**Transcription – Carer 8 (paid)**

Duration: 26 minutes 03 seconds

**Carer 8**: Fine, yeah, yeah.

**Interviewer**: Right, yes. Is it ok or good?

**Carer 8**: Yeah.

**Interviewer**: Fantastic. Thank you. Right. So just for the recording, today's date is the 8th of March 2024. My name is [Interviewer]. I'm a researcher on the PETAL study and this is a feasibility interview with a paid carer. So thank you so much again [Carer 8] for your time today. You have just taken part in the PETAL study, which aims to find out how to best support people with the learning disability who also show aggressive challenging behaviour. I just would like to discuss with you your recent experience of taking part in the feasibility study and your views about the whole therapy and how you found it. This would be very useful for us for the main trial because the plan is that we will test out the therapy with more participants now. So any kind of feedback would be just extremely beneficial and useful for us, if that's OK.

**Carer 8**: Yeah, yeah, no problem.

**Interviewer**: Amazing, thank you so much. Right, so the first question would be is that… Oh, sorry, I forgot to mention that I have a bit of a topic guide in front of me so time to time I may look down, but I'm listening to you.

**Carer 8**: Yeah, yeah, No, no, that's fine.

**Interviewer**: Amazing, thank you. So the first question would be that what motivated you to take part in this study?

**Carer 8**: So what motivated me was the fact that I'm in a management position and I wanted to try and get a better understanding around different types of like autism and behaviours and stuff like that to be completely honest with you.

**Interviewer**: OK, that's brilliant, that's great. If you can sort of think back to the kind of study processes, so these would be things like when we sent out an information sheet to you before you actually joined the study and you also had to fill out some questionnaires before receiving the therapy. So if you can think back, I know it was a while ago, but if you can think back of those things, how did you find them? So for example, the information sheet which I think I sent out to you. What were your thoughts on that?

**Carer 8**: Yes, so it can it can be quite difficult in terms of, when somebody lacks capacity or they are nonverbal you, it can be hard because you don't know their thoughts and their feelings.

**Interviewer**: Um-hum.

**Carer 8**: So yeah, a lot of it you can only go off your own opinion, but yeah, it was it, it can be quite tricky when you're trying to because you can't enter somebody's brain and get that across. So yeah, it can be quite difficult.

**Interviewer**: Um-hum.

**Carer 8:** That was the only aspect like I would, I would struggle with.

**Interviewer**: Ok. Ok. No, I absolutely understand. Yes, that's a bit tricky, isn't it, because you sort of try to infer things from behaviour and yeah, it is difficult, isn't it? Yeah. And so just to get back a little bit to the sort of the beginning of yourself joining the study, so if you can remember, I sent out this sort of information sheet which explained you what the study was going to be about and what your involvement would be as well. And I know that was quite a while ago, but if you can think back, was that sort of information sheet useful to you? Or was there anything which would have been maybe even better to sort of being explained to you at the beginning before you joined the study?

**Carer 8**: And let me just go quickly on to my emails.

**Interviewer**: Thank you. I know it was a while ago.

**Carer 8**: Yeah, I know. Here we go. So I'm on the feasibility consultee, or should I be looking at the other one?

**Interviewer**: Yeah, no, that would be a good form. Yes, it's the consultee information sheet. So sort of, yes, yeah.

**Carer 8**: Yeah, so everything was done in in order.

**Interviewer**: Um-hum.

**Carer 8**: It was, obviously, we looked at the therapy part. We looked at obviously the behaviours. We looked at, where else is on here? What did we look at? Yeah, we looked at like medical history, and carer`s confidence to manage aggression. Yeah, it was all it was all done in order.

**Interviewer**: How did you find actually those questionnaires?

**Carer 8**: Yeah, absolutely fine, yeah.

**Interviewer**: Were they all right? Were they kind of easy to answer and you didn't find any kind of struggle there?

**Carer 8**: No, no, all easy to answer.

**Interviewer**: Amazing, ok, that's brilliant, thank you. Ok, that's really great. Sort of moving on to the part when you actually received the therapy. So in general, what was your experience with the PETAL therapy?

**Carer 8**: So my honest opinion would be it's fantastic, especially for the verbal sides and people who have got more capacity.

**Interviewer**: Um-hum.

**Carer 8**: I just feel with our client, it would have been beneficial for whoever was conducting the therapy to come out to the client and so they could see the behaviours and what could be triggers and what couldn't be triggers then why they are displaying behaviours this way.

**Interviewer**: Oh, OK, um-hum.

**Carer 8**: Yeah, it was really difficult from that aspect in regards to the study.

**Interviewer**: Um-hum.

**Carer 8**: Because unless you see the person that we're working with and what types of behaviours they display, it can be quite challenging in terms of managing that. That was the only difficult part for me was talking to somebody that has not seen the client or been out to the client.

