**Transcription – Carer 4 (family)**

Duration: 27minutes, 36 seconds

**Interviewer**: My name is [Interviewer], I`m a researcher on the PETAL study and this is a feasibility interview with a family Carer 4. Today's date is the 1st of August 2023, and the participant identification number is [participant ID].

Right, so first of all, hello [Carer 4], thank you so much for your time today. So you have taken part in the PETAL study, which aims to find out how to best support people with a learning disability who display challenging behaviour in the community, and today I just would like to discuss with you your recent experience in taking part in the feasibility study if it is OK with you.

**Carer 4**: Yeah, that’s fine.

**Interviewer**: So the first questions are around the study processes, if you remember I have sent you the information sheet at the beginning, then the consent forms and you also filled out some questionnaires with me, so I just would like to generally ask you, how was your experience? Can you describe how was it to take part in this study in general?

**Carer 4**: Absolutely fine, very good. We went with a very good pace I thought, not too fast and not too slow, and yeah, I think it went very well. The information sheet that was sent was interesting.

**Interviewer**: Okay, so did you find that, what did you think about it, was it enough informative or was it may be too long or too short or was it just the right sort of set up?

**Carer 4**: Yeah, I think it was a good, interesting information about what was going to happen and about the right length I would have said.

**Interviewer**: Oh perfect, that's really good, that's very useful, thank you so much. And in terms of the questionnaires, if you remember we had a couple of phone calls (both chuckles), thank you for your patience with that, I really appreciate it. What was your experience with the questionnaires, were there any questions which were maybe more difficult to answer, or in general how did you feel about them?

**Carer 4**: I thought in general it was very good. I would say that some of the questions, and I can't tell you now what they were but were a bit difficult to answer about [Participant 4], and I think some of it is for people that can tell you how they are feeling more than [Participant 4] can but apart from that I think it`s yeah it went very well.

**Interviewer**: Okay, do you mean those question when you have to sort of infer from her behaviour how she might be feeling, which is a bit speculative, isn't it?

**Carer 4**: Yeah, yes.

**Interviewer**: Yeah, but you did very well to be honest and you know her so well, so I think it was brilliant really, a perfect reflection I think but yes, I understand that those are a bit tricky.

**Carer 4**: (Chuckles) Yes, yeah.

**Interviewer**: Yeah, right, so is there anything else you would like to add about the questionnaires or the study processes, or the consent forms or things like that or…

**Carer 4**: No, no, no.

**Interviewer**: No? Okay, right and in terms of moving on to receiving the actual therapy, so what is your experience with the PETAL therapy in general?

**Carer 4**: Uhm, not all the greatest [or impressed?] to be perfectly truthful. I felt for somebody that had [Participant 4] as she is for so long, there wasn’t a lot of information that we could really take out of it, that a couple of things in the book and all that it says try this one for next week, try that for next week, and I really, I felt, to me, I said to the lady [Therapist 6] that was doing it down here, I can understand this more for people perhaps in becoming teenagers and the family still carers but I'm thinking of the family that they lived with all the time, certain behaviours changes as they become teenagers and that, and that I can understand but I felt for us in our situation there really wasn’t a lot to get out of it to be perfectly truthful.

**Interviewer**: Okay, well that's very useful feedback actually. Okay, did you feel like sort of… because I think the idea is that the therapy is personalised, do you think that there was anything else maybe that [Therapist 6] could do to maybe make it more relevant to you or to your situation?

**Carer 4**: No, I don't I don’t, and through her we have got involved with the I'm going to call positive behaviour team but I`m not sure if that's what they're called now, people like that, and [Staff from positive behaviour team], a nice lady is trying to sort out something to make it safer for our car journeys and because it's not safe at the moment and through [Therapist 6] bringing it up was [Staff from positive behaviour team] because it was affecting me, they are trying to do something. What anybody can do is another matter, but it’s been brought to the surface, so that is a good thing because we have been telling people for literally years that it`s a problem, and it`s almost a case of `Nah, that’s not a problem` until it is a problem (chuckles) so in that respect that was very helpful.

