**Transcription – Carer 7 (paid)**

Duration: 43 minutes 59 seconds

**Interviewer:** So now, I can actually start the interview. Thank you for those few bits. So, for the interview, I have some questions in front of me, so I might sort of look at them. But I'm still listening. Okay, so yes. Again. Thank you so much for your time today and for participating in the PETAL study. So, these are just questions about your experience, and we use them to make improvements and see what went well. So, my first question would be, what motivated you to take part in the PETAL study?

**Carer 7:** Oh, well, I've been working with learning disability, and specifically one with the severe challenging behaviour. And that's what motivated me to be part of the study, because I want to see that change in that person from being aggressive to being either moderately aggressive or even nonaggressive. So, I want to sort of, I want to see the change. And since they said the aim of the study was to see how we can positively change the behaviours of challenging learning disability patients or persons. I really want to see that change. That's, why, that's what motivated me.

**Interviewer:** Yeah, that's great, thank you. And can you describe what it was like to take part of the study?

**Carer 7:** It was very educative because there are a lot of things that we have been doing with him that we never knew had names, or people had done them before. But when we are doing this study, we find out that these are things that we are doing, these are the names of the things that we are doing. So, it was more educative, and it was also very enlightening. And also, it improves our ability to calm him down. To move him from being too aggressive to being found in the green zone. So, these are some of the things that I picked up in the study.

**Interviewer:** Hmm, okay, I see. Yeah, that's really interesting. You kind of put a name to things you are already doing. That's great. And I think so… You weren't the person who did the initial questionnaires right with [Participant 7]. Do you remember doing any questionnaires?

[unintelligible due to bad sound]

**Interviewer:** Oh, sorry

**Carer 7:** I wasn't.

**Interviewer:** Yeah, I think that might have been his mom, who did that. So, I'm going to, yeah, so I'll skip those questions. But did you have any thoughts about the information sheet? Did you think it was sort of easy to understand, or..

**Carer 7:** Yeah, it was clear.

**Interviewer:** Okay, that's good. I guess more specifically about the therapy, and you already touched on this, but what was your overall experience with being part of the PETAL therapy?

**Carer 7:** As I said, it’s enlightening. It was able to teach us how to cope with him, you know. Like how we should talk to him. How we should change his… not giving him… not giving him a direct [unintelligible] making sure… These are things we've been doing but we never knew that names. So it gives us more confidence once we are doing to pursue those strategies in managing him. Of course, we know that for him, it gets heightens by remembering things that have happened in the past. With either the other service users or with any other person that he has encountered before, for example, somewhere in the school, or someone at home, or someone in the streets. He can just pick any one of them up and then use that to be aggressive. So like, we had to learn how to be able to take our time to make him process, to understand that what he's saying is in the past. And that it doesn't need to be aggressive for him to pass out his message. Sometimes he has been those things just because there is someone that is doing something he doesn’t like. Or he wants something to happen that isn’t happening. For example, he wants us to take him out and we don’t take him out. Maybe feels like this person is talking too loud on the phone. You know someone is… instead of paying attention to him, possibly doing something else. He uses that, uses those things, those imaginations to spark up aggressive behaviour. We learn how that…we have to look for the triggers. And then from identifying the triggers, we are now able to… because if I guess the trigger, the result is better than just talking to him to calm down directly.

**Interviewer:** Yeah, that's great, I mean, if you can sort of get the triggers, maybe sort of, you know, before it happens, before the aggression happens. Yeah, that's great. Thank you and did you feel like during the sessions… Were you able to, you know, say if you had any concerns? Were you able to express those during the therapy?

**Carer 7:** Yeah, we were experiencing concerns. There are times when we're doing the therapy. We will be in our, of course, our natural environment situations. Like yesterday he hit someone at the back on the back or he hit a man on the chest, right? And then [Therapist 4] will relax “How do you feel doing that? Do you think it's right?” So, she would bring out the fact that what he is doing is not right. Because staff don't like you to be hitting them. You know, you [Participant 7] have the tendency of, even if you are enjoying yourself, you have the tendency of hitting something. You tend to hit staff, instead of hitting the staff, you hit your hand on the wall, or on the door, or something. And you have to do injuring yourself and our own goal in taking care of him is to ensure that we would protect him from injuring himself and we also protect ourselves from being injured. Because he's not the only one we are looking after, we also have to look after ourselves so that he doesn't hit us somewhere that…I mean might cause permanent disabilities for us, you know. So, these are concerns that we usually bring up, we discuss it. And at times he agrees. But of course, he always agrees. To say he will not do it again is a different thing. “I will stop it. I will stop being abusive”.