**Interviewer**: Um-hum.

**Carer 8:** Yeah, that was the most part that I found really difficult. And the other part would be the, the erm, I'm trying to think of the words.

**Interviewer**: That's ok.

**Carer 8**: So trying to bring somebody back down to baseline when they're in a heightened mind by doing like calming techniques, et cetera, they didn't, they wouldn't work for our client because all the breathing exercises because again, she lacks capacity.

**Interviewer**: Um-hum.

**Carer 8**: And she wouldn't do. She wouldn't let you touch her or do exercises or breathing techniques or anything like that, so again, strategies like that weren't beneficial to the client.

**Interviewer**: OK, so yeah, it sounds like maybe some of the tools were maybe not so applicable to her.

**Carer 8**: Yes, yeah.

**Interviewer**: And what about the calm down tools because I think there was one session which probably touched on those as well. Did you find that useful or?

**Carer 8**: Yeah. Again, we couldn't.

**Interviewer**: Right.

**Carer 8**: No, no, not for our client, but it would be good, it would be good for somebody who had challenging behaviours but also had the capacity to understand.

**Interviewer**: Um-hum.

**Carer 8:** It would have been better for that client. Absolutely, yeah.

**Interviewer**: Um-hum. Ok, ok, I see, so we are kind of touching on what we're not so useful maybe around the PETAL sessions. Did you, was there anything that you would have maybe liked support with, but that was not kind of addressed in the sessions?

**Carer 8**: So the one I liked the best thing about the session was the Broset checklist.

**Interviewer**: Right, ok.

**Carer 8**: We found that tool really useful because it gives you a better insight and a better understanding in terms of. So in our company we do use ABC charts, but they're not detailed as the Broset checklist, so the Broset checklist got your thinking outside the box and it went into more details in terms of what's going on around you, who's around you? What could have been the trigger? Yeah, it was. That was amazing because it ticked so many boxes to try and find out what her triggers were. So I absolutely loved that part of it. It was brilliant. The Broset checklist, yeah.

**Interviewer**: Oh, that's brilliant. Is it something which you would probably be using in the future as well? What do you think?

**Carer 8**: Yeah, so it's something that we continuously use with the girl we look after, yeah.

**Interviewer**: Amazing. Oh, that's really good. I'm glad to hear you know that you found useful things as well. Was there anything else which you found sort of the most helpful from the therapy content, apart from the Broset checklist, if you can kind of think back?

**Carer 8**: So the Broset checklist, what else was that? I have got a list, just bear with me.

**Interviewer**: That's ok. Thank you.

**Carer 8**: Where was my list here?

**Interviewer**: Thank you for looking them through. I know there were lots of things.

**Carer 8**: Oh no, it's fine, it's fine. So other good thing about it was breaking down a communication passport into basically the key elements and it being very just a short, precise and to the point with the relevant information on, but not too much of it.

**Interviewer**: OK, that's really good. So did you then make a new communication passport, maybe, did you update [Participant 8]`s based on that?

**Carer 8**: Yeah, we updated [Participant 8]`s on go through the session.

**Interviewer**: OK, that's brilliant. That's really good. And could I just ask you that, was there any sort of change which you have noticed maybe in her behaviour in terms of you know the frequency or the intensity of challenging behaviour maybe during or after the therapy? Or that's hard to tell?

**Carer 8**: To be honest with you, yeah, it is hard to tell because [Participant 8] had only just come to us, and the transition periods, it's obviously always the hardest.

**Interviewer**: Um-hum.

**Carer 8**: And but now [Participant 8] is in a really good place. But one thing we did do with the PETAL study is I made sure that all the staff were on the same page as me.

**Interviewer**: Oh that's amazing, so consistency, that's key, isn't it?

**Carer 8**: Yeah, yeah, it's consistency has been amazing.

**Interviewer**: Brilliant.

**Carer 8**: So we're not, I mean, for the whole of therapy, just to give you an example for the whole of therapy, we had no, we had no incidents, which meant we didn't need to use any safety intervention on her to keep her safe and staff safe, so that has been it's been amazing like we're all on the same page, we know what we're doing and we manage her behaviours better. And yeah, it's been going good. That was part of the PETAL study about all being on the same page, yeah.

**Interviewer**: OK, that's fantastic. I'm really, really glad to hear that, amazing. So then do you think that the PETAL sessions sort of made a difference on how maybe you and other staff members handle episodes of aggressive challenging behaviour?

**Carer 8**: Yeah, yeah.

**Interviewer**: Yeah, no, that's that's fantastic, great. And if I can just sort of dig into a little bit more detail, so what do you think that what do you do differently as a result of the PETAL therapy?

