**Professional/clinician**

A Yeah. Because it’s hard you know, because as a parent, and especially as a parent of a child with special needs, you also have to have one eye on them. Because especially with (Name of patient-participant) epilepsy, especially as she can be a little bit disruptive and she’ll do things that are not always appropriate, so how can you concentrate on what’s being said by the consultant, by the doctor or whoever it is that you are seeing, and keep an eye on your child. So you know if I’m able to take that away I just think everybody’s going to get a better service within that timeframe. Because it is only a timeframe, it might be a 20 minute to half hour appointment you know because everybody is so pressured and so busy, so let’s get the best we can in that option for all concerned.

**Family member – lives with patient-participant – person with learning disability**

This one’s about being included – the picture’s not so good. But being included. Do you feel like you’re included in (name of participant’s wife/patient-participant) healthcare appointments?

A I’ll put it into there [participant places symbol under ‘happy’ top-scale symbol].

Q You’re happy with being included. How do they include you in (name of participant’s wife/patient-participant) healthcare?

A They just say how…..oh….[sun is in participant’s eyes]...

Q So, included, how do the doctors and nurses include you in (name of participant’s wife/patient-participant) healthcare?

A Well they….sort of like ask….well how long has she been having them for? And I say “well I think it’s been quite a while” and ??? I suffer with angina.

Q So they ask you questions that you can answer, mmm.

A Aha.

**Carer**

Participant – So, to being with, I’d say it was all [name of psychologist] and then as the year and then the months went on, [name of psychologist] was like… but even if it was all [name of psychologist], it was all very [patient-participant] centred, does that make sense? So, [name of psychologist] wouldn’t say anything unless she got permission from [patient-participant] first. Towards the end, when [patient-participant] got her confidence, that’s when [name of psychologist] said, “ok, let’s start co-chairing the meeting. You sort out the agenda with what you want to talk about and then we will discuss it, either bring it up or because you’ve given me the agenda, if you’re not comfortable with talking, then I will.” I actually think that was massively positive in encouraging her independence and confidence because… once-upon-a-time she wouldn’t talk, she might go, she might go do things that weren’t in her best interest, like get on a train to London and being picked up by the transport police, but now she will come and she will say… she will talk to us, she is very open, you know, “I’m going to [patient participant’s partner],” and when she gets there she will ring, she never had done nothing like that before. I think she got the confidence… confidence and trust, I think trust is massive for her… well I know, I don’t think, I know trust is massive for her. She only lets certain people into her flat that she trusts. She will only go and engage with staff if she trusts them. So, that buildup of trust takes a long time, and I think [name of psychologist] installed that in her by encouraging her to speak out. You know, she was able to turn around to my mum one day and sort of say, “this is how you’re making me feel sometimes,” whereas once-upon-a-time she was never able to do that. So, I think it’s brilliant. Absolutely brilliant.

**Carer - lives with patient-participant**

Because of her learning disability, most departments try to meet [patient-participant] on her level. Sometimes that doesn’t happen, and they talk about [patient-participant] and not to her, but most are open to if I step in and say, “can you please talk to [patient-participant], she can understand this if you explain it in a simple way,” most are quite open to doing that. So yeah, it’s been a mixed bag for [patient-participant],

**Family member – lives with patient-participant**

A Yeah. But me as a mother, call for (Name of son/patient-participant), you know they know that I am for him. (Name of son/patient-participant) doesn’t speak that much so I have to speak for him.

Q How do you find your mum speaking for you (Name of son/patient-participant)?

B I don’t mind, I don’t mind.

A At the moment I’m talking on behalf of him. But there will be a time he needs to talk for himself you know, I won’t be here all the time for talking you know. But as long as I’m here I’m talking on behalf of (Name of son/patient-participant) all the time. There will be a certain time when (Name of son/patient-participant) has to talk for himself.