**Interviewer**: Okay, so it seems like it helped to bring maybe issues more to the surface and focus more on them and finding solutions?

**Carer 4**: Yeah, yeah.

**Interviewer**: Okay, that's actually quite positive.

**Carer 4**: Yeah.

**Interviewer**: That's brilliant, so then this lady [Staff from positive behaviour team] is going to sort out some additional support for you basically for the car journeys?

**Carer 4**: Yeah, yeah, that`s what we are hoping.

**Interviewer**: OK that's actually really good, that's brilliant, thank you.

**Carer 4**: Yeah, yeah. And I don’t know if you want me to bring this up now…

**Interviewer**: Anything, please, yes.

**Carer 4**: I`ve got the book here that we`ve been going through and I particularly want to say about the Broset checklist that really doesn’t cover [Participant 4]`s problems. I filled in as and when and luckily I'm very pleased to say very few ABC charts which you know we do to a certain extent anyway and we have just had a review with the psychiatrist and [Staff from positive behaviour team] also has got some of that, but because my husband is a learning disability nurse, I was saying to him `Come on, we`ve got to do this, have a look at it` and really we found the Broset checklist is not [Participant 4]`s, so it doesn't, it's not for everybody, that's what I'm trying to say.

**Interviewer**: Okay, so maybe it was too specific for a certain group of people with certain kind of behavioural presentations?

**Carer 4**: Yeah, yeah, the first couple of things – confused, irritable, boisterous – no, she is none of them. Verbal threats, obviously no, because she doesn’t [speak], although there is noises, and but physical, see, she just starts, she goes straight to the start, there isn't anything very often up to it, just follow on at the time, so the Broset checklist really is not for [Participant 4], I just wanted to say, so people like [Participant 4], it isn’t really for them.

**Interviewer**: Okay, that's very useful as well, thank you. Okay, and in general, how did you find the workbooks, not necessarily or specifically maybe the Broset checklist but to use the workbooks. Was it useful, or?

**Carer 4**: Yeah, very very good I thought, yeah. Very interesting, yes.

**Interviewer**: Do you think that maybe in the future you would refer back to the workbooks sometimes?

**Carer 4:** Yeah, yeah.

**Interviewer**: Yeah? Okay, that's very positive as well.

**Carer 4**: Yeah, yeah.

**Interviewer**: Okay, and were there anything maybe which made it easier or harder for you to attend the sessions? Any sort of facilitators or barriers?

**Carer 4**: No, we did it at the [Participant 4`s day service], so the senior carer of [Participant 4] was at the meeting as well, and we did at 11:30 to 12:30, which is when [Participant 4] finishes at 12:30 on a Tuesday, and a couple of times for the time I was trying to hide the car away (both chuckles) because if she sees the car, she wants to go home, so a couple of times we had to, I won`t say cutting the meeting short, but finish very abruptly, [Participant 4] is waiting to go and before she gets upset like we go, uhm, but it worked quite well doing it at the day service I think, with the input of the day service, which also in itself brought up a couple of things that they don't do with [Participant 4] that I would do at home.

**Interviewer**: Oh, okay.

**Carer 4**: And particularly I have always done it, and I think they know but you know they still don't do it they said [Participant 4] like sticking gluey sticking or sticker sticking, and also the other thing was back along they said that they want to, a couple up their ladies was going to start doing sort of like jazz exercise sort of thing, musicy exercise, so I said to [Senior carer of Participant 4], this chap, I said `Oh you never started that, do you?` he said `Oh yeah, we do it on a Monday` when of course [Participant 4] doesn’t go on a Monday. Then I said [Participant 4] would love that because he said something about [Participant 4] joined in some dancing that they were doing, well she loves that sort of thing, so he's trying to do it that they do it on a Tuesday when she's there rather than a Monday when she is not there but I thought `Well, you know you're not helping yourself, are you?` (chuckles). So in that respect it brought to light a couple of things that was just so well, never happened sort of thing, so it brought to light a couple of interesting things for us to talk about yourself so that yeah, it was good.