**Carer 8**: What do you mean, sorry.

**Interviewer**: So in a way of supporting her, so do you, do you kind of support her in a slightly different way or you just said you implemented the Broset checklist, which is great. Is there anything else which sort of maybe you or the other staff members do differently as a result of the PETAL therapy?

**Carer 8**: Yeah, so when [Participant 8] was getting heightened in behaviours, basically, we were going off like, so like we were going off like erm, green, amber and red.

**Interviewer**: Um-hum.

**Carer 8**: But certain staff will let in [Participant 8] get to the red stage before they intervened.

**Interviewer**: Oh, I see, OK.

**Carer 8**: So basically what I said was as soon as [Participant 8] starts with heightened behaviours, we remove her from the room that she's in straight away, whether she's whether she's still in green or not, we remove her from that area because [participant with ID] can go from no to 60 in a split second so people were intervened too late during the process. And so because everyone's been on the same page and they started as soon as [Participant 8] got heightened and they removed her from that room and de-escalated another room, it worked a lot better for us and [Participant 8] returned to baseline a lot quicker, a lot quicker, yeah.

**Interviewer**: Oh, that's amazing, OK, that's fantastic. It sounds amazing. I'm really, really pleased to hear that. And so you do say that that her behaviour is more sort of, kind of, is maintained or she's supported in a consistent manner and that that's seems like it's really helpful.

**Carer 8:** Yeah, yeah.

**Interviewer**: Because she knows as well then what to expect, isn't it? Because once there are inconsistencies, it's uncertain, isn’t it, for a service user.

**Carer 8**: Yeah, yeah, it's yes. So like I was explaining to [Therapist 4], so like with [Participant 8], if she so basically with [Participant 8], if she's we put healthy boundaries in place because [Participant 8] likes going to pubs and cafes for a drink and we get her a bottle of coke, Diet Coke, Coke Zero or whatever. But even when [Participant 8] was showing signs of aggression and hitting staff in the morning, staff would still take her out for that drink. And that's not it's not healthy because [Participant 8] then would think that she can do them behaviours without any consequences and.

**Interviewer**: Um-hum, it's a bit of reinforcement, isn't it? Yeah.

**Carer 8**: So yeah, positive reinforcement basically and again, getting everyone on that same page like [Participant 8] does understand a lot more now that she can't do the, behaviours to staff and still expect to go out for that drink or to that cafe or that pub. And again, it was it was all healthy boundaries, it was all positive reinforcement. And yeah, [Participant 8] has obviously come round to it, she's learnt, and yes, she's in a better place. She has, if we go on a like walks now, she can hit out half-heartedly, because that's a learned behaviour that she's had instilled in her for so many years, but there's no aggression with it.

**Interviewer**: Okay, that's lovely.

**Carer 8**: Yeah, so it, so it'll just, it'll just be a quick backhanded slap to your stomach or to your arm or something but there's no physical aggression there. It's just it's like she's got a tick or Tourette's, and she'll just smack out there's just no aggression, and I think from when [Participant 8] first started with us, the aggression was absolutely terrible, but now she doesn't do any of it. So yeah, everyone is just so much more happier as well.

**Interviewer**: Oh, that's so fantastic, I'm really pleased to hear this, really, it's amazing. Really, really great, fantastic.

**Carer 8**: Yeah, yeah, I think we, I think we needed a lot of the PETAL study did teach me about positive reinforcement and staff as well, so I'm happy about that because I just didn't know whether because sometimes when you when you go into work, you don't know if you're doing right from doing wrong, and then for instance like me not letting [Participant 8] go to a cafe or a pub when she's still displaying behaviours of hitting staff and stuff like that was I in the wrong to take that away from her? But thinking back now, no, it's been the right thing to do because she's learned that she can't do them things and still expect to go to them places and it's just all been, yeah, it's all been positive.

**Interviewer**: Oh, that's fantastic, I'm really pleased. Yes, I guess with reinforcements, it can be a bit tricky to even be aware of that when we reinforce behaviours, isn't it?

**Carer 8**: Yeah.

**Interviewer**: And it's very useful to sort of take a closer look and realise, like, oh, hang on, I was just reinforcing something that I might be doing it or you actually realise, that's really good, I have not reinforced that kind of behaviour so that will be less likely to happen in the future. So well done, that sounds fantastic, I'm really pleased to hear all of this.

**Carer 8**: Yeah, yeah.

**Interviewer**: Really, really great, amazing. Right, let me have a quick look at my questions. Yes, so we have covered more or less of which sessions were not so useful, weren't they, I think you did tell me. What did you think about, sorry, I'm a bit jumping topics, but what did you think about the carer`s well-being session, did you find that useful?

**Carer 8**: Erm, and the carer wellbeing. We just really talked about how I was feeling, not how not how all the staff were feeling.