**Carer**

Participant – Yeah, it’s like now… so, we do a meeting now and I’ll say to her, “give me what you want to talk about within that meeting,” so we continued that on. She’s involved in… to be fair, we do team meetings and we actually, normally, the person is involved with their review with my team and then team meetings are normally close-knit team meetings, but because [patient-participant] has always had a say since [name of psychologist], we involve her in those meetings as well. Sometimes you do have to have meetings without her, but it’s better to have them with her because she then knows that we understand what she wants, do you know what I mean? So, yeah, the last meetings we had there was her mum and dad involved in all of them. Which means that she is definitely leading her team which means that she is definitely leading her team because we’ve got nothing to hide… not that we do, does that make sense? It’s all out in the open, you know, if we say, “that’s not the best route to go down, have you thought about doing this?” to her in front of everybody rather than behind the scenes, if you know what I mean. So, she really is leading everything.

**Carer**

A And let them control the situation where they can. And to talk with, rather than talk at.

**Carer**

Q You used the word ‘respect’ to talk about how the psychiatrists treat (name of patient-participant), “they always treat him with respect”, his doctors do.

A Yes.

Q So my first question about that respect thing is, how do they treat him with respect? What does that look like to you?

A I think that they always address him as (name of patient-participant). He likes to be addressed as (name of patient-participant), and I think he immediately gets that. I think sometimes doctors being doctors they use sort of big words let's call them that….or in (name of patient-participant) presence when they're talking across the table to other professionals who understand, and at which point (name of patient-participant) puts his head down. And I always know that he… (name of carer 1) attends these appointments more than me with him these days. But in the past, I've always known that's when he's kind of shutting down a bit, means nothing to him.

**Carer**

A Their demeanour, you know it all comes back to I suppose the communication. It’s being high spirited, happy, and then being kind as in fulfilling the way that you want the appointment to be. You know just being kind about it, offering….you know “would you like this to be done”, you know if there’s a need for blood tests or whatever you know, rather than just saying “this is going to happen, right we are going to do this”. Give the option of asking “do you feel that you need something else from this appointment” rather than just assuming that what I’m telling you is the way it’s going to be.

**Carer**

Q Yeah, where they can understand those choices and it’s a meaningful choice kind of thing.

A I’m trying to think now really. I mean….yes. A few times, especially if I can remember correctly that is, during (name of patient-participant) appointments, you know they’ll ask his opinions, like “is that OK with you” sort of thing, those sort of questions you know. So that sort of thing is where it comes then to asking “are you OK with it” your respect for that and your choices and listening to it.

**Carer**

Q What I’d really love to hear from you is maybe a story of a good healthcare appointment that you observed as a support worker.

A Oh, there is one of recent….the one that (name of resident 2) had. So she had a support worker that came in here for a planned review and as you’ve met – I know you met (name of resident 2) I know you met the other lady.

Q Yes.

A So she’s not verbal?, she can hear what you can say, she do hear you when you speak but she’s not verbal?. A lot of fact that even if she can’t reply she was telling her what she was here for, what they would discuss, like in a way of carrying her along. Because we all know she can hear even if she can’t speak, and telling her what the outcome is and everything. That’s what I like. Like it was so impressive to see that, not like saying “oh she can’t speak so there is no need to carry her along”. The fact that even if she can’t speak she still talked to her to tell her that “my name is this, I am your new social care worker appointed. I love your room, I love these” like she was chatting with her even if she can’t reply her back. It was so lovely to see.

**Patient-participant – person with learning disability**

Researcher - Perfect there you go, great, imagine you are a doctor, the world’s best doctor, what are the kinds of things you do, how do you treat your patients, take your time and talk me through it

Participant – I normally, always use the stethoscope and check the stomach, you know the heartbeat, take temperature, use things on their knees what do you call it

Carer (?) - Reflex

Participant – Reflex yeah, use reflex, give medicine if they need it and bandage them up

Researcher - And how do you treat your patients?

Participant – Smiles and jolly, and talk to them about things, not be horrible to them

Researcher - So what kind of things do you and your patients talk about?

Participant – All sorts like how they are, what can make them better, what they can do for themselves, what I can do to make them better

Researcher - And what does, when you said you would talk to your patients and be jolly and not be horrible to them, what do horrible doctors do?