**Interviewer**: Yeah, so maybe these are sort of points of improvements as well, isn't it?

**Carer 4**: Yeah, yeah.

**Interviewer**: Because did you say that [Senior carer of Participant 4], the team leader? Or support worker at the day centre, is he going to try to then accommodate the session, so that [Participant 4] could take part?

**Carer 4**: Yeah, yeah, he is her senior carer.

**Interviewer**: Senior carer, right, sorry, okay. So could it be that maybe having the opportunity of being altogether with him as well helped the communication perhaps?

**Carer 4**: Oh yeah, definitely.

**Interviewer**: Yeah, maybe the understanding, and then maybe he understands more of your point of view, and you can as well teach him ways of supporting [Participant 4] maybe even better. I'm sure they're doing an amazing job.

**Carer 4:** Yeah, they try, they try (chuckles).

**Interviewer**: Yeah, of course and there is always room for improvement and you know her the best, so you are the expert by experience.

**Carer 4**: Yeah, yeah.

**Interviewer**: That's really lovely, that's very very positive. Then there is a kind of a main question is that what did you find most helpful from the PETAL therapy? If there would be anything, if maybe the sessions made any sort of difference apart from the things we have spoken already about?

**Carer 4**: I've just got this, let’s have a look at the book here.

**Interviewer**: That’s okay, of course. Is there any way that you may handle certain situations when [Participant 4] exhibits challenging behaviour, if you handle situations slightly differently because of the PETAL therapy, do you think?

**Carer 4**: No, I don't think so to be truthful. No, I don’t think so. Uhm, like I said, I think we've been doing it so long now that we've gone to, and I mean one that I particularly checked here, when we were doing it and all that, it said avoid over reacting, and I mean I've always said you have to be so positive, I'm not being funny but even if you like broke your leg you got to smile and say `yeah, that’s okay`, because if you go `ouch`, that sets her off, so then you`ve got two problems rather than one.

**Interviewer**: (laughs) Yes, I remember, we have spoken about this before, yes.

**Carer 4**: Yes, or things like that, so to be perfectly truthful, we were doing this anyway. And the other point was that, similar one was which is what I brought up with people is that says `set boundaries`, and that we're still trying to find somewhere for [Participant 4] to go, there is absolutely nothing, there's no supported living and there's no residential, there's nothing, and my husband is now actually got in touch with a company, which is countrywide and said `have you got a space anywhere because we'll move`. We can't get anything at all down here and [Participant 4] needs to move on because she needs new boundaries and things that we cannot do with her at home. For instance, our latest little thing is when she gets out of the car now, we have to go down the shop which is about I'm going to say like 200 metres down the road, so it`s not that far, but it's what she buys. She buys two cans of drink and a thing of chocolate buttons or Smarties thing she`s into at the moment but the trouble is we've had to do it when we come back from the [Participant 4`s day centre], will take her out later on because she'll want to go out when [Husband of carer 4] comes home, then so we either got to get into a problem because we are saying, `No, you cannot go down the shop again`, then we`ve got to try and get her in, remember we live on a main road, or we just go down the shop and let her buy it again. And she's overweight, I`m not going to argue about it, she is overweight, and we tried to make sure she buys one can of drink, she likes that monster drink or Lucozade but we are trying to buy one and then the other one is a zero calorie one as much as we can. Luckily the local shop has got them, because some shops you go they haven’t, but it's that sort of thing that when she goes in once, it becomes repetitive. And she hasn't eaten sweets today when she`s come home, she hasn't even drunk her drink. We now have a cupboard full of candies (laughs), so I`m trying to hide them anyway so she doesn’t keep drinking them. Well, it`s things like that, if she was away from us in somewhere else, she wouldn’t be in this situation, she is with us, the boundary setting I`ve always said it`s a big thing but it`s easier said than done sometimes.

**Interviewer**: Um-hum, yes, yeah because I guess you don't want to trigger her, obviously.

**Carer 4**: Yeah, well, no.

**Interviewer**: Yeah, it is to find a kind of balance.

**Carer 4**: Yeah, and I just got to let her do it because I can't afford to get down the shop and then they it's unfortunate that you happen to be opposite a nursery now, so if there are kids outside and they start squealing, she`d be really upset [loud noises from children are upsetting for Participant 4].