**Interviewer**: Right.

**Carer 8**: But with me, I am like strong headed and strong minded and so, nothing, [Participant 8] it's never ever affected me mentally because I am so strong minded. And I've seen them behaviours a million times over, so it doesn't phase me in the slightest. But yeah, I've always been in a very good place and yeah, it was just it wasn't it wasn't something that I needed.

**Interviewer**: Um-hum.

**Carer 8**: But obviously some of my staff to begin with obviously were very deflated and but because they were all new to the, to the care system and they didn't have an understanding around autism and things like that. But now I think they're all basically live in their best life with, with, with [Participant 8] and they're in a much better place because I've given so much, so many tools and so much advice to do their jobs. Yeah, it's, it's been fantastic for them.

**Interviewer**: Oh, that's amazing, I'm so pleased. That's a really really great thing. And I'm so happy that you could pass on, sort of cascade all the information and then sort of share all sorts of tips with all your staff members. That's really, really great.

**Carer 8**: Yeah so everything that I learned from, obviously everything that I learned from the study, obviously I implemented and give them the tools from that as well, so it's a waste of time me keeping it all to myself because they're not going to learn and sharing is the best practise so.

**Interviewer**: Absolutely, amazing. Oh, sounds fantastic. Great, and if you kind of think back, is there anything that you think we should change on this therapy? So you did touch on a little bit about the therapy may not be you know sort of in terms of the delivery, it is a bit hard maybe to deliver it for someone who is nonverbal or who lacks capacity. Is there anything else which you think we should kind of change on the way?

**Carer 8**: So the only thing I would change, yeah, it's not so much changing, it's probably a different delivery aspect of. Because [Participant 8]`s behaviours and her autism and obviously being nonverbal, lacking capacity, is like [Participant 8] has been completely different to all the people I've worked with before. So it just would have been for me, it would have been better if somebody would have come out and spent some time with [Participant 8] and with the staff.

**Interviewer**: OK, um-hum.

**Carer 8**: And then gone from there so they can see what she's like, why she's doing it and then talk about what they've seen and how they would manage it and stuff like that, yeah. That's the only thing I would change if it's, if they ever get someone as complex, just what [Participant 8] was.

**Interviewer**: Yes.

**Carer 8:** It just would have been better for somebody to come out, see her the way she is, why she's doing it and then talk around that specifically.

**Interviewer**: Um-hum, OK.

**Carer 8**: But yeah, that's that's the only thing I would change, yeah.

**Interviewer**: OK. And in terms of the content and maybe the workbooks as well, sorry, I forgot to ask you about them. Have you used the workbooks during the sessions with [Therapist 4]?

**Carer 8**: Yeah, yeah. We used the word book, yeah, I think everything is absolutely spot on. I think [Therapist 4], who delivered the PETAL studies to me was absolutely spot on. And yeah, his delivery was very beneficial and exceptional the way he delivered it. Yeah, I can't I've got no faults on the booklet, the content of it or the delivery of it.

**Interviewer**: Fantastic. Would you actually consider using the workbooks maybe in the future?

**Carer 8**: Yeah, yeah, definitely, yeah. I have got an e-mail copy that I always refer to. So yeah, I always have a read over, yeah.

**Interviewer**: Oh, fantastic, it sounds like, I'm so happy to hear all of it. That's great. This is what we were hoping for, you know, so it sounds really, really positive, great. Let me see. And could you raise any concerns during the therapy sessions with [Therapist 4]?

**Carer 8**: No, no, no concerns.

**Interviewer**: No concerns, but if you had, maybe any concerns could you would you have been able to raise, so you did you feel kind of safe to bring up any issues and things like that?

**Carer 8**: Yeah, I'm literally just so open, honest, and transparent. If I don't think the PETAL study would work for anybody, I would tell you. Or no, me and me and [Therapist 8] are on the same page. Like, yeah, I've, you know, I have said, like what I've told you I have said back to him like there was certain elements of the PETAL study obviously that wouldn't work specifically for [Participant 8] but like I said to you, it will work better with somebody with capacity and more understanding and someone who's more verbal, yeah.

**Interviewer**: Um-hum. So maybe for someone on a mild to moderate spectrum.

**Carer 8**: Yeah, yeah.

**Interviewer**: Um-hum. OK, that's actually a feedback which I got from another carer as well, so that's really useful. It's all very, in a sort of testing phase. So basically, if in the main trial it turns out that it is effective, then there are different ways of thinking of, right, so for which maybe population or for which group of people it is the most helpful, so these feedbacks are absolutely amazing. Thank you so much for that.

**Carer 8**: Yeah, yeah. No, no, it's absolutely fine. Yeah.

**Interviewer**: Yeah, fantastic. Right, let me see. And is there anything about the PETAL therapy that we have not covered and you would like to talk about?

**Carer 8**: No, everything was covered to my expectations, yeah. OK.

**Interviewer**: Amazing. OK, thank you so much. So let me just stop the recording.