Participant – Like not even talk to you about anything, you know not even talk when you do things, just do it, not speak to you about what they’re doing, if you don’t know what they’re doing you might jump and you don’t want that

Researcher - When you talked about the horrible doctor you actually did like a grumpy face

Participant – Yeah

Researcher - Do you think it’s important to also, with your patients you said you smile, so it’s important how they look

Participant – Yeah

**Carer**

We have the patient and the kind one that would want to treat them nicely, and anything they say, even if they can’t really understand, they will ask you, the social care worker, for their name. They will ask you the support worker to like translate and try to get to know them so they can be able to provide the care they want or they need.

**Patient-participant – person with learning disability**

Q OK. And then what happens?

B So we…my mum discusses about the medications and it’s going good, straightforward. Then a brand new medication. Then it was the ??? when I was a kid so this is back once at the time I experienced the ??? was a new medication.

Q Yeah. And the medication helps you I hope.

B Yes.

Q Do you mind that the doctor mostly talks about the medication with your mum?

B Yes I don’t mind.

Q Is there any part of you that wants to be involved more in that talking about the medication, or are you not bothered?

B Well between (Name of epilepsy consultant) and my mum I don’t mind. My mum has got control over the medication and when to order and date, so yeah I’m used to it.

**Carer - lives with patient-participant**

Participant – Humanising care is by being there for the people that need care… especially the people that are vulnerable… it’s listening, being kind and gentle, not being too formal but also communicating to the person that needs care and not talking over them or talking to their carer instead. So, their point of view… even if the person that needs the care, even if it seems irrelevant, they are cared. I think the thought that that person has been listened to will help that person, the feeling of being listened to… in a way it helps them to regulate themselves into their self-esteem

**Carer**

really been excited about every time (name of dietitian) comes and when (name of dietitian) comes she always talks to (patient-participant) and I just happen to be there so another member of staff will be there but we are irrelevant because (patient participant) is the person she has come to see and it’s really refreshing to see, it’s so nice that there is someone there to just be there for that person and know that we are only the support, so (patient participant) loves that, she feels like she is in control of that, she’s asking questions, she’s getting information and after the appointment she is always very excited to take on board the information she has been given and the ideas that have been given and shared so she is always very excited to start doing those things, for instances changing the way she is doing her morning breakfast so instead of having cereal she will have a yoghurt, just little bits of information but because of the way it’s been put across she is excited to do it and excited to have that information, so she is always looking forward to the next appointment as well rather than thinking oh god I don’t want to do that, because everything is explained really well, everything is understood, why you are doing it, why we might be saying this might be a good idea, so that’s a really good one for (patient participant), she always excited to see what she is going to be doing next and how positive (name of dietitian) has been about her journey so far and maybe when (patient participant) hasn’t lost a little bit of weight one week or one month, it’s not a big deal, it’s a kind of encouragement to carry on what she is doing.

**Carer - lives with patient participant**

Treating them exactly the same as they would with someone without additional needs; with respect, listen to them, be kind to them, involve them rather than exclude them to the extent they are being excluded in mainstream society. I think to humanise the healthcare would be a massive benefit to people with learning difficulties. If they were being, sort of, discounted a bit, perhaps ignored a little bit, or not believed in some sort of way. I think it’s a good thing if you can humanise it even more because most GPs and healthcare staff are fine but some of them, like that very senior consultant was an absolute dickhole!

**Family member – lives with patient-participant**

A Well not judging on face value, don’t judge them. I mean look at them and listen to what they’ve got to say, but obviously be at their level. I mean use words that’s not too complex and keep it very basic for them to understand if they’re going to talk to them. I mean you mustn’t tar everybody with the same brush, so the saying goes. I mean if you know there’s something wrong - I mean be respectful first of all, don’t ask if there’s something wrong with you I mean be respectful - and explain, you know explain if there’s…..I don’t know whatever there’s got to be….I’ve lost myself….explain to like….