**Interviewer:** I see yeah. That's good. And was there anything that made it sort of easier or harder to attend the sessions?

**Carer 7:** One of the things that made it harder to attend the sessions is the fact that we don’t get the links early. Yeah, like we are doing it every Monday, and the person that's sending the link to us only comes online after 9am. That's your 10.00 'clock. So, the link comes in around 10.15, 10.30. And mind you, we are also…It's not only one person that is working. We have several people working with him. So, if you send it to the team leader and the team leader has to make sure the person that is on duty gets the link. And usually to send those links across to [Participant 7] we have to go through home. Because, as you know, carers cannot allow service users to have their number to send things to him directly, we send it to the mum and then the mum will send it to [Participant 7]. You understand? So, with that, it was challenging. In fact, by the close of the sessions I had to ask [Therapist 4] to start sending these on Friday. Although it was not successful. But because of that challenge, we wanted it to be coming earlier.

**Interviewer:** Yeah, because actually, you were our only participants who were doing the therapy online. So, I think, yeah, I think there's a lot to learn from that, you know, the logistics to make it easier for if someone else in the future also does it online. Yeah, things like that meeting links is something we need to consider.

**Carer 7:** It needs to be earlier to be better. But when you send links late… there are times, even the person that is supposed to start the meeting would be doing something else, and then we'll might remember that. And you cannot call that person easy, the number of the carers, or the service user. So, we have to depend on the mom sending the link, and at times [Therapist 4] sent it to the mum but the mum is doing something else. So, between that 30 min anything can happen. And that can make you miss the session.

**Interviewer:** Yeah, yeah, of course. Yeah, that's something we'll have to sort of be considerate of in the future. Oh, yeah, thank you. That's really helpful. Because, as I said, we've only done it online once. So it's really helpful to know that. And you said, missing sessions. I don't know, if you remember, roughly, how many sessions would you say you attended?

**Carer 7:** We attended 14 sessions.

**Interviewer:** So, you attended pretty much all of them, really.

**Carer 7:** Yeah, we attended 14 sessions.

**Interviewer:** Hmm, did you ever have to miss a session?

**Carer 7:** One session or so.

**Interviewer:** And was there any particular reason?

**Carer 7:** It was the reason that I mentioned. Because we missed one session, no, we missed 2 sessions. One was because [Therapist 4] who was supposed to start the session had another appointment, so she was not able to join. And then the other one was they sent the link, but the people that were on duty got the link and we are not able to join the session early because of that small time difference, you know. They were not able to join the session early. They had to postpone the session. You know what I mean.

**Interviewer:** Yeah. I understand. Okay. And so, you mentioned a few things, but what would you say you found the most helpful from the therapy?

**Carer 7:** The most helpful if I could clearly remember. In terms of helping us. But I think, I think one of the most helpful things was bringing out the triggers. There was a session we had about thoughts and bringing out the triggers for [Participant 7]. That was the most useful session we had. Yeah.

**Interviewer:** That's good. And I mean did you… Do you feel like the sessions made a difference in how you handle his challenging behaviour?

**Carer 7:** I think it makes a difference. Difference is that it gives us more confidence handling the challenging behaviour. We are not afraid as we have before, because we don't know what his trigger is. We were not able to ask him directly what the problem was, because when he triggers, he will not tell you. That is because is of what is happening there, I'm telling you. No, you have to identify it yourself, mind you, that's a difficult process. You have to identify it yourself, because if you don't identify the trigger, you will try to calm him down by talking to him, saying all sort of things to him. It will be able to see if he has calmed down, but it is not, it will just pop up again and he will do the worst thing.

**Interviewer:** Mhmm. Yeah, I, see and have you noticed as you've been doing the therapy and you've now finished. Have you noticed any changes in sort of the frequency or intensity of [Participant 7]’s challenging behaviour?