**Interviewer**: Yes, of course, yes, I remember that that is something…

**Carer 4**: Yeah, so I am hoping that she's got can in both hands so she can`t go (laughs)… But it`s things like that that in the book it says about setting boundaries and all that, I think to be truthful we've been doing it so long I think there isn't a lot more to do really on it.

**Interviewer**: Okay. And for example, this particular issue about the shopping and that it becomes a repetitious thing for her, did you discuss this with [Therapist 6]? Did you have the space to talk about these recent issues?

**Carer 4**: Yeah, yeah, and also [Staff from positive behaviour team], because one of our ABC chart was, we had a bad one when we were on the edge of [Town] and that we were at the little cafe and had a, [Participant 4] had an ice cream and then she wanted another one and we said no, so we got her out to the, saying into the car and we got about 50 yards down the road and she just flew at us. Now, looking back, we've noticed, we do discuss it when we get home that is there anything we could have done different and talking then to [Therapist 6] and [Staff from positive behaviour team] at different times, we decided in that respect that you got to let her have another ice cream, it's not worth that sort of behaviours for an ice cream. The problem is if you sat in the cafe, she would eat the whole freezer (chuckles) but if we let her have an ice cream and took it into the car and therefore she was eating it when we left, it's possible that might have been alright, so it is something to think about for our future, I think so. But it’s the little things like that, and then you, in the end, you just don't go in anywhere, all we do end up is driving around because we know there`s going to be a problem if we go in, so life is not very good at the moment really.

**Interviewer**: Yeah, I understand.

**Carer 4**: It is a difficult one, but I would say that it's been interesting but as for having to change much of what we do, probably no.

**Interviewer**: Um-hum, and do you think that filling in the ABC charts did not also offer further support?

**Carer 4**: Well, we did, we've always done them, we do them anyway.

**Interviewer**: Um-hum, yeah, you have done them already.

**Carer 4**: Yeah, that's what I, yeah, we have done them for the psychiatrist and before the psychiatrist, and behavioural people, we have done them before, so we, just me and [Husband of Carer 4] we do this like with the ice cream visit, we do discuss it if we've had a bad one when we've been out we come home and when [Participant 4] is usually gone to bed, and then will say `Well, is there anything we could have done different`, but like I said I think perhaps a few years ago doing it might have made more difference than now, that's what I was thinking.

**Interviewer**: Um-hum, okay, that's very useful actually, thank you. Yeah, but I like the fact that you reflect on the day with your husband of `Okay, so what we could have done maybe differently`, I mean you're doing amazing job already, that's for sure, yeah.

**Carer 4**: Yeah, yeah.

**Interviewer**: Okay, the next question is that which PETAL sessions were not so useful? If you maybe look back in the books or if you can just think of anything?

**Carer 4**: Well, yeah, [Therapist 6] decided that we wouldn’t do the Emotions [Module 4], she didn't think that that would be able to be done with [Participant 4], so we didn't do that one at all.

**Interviewer**: Okay, did you agree with this decision?

**Carer 4**: Yes, yes, I quite understand, yeah, yeah.

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

**Carer 4**: So that one, and healthy habits, we discussed quite a bit on that one as well, for eating as much as anything, but you know you can only do what you can do sort of thing but that that was there, we did discuss that one quite a lot actually.

**Interviewer**: Okay, and which sessions were do you think the least useful let's say?

**Carer 4**: Oh, can I also say for me I thought the my wellbeing [Module 6] was very good because as we did that when [Senior carer of Participant 4] was on holiday purposely and so if it was just me and [Therapist 6].

**Interviewer**: Oh lovely.

**Carer 4**: And I thought it was nice to talk to somebody about problems (chuckles) because we all have them, and yes, that was very good for me.

**Interviewer**: Oh, that’s really nice! Did you feel like you could take home things from it, maybe implement small changes as much as possible to make your wellbeing a bit better? Because obviously there is quite a lot of burden on you.

**Carer 4**: Yeah, yeah.

**Interviewer**: That's lovely and that's nice that it was just the two of you, so it was a one to one.

**Carer 4**: Yeah, I think it would have been different if [Senior carer of Participant 4] has been there, he is a nice chap and all that, but I think that one to one, that worked well I thought.