You know if they’re going to talk to somebody I mean and you know there’s something wrong, be understanding and respectful of that person. I mean don’t judge a book by its covers. I mean you need to take time out and listen to them. And you could sum it up, you know in the first couple of words, you know. I mean just be caring to the fact that it could be a child or a relative to that person. I mean whether they like it or not or they feel a bit embarrassed trying to talk to that person with the learning difs or what, or have got a disablement, I mean they need to stop and think, those young people you know or those adults have got feelings and they can see, they can hear and they can feel. I mean they need to step back and take into consideration of that person who they’re talking to and treat them like a human being by way of giving them time and giving them enough time to understand what you are trying to tell them. And if you feel that they don’t understand obviously speak to the person that they are with, but also looking at that person, talking to them, but also talking to their carer or their parent, whoever is with them, addressing them as you would do with any other person. You know include them, don’t….I can’t think of the word….exclude them is the right word, is it?

**Professional/clinician**

Quite often in clinic when we go to clinic (Name of patient-participant) in the past can be quite disruptive, so I take her out for a walk so mum can talk openly with the consultant. You know I’ll engage with (Name of patient-participant) so that that dialogue that is required around her needs, I try and keep things a little bit better for the appointment to be more productive, as opposed to trying to work around them.

I can catch up with the letter and I can catch up with what’s been said afterwards, but it’s more about (Name of patient-participant) having her needs met in that moment and mum and dad having the freedom to express themselves, to be able to say what the issues are and what the difficulties are. Because otherwise it’s not going to be productive is it, it’s not going to get…and the appointment will just – I can’t say fail – but they won’t get out of it what both parties need. So that’s the type of thing that I try to do, to try and be the middle man you know, to help within that.

And I love spending time with (Name of patient-participant) anyway, she’s such a lovely young woman and she’s so funny. And when you get to know her she’s got her own communication style and she says things for different things. And I can work that out I can…but other things, and I love to help her. I don’t know where we are, but yeah. But that’s my aim within our sessions, and just to give the family the opportunity to ask questions and if I can find out an answer then I will, if I can’t then I’ll openly say “I don’t know, I’m not sure what that is”.

**Carer**

Where there are some, there are a few, I’ll call them too professional, they just want you to speak and not listening to the patient you came in with, the disabled patient you came in with. So they will be like they don’t want to waste their time, they have people waiting, or they have people waiting. So that’s my own feeling.

**Family member – lives with patient-participant**

A To me it’s to treat people how you would want to be treated. I personally don’t understand how people can be rude. Unnecessary. I just feel like there is a lot of rude people out there that like to be rude to people. So I just think treating people nicely. Communicating and explaining situations. And with (name of daughter/patient-participant), it’s nice that people say (name of daughter/patient-participant) name and speak to (name of daughter/patient-participant).

**Family member – lives with patient-participant**

Q There was a moment when no-one had spoken to her, (name of daughter/patient-participant) in a few minutes, and then suddenly….and (name of consultant - epilepsy) was talking and she was directing it at you and your wife. And then I just heard her say “Fucking Bitch”.

A That’s right. I remember that.

Q And I thought “she’s brilliant”. I love her look, I love that she like can speak for herself. Advocates always tell us, the guys on our project who have learning disability hate it when they talk to the carer and not them. And I thought this is obviously somebody who is able to express themselves….

A Oh, in a funny way sometimes as well.

**Family member – lives with patient-participant**

Q And I wonder what you think about…because obviously people have to change their communication to suit the person they’re talking to, how do you do that in a way that’s not talking down to somebody?

A Even talking down, like sometimes you’ve gone somewhere and someone didn’t say hello to (Name of sister/patient-participant) because they think she’s non-verbal but they haven’t even….even if she was non-verbal they could still say hello. I feel like that’s talking down if you just ignore someone’s there completely. And I feel like talking down doesn’t have to be like something rude – I don’t know actually, I don’t know what I’m trying to say.

Q So it doesn’t have to be something rude.

A Yeah, talking down to someone doesn’t have to be something rude, I think you could just be like the way you act as well. Yeah like not acknowledging someone’s presence.

Q You’ve also talked about dignity and respect. So how can doctors and nurses show dignity and respect to patients and people?

A Well like (Name of sister/patient-participant), she wouldn’t be aware if someone were giving her dignity. I feel like even if she doesn’t respond you should ask, like “oh I’m going to do this now, is that OK”, something like that. I think it’s just respectful to do that, even though she probably doesn’t know. But yeah.

