviewer**: And so you know, you mentioned the 2 workbooks, the carer one and the participant one. Did you, I mean you already sort of said this, but did you find them helpful or not?

**Carer 6**: Yeah, I think they are helpful. As I said that I think that maybe you need that book, because it's bit more in depth into what's going on. But I think we should also have the same book as the service users, so that when they're working for it, we can see exactly where they are. And sometimes it didn't correlate, is that the right word, to where he was in the book. So it's a bit difficult to find where he was and where we were in the big book. Still, yeah, the same book then we could say, okay, so this is the theory behind it. And this is the practical, what are the better words.

**Interviewer**: Yeah, definitely. There were also some home practice tasks in the books. Were you able to do any of them in between?

**Carer 6**: Yeah, we worked on some of them. We worked on the communication plan. You know some of the emotional things. Some of them, the service user didn't want to do. So, we had to try and persuade him do it. And he did, some of them, but not a lot of them. So I mean, maybe did every other week, or something like that. You know he didn't do every single one when it was supposed to be done and nor did we. To be frank, we didn't do, cause if he didn’t do it, it's it was a bit difficult to get everybody to get on board with it, you know. I mean without me being there all the time. It was a bit difficult for me, I have to say, to get everybody to, you know. I mean I'll put some out there, but you know, it's a failure on my part really.

**Interviewer**: Yeah, I understand, that's okay of course and do you think, you would maybe keep using the workbook after?

**Carer 6**: Yeah, yeah, I think so, yeah.

**Interviewer**: Okay, that's good to hear. And did you feel because there was obviously quite a lot of different sessions on different topics, did you think, which sessions did you think were not as helpful for you and [Participant 6]?

**Carer 6**: No, I thought they followed the plan, you know about it, so I think they were all interlinked, and they were all valuable because this is a trial, and it's to see what works with him. You know everybody's different, aren't they? So, you know, so it was, I mean, it was not repeated, but it was using different tools, you know same sort of thing. But it was just seeing that which tool would work. So I don’t think they were unusual. I mean what he finds useful afterwards would be different, you know, I mean that would be for him to find. Is that you know, what would he like to use, you know? Would he like to use Smiley faces? Would he like to use colours? Would he like to use words or whatever. So I think it will, I think if it's I think they were all useful really.

**Interviewer**: Okay, that's good, yeah. Do you think there was anything you would have liked support with, but it wasn't included in the sessions?

**Carer 6**: No, no, no, it was fine.

**Interviewer**: Um, good and did you think that the therapy sessions were maybe too time consuming?

**Carer 6**: No, no, think there were whatever half hour I think? Yeah, no, no, it was fine.

**Interviewer**: That's good. And you already mentioned about the workbooks, which is quite useful feedback. But do you think there's anything else we should change?

**Carer 6**: I couldn't think of really, I'm, no.

**Interviewer**: Okay, it's okay, and do you feel like there was anything kind of in relation to the environment. I mean, you mentioned not having sort of a lot of space to do it.

**Carer 6**: I mean, it's probably that's probably like a lot of places. There is no dedicated room, is there? I mean, but that's just the way we made the best of this situation and the environment we were in, in order to keep it private, and then also as comfortable as possible. You know what I mean, so he didn't want to go somewhere else, maybe 500 square or something in a meeting room, or something like that, and if you make him less comfortable and all as well. I think it's best meaning, I don't know for everybody, but for [unintelligible] it was best that it was at home. And he can do his activity so it's not that much a break in his routine, especially if you know somebody's routine based, you know. It’s a problem then to go travel somewhere in order to tick the other boxes. And it's a way at it's a, it's a sort of compromise, isn't it? That's something that might not be the best environment, best environment for in terms of privacy and comfort, but it might be best for them.

**Interviewer**: Yeah, of course. And I mean, you are able to make it work, so that's the most important thing. And yeah, do you think there was anything that could have been improved in the way you were supported throughout the [therapy?]

**Carer 6**: No, no. We were supported great. We were listened to, you know. It was a friendly environment, you know. There was no pressure, no judgement, as I said, and it was fine.

**Interviewer**: That's good, I am oh, glad to hear that, and I guess the last thing to ask is just is there anything that I haven't covered here that you would like to talk about?

**Carer 6**: No, no, no, no. I’ve mentioned about the book, about the obviously having the resources available, you know. And then such just that one make sure that we do get a copy of the findings. And maybe that's also sent to [Name of service] head office or something like that. Maybe I don't know how it will work or to be to the service user for sorry, the service manager for [Community learning disability team], or something like that, don't I don't know how it all works. I don't know in terms of that would all work. I don't know, but I mean I'm assuming it's just there's no, I don't know how it will work, so say so. I don't know whether there's a confidential issue regarding that. Yeah, that's it, really.

**Interviewer**: Yeah, well, we post updates on our website, and we'll be starting sort of the main trial soon. And yeah, I think after the main trial, and after the results are kind of analysed, I think that's when we'll start sharing them with more people. See how it went.

**Carer 6**: Is it 5 years from now the project?

**Interviewer**: It should be about 2-3 years more, I think.

**Carer 6**: Yeah, that’s fine then. I will be gone by then. If he's gonna be 2 to 3 years and I`m happy to add anything I’ve said, I mean, if it's if it's before that, I would just like to have a look at what what's been recorded about me. Is that possible? Does that make sense what I’m saying there? You know, like the individual, I mean, I don't know. Sorry I don't know. I don't think I'm explaining myself properly. You know the individual, I mean they were recorded weren’t they, the individual sessions. What happens to those recordings? Are they kept separate from the things? You know what I mean.

**Interviewer**: Yeah, so they are kept safe, separate. They're uploaded on a system called [Encrypted system] which is encrypted. So they're not really, it's not just on someone's computer and they were deleted from the original recording device. And they're just used for checking that the therapy, the sessions were okay. You know that they weren't too different from, you know, one person was doing this thing, it's just kind of a quality control.

**Carer 6**: Then is those sessions, are they kept, when you do the report? Or they kept separate from the main reports sort of thing?

**Interviewer**: Yeah, the sessions

**Carer 6**: Yeah, that’s fine. I'm happy, you know. I mean, you know, sometimes, you know, like I do, I mean what I'm trying to say is, I'm not saying that, you know, be careful what I say. Sometimes you might say something that's not correct or something like that, and you know, people judge you for that. You know I'm talking about my sort of organization. So as long as it's the case that those sessions are kept separate, you know. Obviously, unless it's something that could cause harm to somebody. I understand that with confidential. If those are kept separate, then I am happy. Before anything else to be put forward so that anybody else can see that, you know. Does that make sense, in my organization? We don't see your research, you’re a researcher, your research is your research, you have to research things. So I'm happy. I'm just trying to not protect myself. I'm just trying to make sure that I'm not putting myself out there in something that somebody then can question my professionalism, or work ethic, whatever you want to call it. Do you see what I am trying to say there?

**Interviewer**: Yeah, I understand. The recordings are more so to check how the therapists are doing to be honest. And the recordings are not gonna be shared at all, you know. Obviously, we would never put anyone's name out there. All the data is kind of anonymised when it gets published. So I wouldn't be concerned that your yeah.. But of course I can email you more information about that.

**Carer 6**: No, no, I will take your word for it. If that’s what you say, that’s what you say, you know me that’s fine.

**Interviewer**: Okay, that's great. I will stop the recording now then.