**Interviewer**: It's more personal, isn't it?

**Carer 4**: Hm, yeah, yes.

**Interviewer**: That's lovely, that`s really good to hear.

**Carer 4**: And what was the question after that? (laughs)

**Interviewer**: Yeah (laughs), I`m trying to see the guide, because we are covering lots of things already, so I just kind of have to see where little gaps are.

Were any of your concerns or worries responded properly during the sessions, how did you feel about that?

**Carer 4**: Fine, no problem.

**Interviewer**: Yeah? Okay, and were you be able to practise the home practise tasks between the sessions? How did you find those?

**Carer 4**: I did look (chuckles), I did read them, and do as I could but there wasn’t an awful lot to do, and funnily enough, one of the sessions, and [Therapist 6] did come along with, uhm, I`m going to call it a passport, I think we didn’t know what they call it…

**Interviewer**: Is it the communication passport?

**Carer 4**: Yeah, yes, that’s it, and she brought one that she had, I don’t know whether it was from an idea or whether she just had one, but [Participant 4] had one when she left school, which is 4-5 years ago now but because she has just started respite at [Participant 4`s respite service], I just updated it, because I thought when reading it `Oh, some of these needs changing and add into in and all that`, and one of the thing was to change and adapt to, so I said `Oh, I have just done that one` (laughs).

**Interviewer**: Okay, that’s really good.

**Carer 4**: It just brings it to the front of your mind and had I not just done it for a reason then yes it would definitely been a good thing to do. There wasn't an awful lot to try and implement.

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

**Carer 4**: But, uhm, yeah (looking thought the workbook). I can't think of anything here particularly.

**Interviewer**: That`s alright.

**Carer 4**: (still looking through the workbooks) No, I don’t think so.

**Interviewer**: Okay, thank you for having a look for me (laughs). It's good to have the workbook as a reminder, isn't it? Because it's been sort of spanning across, how long were they, two, 3-4 months, four months almost the sessions?

**Carer 4**: Yeah, yeah.

**Interviewer**: And was it okay for you to arrange as well the times, of finding time basically for the sessions, was that fine?

**Carer 4**: Yeah, yeah, no problem at all.

**Interviewer**: Okay, and was there anything else that maybe we should change in terms of the content of the therapy, the delivery of it, the questionnaires, any of study processes or anything around the therapy and the whole study?

**Carer 4**: No, I don't think so.

**Interviewer**: No? Okay. Uhm, let me see, and do you think that, is there any way that maybe the way you were supported during the therapy could be improved in any ways?

**Carer 4**: No, I don`t think so.

**Interviewer**: No? Okay, uhm, let me just have a very quick look on all of the guidance questions, but I think we went through pretty much everything. Yeah, we spoke about what was most helpful and what was maybe less helpful (both chuckles). Yeah, so how was your experience overall?

**Carer 4**: Good, good.

**Interviewer**: Okay, so in spite maybe that you have known so much already and how to support [Participant 4], it maybe at least helped to bring those issues to the surface?

**Carer 4**: Yeah, I think that’s right, yeah.

**Interviewer**: That’s actually quite positive, yes. Is there anything else about the PETAL therapy which we have not covered, and you would like to talk about? Is there anything which spring to mind?

**Carer 4**: No, I don’t think so.

Interviewer: Okay, I`m going to have one more look but I think we covered pretty much everything, yeah, I have the feeling that I forgot something (both laughs), I hope not. Yeah, we spoke about that, okay, right, okay, yeah, I think we pretty much covered everything but I'm very pleased that there were still positives and [Staff from positive behaviour team] is going to as well help you with the car journeys and hopefully that will be some sort of further support as well from her in general as well about supporting [Participant 4].

**Carer 4**: Yeah, yeah.

**Interviewer**: So is there anything else you would like to add?

**Carer 4**: No, I don't think so.

**Interviewer**: No? [chuckles] Alright then, okay, so I`m going to stop the recording now, thank you so much for your time.

**Carer 4**: Thank you.