**Carer 7:** Hmm. I would say, we are managing it better. I would not say the frequency has reduced, no. The behaviours are coming but it’s just that, as I said earlier, we have better understanding on how to tackle it, and also we now are more confident in tackling it. But for the challenging behaviours, they come every day, just like it was before. Some of, most of them do not lead to incidents now, because of people managing it. But of course, they come. He will be aggressive morning, afternoon, and evening. And of course, that's the issue of him being most aggressive at night especially 11-12pm to 2am. That one is still there. So, but what I notice is that staff are becoming more confident in handling challenging behaviours from [Participant 7].

**Interviewer:** That's good, that's great. And yeah, I mean, you've just recently finished. So, I guess you'll see how things kind of progress after you are done. That's good. And you know. You remember, during the therapy there was workbooks, and there was one for you, and then there was one for [Participant 7].

**Carer 7:** Yeah, one for family and direct care. And then we have one which is for the participant with learning disability version. So, we have those 2 books.

**Interviewer:** Yeah. Yeah. And what did you think about them? Did you find them helpful?

**Carer 7:** Yeah. And especially one for the participant. Hmm, hmm, yeah. We are frequently using that one.

**Interviewer:** You are mainly using [Participant 7]’s one? That's great. And there were some kind of home practice tasks to do in between sessions. Were you able to do any of them?

**Carer 7:** You said, what?

**Interviewer:** You know, there was the home practice tasks.

**Carer 7:** Right, we did all of them.

**Interviewer**: Oh, really, that’s great.

**Carer 7:** [unintelligible due to bad sound] We are still doing some of them. We are doing some, where you have to look at what you did today. Right, those kinds of things. There are like expressions. Yeah, we have daily activities. “How do you feel about doing what you do today? How do you feel doing it?” Those kind of things.

**Interviewer:** No, that's really great. Actually, something I we've heard as feedback from other people is that it was kind of hard when there was multiple support workers working with someone to sort of get everyone on board with doing the tasks. Did you have any sort of issues with that? Or I guess, as a team, how did you communicate? Sort of what information needs to be done?

**Carer 7:** Usually for every change of shift. We'll hand over to the next. Like, for example, the therapy was happening every Monday, so the staff that are on duty when they change over to the staff on Tuesday, they will give them all a briefing about what to do. Because he continues doing his home exercises even after the day. I think they'll give them what to do. We have a session usually if he's not going out. If the service user is not going out, we have sessions for him, where you do colouring, puzzle, juggling, mathematics. During these sessions we will bring in the assignment, the home sessions to do. So, it passes on from one carer to another. So, it was not most challenging for us, because this is something that we do every time.

**Interviewer:** Yeah, that's really great that everyone was able to help out. That's great. And was there any sessions in the therapy that you think, you thought were not as useful as the other ones?

**Carer 7:** That's…When was session better than the other one…Hmm. Where he is supposed to identify faces. You know: ”How you feel. This is how you feel.” I don't think that made the most difference. It was just identifying them, but it was not practicalizing them. You know, it was not like using them in practice. I don't think, I don't know if that's if that is this works [unintelligible due to bad sound]. Because I feel like the calming techniques, relaxation techniques, techniques of identifying triggers, communication techniques like how to communicate with the service user, how do communicate with him at different levels - when he's calm, when he is the amber zone, or when he's aggressive in the red zone. How do we communicate during those times? I mean, these were very, very important. Okay. but the other ones like, well, you look at the faces, those ones I don't, I don't think… Yeah he will identify the faces, but it doesn't make much difference to him. I don't know. Yeah. This is Happy Face. This is a Sad Face. But it doesn’t make much difference. What difference does it make? Does it make him calm? If he has a happy face, does that mean that he's going to be happy? Doesn't mean that it can be. He can identify “How do you feel? I feel happy”. This is every time for him, even if he acts aggressive, as soon as the accident is over “I feel happy”, after 1 min goes back to being aggressive. I don't feel like this one was helping as much.

**Interviewer:** Hmm. I see. Do you think he is usually able to identify his feelings, like he usually knows what he's feeling. Maybe that's why it wasn't really helpful. If you already...

**Carer 7:** Yeah, I think so. I think he doesn't know how to identify some of his feelings. You will, every time you ask him, even if he is aggressive, you ask him - “I'm happy” - “And by the face that you have now, how do you feel? You don’t look too happy”. And then, by the time you turn your back, you [i.e. Participant 7] do something, you now start fighting people.

**Interviewer:** I see, yeah.

[interruption for a few minutes]

**Interviewer:** I mean. So, I think the last thing we were talking about is sort of which sessions weren't as helpful. And I wanted to ask, kind of going off of that, is there anything that you think we should change when delivering the therapy in the future?