**Family member – lives with patient-participant**

A No she went to the, is it (name of hospital)? (name of town) (type of service - a multi-disciplinary team). She had a couple of appointments with them. We went to the…. I went to the appointment and we were in ??? and I think we had to go there twice. And then she had to go to another place then up in (name of town), I want to say (name of town), and she had to go there but I wasn’t allowed to go in with her because they had questionnaires and things like that. But for the one where she went where they asked about her family background and her childhood, so I went into there. And then they were asking her questions “can you tell us…(Daughter/patient-participant)”, “yeah”, like “no you can’t”. And the woman said, she’s looking at me then as if to say “who are you” like or “what’s it got to do…”

Q Be quiet mum.

A Yeah. But then like I said to the woman, instead of just asking these people can they do….

Q Tell them to turn ???

A Yeah exactly. So like I said to the woman, am I locked then? And there was a clock behind us like that, right. And then I said to the woman, I said “can you ask her to tell you the time”. So she said “oh”. And then she said to (Daughter/patient-participant) “can you tell me the time”. So (Daughter/patient-participant) is looking at the time there….??? And I said to her “is that normal then for a (early 20s) year old to look at the clock and then work the time out like that?” I said because to me it’s not. I’d look at the clock and tell you it’s 7 o’clock, or 10 past 7 whatever the time is, I’d tell you what it is.

**Family member – lives with patient-participant**

A Well always appearing to be interested in her as a person and talking directly to (Name of daughter/patient-participant). She’d talk to us as well but she’d also be talking to (Name of daughter/patient-participant) and communicating with her and seeing her reaction to what she was saying. And I think the fact that (Name of consultant) didn’t just talk to us about her, like the old business of ‘does he take sugar?’ I think that (Name of daughter/patient-participant) felt that (Name of consultant) understood her and she just trusted her. And I think that was simply by (Name of consultant) communicated directly with her. Even if she was talking to us she’d be sitting, looking at (Name of daughter/patient-participant) and holding her hand, and I think there was then a communication. And I think that’s how that probably built up that relationship. And has probably improved. It was always cemented by the way that we, when we were at home, talked about (Name of consultant) that, you know how lucky we were to have her help and so on. And if she didn’t feel very good “do you think we ought to try and tell (Name of consultant) about that?” you know.

**Carer**

Researcher – I wonder if you could tell me some stories about any NHS services that (patient-participant) has received, does anything spring to mind both good and bad.

Participant – So, I think it varies to the person, it doesn’t necessarily vary in the job role and it depends on the actual person, so I know that (patient-participant) has been to appointments where nurses have addressed her directly as it should be and talk to (patient-participant) about how she is feeling and what is happening, you know the next steps of different things, but she has also been positions where a nurse, one particular nurse has spoken directly to the support staff also overlooking her which she did come and speak to me about that and that was really quite upsetting because she is not silly and she found that a little bit as you would as... obviously when you go to an appointment you expect to be addressed to you, so the staff had to remind that particular nurse that (patient-participant) was right there and she was able to communicate her own needs, that’s only happened twice I want to say because she didn’t see that nurse again. Overall (patient-participant) has always said that she has found it easy to talk to in other professions,

**Carer**

So 9 times out of 10, she has come home from different appointments feeling quite positive about things but she does voice when she is not overly happy and I think it is genuinely when certain practitioners will talk about (patient-participant) to people rather than talk to (patient-participant) about what’s going on and sometimes the information may not be completely to (patient-participant's) level of understanding, this is only from what I am gauging but it’s almost like a conveyor belt, they are just waiting for the next person to come in and get information across quickly so you can go. But (patient-participant) has always spoken very highly of appointments and always come home quite excited apart from those few times.

**Carer**

We’ve got an individual that’s currently involved in a meeting because she just… it’s too much for her, she doesn’t understand what we are talking about, she doesn’t get it… so, we do have meetings without her but there is our reason for having meetings without her, it’s not because we need to talk about her behind her back. We just need to know what we are doing for her; we are getting right moving forward. So, there is always worries, isn’t there, with how you deal with situations? I think for [patient-participant], we deal with it that way because that’s right for her.