**Carer 7:** Oh, yeah, I think when delivering this type of behavioural study we need to be… disciplined. We need to be able to assess ourselves, maybe after every session. Like, for example, we say do the first 3 sessions - like how to get to know you, what is aggressive behaviour, what is challenging behaviour, and then come to communication. We need to reassess. What the questions that I think we should be asking should be – “What has the service user gained, and what have the carers gained?”. I mean, those things should come out. They should start coming up during the sessions. So that we see at the end, we see accumulative change in the behaviour of the service user and the carer. Because the service user is doing training, but the carer is also learning from this process. So, I think we should… That's one part that I think, we need to improve, right? We need to make sure that the assessment is not only coming at the end but make sure it comes in between sessions. Like we take a look at one bulk of chapters that we think are related, and then we assess the person, we assess whether they are making any change. Like, for example, after the communication, do the carers now try to communicate with him better, and then also has there been a change in the way he [i.e. Participant 7] is responding to the carers because of that. You know, those are the things that maybe we should be asking ourselves when we are doing it next time, you know. And also, I think what makes it difficult in the whole process was the fact that it was online. You know, there are times…well, because it's online, some people do not concentrate well. So, I think having it face to face would have really helped rather than doing it online. Well, it should not be much of a difference, but I just think it's just a subtle thing, you know. When people have someone coming to them and then sitting with them and then there is concentration and then they are looking at how they are behaving within the household, how the interactions happen makes more sense than when you're out there like you're just talking to me now. You don't know what else is happening around my environment other than seeing my face, you know. So, I think, I think we have to also look at that aspect. Maybe how we can improve it. We can make it better than just being online. We can do a strategy where you have some sessions online, and it's 1-2 sessions that you can do face to face. Because mind you, those face to face interactions, I'm telling you, they make more sense, you know. So that's my current opinion.

**Interviewer:** Yeah, definitely, I think the plan, yeah, I think the plan was to deliver in person. Because we think the same as you. I think it's really helpful to be in person, because, you know, you see the person's body language, you see what's going on. I think it was just in [Participant 7]’s case because he kind of moved, that's why it had to be online. But yeah, it's still really helpful to know. In the future if someone else has to have it online, that it might affect, you know, how well the therapy works. So that's great. Thank you. Was there any kind of other factors in the environment that you think influence the therapy? Did you have kind of the space and resources to do it?

**Carer 7:** We have space. We have resources. No problems because internet is wonderful. Our space is big. [Participant 7] sits comfortably. The support worker also sits comfortably. So, we don't have problem with those. The only time we had issue was when there was a challenge with their own internet [i.e. Therapist 4], they had a challenge with your own Internet, I think in the office. So, on that day, we're not able to have the session because of that.

**Interviewer:** Of course. And is there any anything that could have been improved, do you think, in how you were supported throughout the process?

**Carer 7:** Can you come again, please?

**Interviewer:** Oh yeah, I'm sorry. Just yeah, anything that could have been improved in the way that support was given to you?

**Carer 7:** Yeah, I think I've mentioned the most important one, being that maybe we need to like, continue do in the session assessments and looking at improvement, things that have changed, things that we think that we need to improve whilst we are doing this session. I was thinking that could maybe make a big difference, right, not only the service users but also the support worker. Because the support worker can be like “I was doing this right. Oh, no, I was not doing this right. I was doing this, but if I do it like this, it would have been better for me, so next time I'll do it like this.” Because I learned from this session that when I'm communicating, instead of speaking loudly when I'm cautioning [Participant 7] I can speak softly but with clear instructions “[Participant 7], stop hitting. Hold it and stop hitting [Carer 7]. That is not good.” You know, I mean those kinds of things.

**Interviewer:** Yeah, that's great. That's fine. I think. To be honest, that was all of my questions. Is there anything else that you think we should talk about?

**Carer 7:** Yeah, I want to ask, what's the next step after this thing?

**Interviewer:** Well, so because this was part of the sort of the feasibility study which is kind of like the first test of the therapy. Yeah, this is sort of the end of the therapy for [Participant 7]. But for us, we're just now starting to sort of get more participants added. Yes, once we recruit everyone and they finish therapy. Then-

[There was a technical problem and the recording ended but Interviewer just finished explaining and then they said thank you and goodbyes]