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

But like I said, it helps that the carer on that [day if the week redacted] actually works at (name of day centre), so that to us is a lot of peace of mind.

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

I mean the turnover of different people is quite a lot. (name of daughter/patient-participant) healthcare workers changed twice or something like that, and that’s annoying. Because the problem being then, and it’s happened all the way through, they never seem to know what they’re been doing to add to the problem. So we keep having to regurgitate everything that we’ve been through, you know what’s wrong with (name of daughter/patient-participant) blah, blah, blah. And that information has not sort of been fed down to the person taking over or something like that, it’s not…how can I put it….there doesn’t seem to be any communication if you like. That’s disappointing. Because it’s hard to sometimes talk through (name of daughter/patient-participant) health. I know (participant's wife/patient-participant's mother), it does upset you sometimes when you keep having to go through her life and stuff like that. So there’s that.

Joint interview: **Patient-participant – person with learning disability and Family member – lives with patient-participant**

NB. A = family member of patient-participant; B = patient-participant;

B Sadly we can’t go back to the (name of hospital) any more, I don’t know why.

Q Why not?

B We had to go all the way to (name of clinic) isn’t it, hospital? Hospital was it where we had to go when I had a big one?

A It’s too close to ???

B Oh.

A He’s talking about (name of clinic), that was when you went to…

B That’s the one.

A (name of clinic) [redacted] that was when you were younger. And since he’s been adult you come to (name of hospital). The other one was the children’s hospital. He does have small ones now and again, but otherwise not a huge one ???

Joint interview: **Patient-participant – person with learning disability and Family member – lives with patient-participant**

NB. A = family member of patient-participant; B = patient-participant;

A No. Since the COVID time, that was a huge gap there. And then ??? and that’s when we met Dr (Name of epilepsy consultant).

Joint interview: **Patient-participant – person with learning disability and Family member – lives with patient-participant – person with learning disability**

NB. A = patient-participant

Q They’re the same people that come every day now?

A No, some other people might come.

Q But these two are regular are they, you see them a lot?

A Yeah.

**Professional/clinician**

A I met (name of patient-participant) for the first time when I was a student nurse on placement, the team in [redacted, past 5 years] I think it would have been. And I think at the time it was just she’d….yeah she was just going to the caseload so my involvement sort of started then. I was also a student on placement in the team in [redacted, past 5 years] as well so continued working with her then. And I think it was round about the time that she’d not long come out of hospital after she had been admitted with, I think it was ? poisoning I believe at the time where she had sort of… they did accidental overdoses of the medication for epilepsy, so I sort of became involved then. And as part of my learning experience and carrying a small caseload I was encouraged to sort of go out and spend some time getting to know (name of patient-participant) and obviously her husband and to develop a relationship with them. Yeah. So then when I came back into the team then as a qualified nurse in [redacted, past 5 years] (name of patient-participant), obviously because I’d had that relationship with her and the knowledge of her, and for continuity of care as much as possible, she was allocated then to my caseload. So yeah I’ve been involved with her for a year since. So I obviously go out to see her whenever I can, give her a call whenever I can, support her with anything that I can really around her healthcare.

**Professional/clinician**

Obviously we keep a lot of people on our caseload if they’ve got sort of epilepsy, if they’re having rescue medication, so we will sort of hold their risk assessments and medication plans and things and make sure that they’re all up to date and all still current and relevant, obviously in conjunction with the epilepsy service as well.

**Professional/clinician**

Q I know that different LD services choose who they work with or work out who they work with in different ways. So how does your Trust do it, how does your group do it?

A I think sort of mostly obviously if there is a health need, if there’s a physical health need, you know if there’s epilepsy or if there’s some memory problems, if someone’s diagnosed they will stay on the caseload and we’ll review. Behaviours, if there’s challenging behaviour for somebody then that’s something that we will be involved with.

**Professional/clinician**

I think the [home care] team, as I said was only supposed to be an interim measure so ideally to find an alternative provider to go in and do the evening call. In an ideal world it would be the same provider that’s doing the call in the morning. But this was only last week that I emailed (name of social worker) the social worker, and only Friday that she came back to say that she’d been told no that they couldn’t commission an ???

So that’s not something that I’ve looked into yet, but my next steps now will be to sort of speak to my manager about that and say “this is what’s happened, what do we do, where do we go?” Do we go back to Commissioning, do we have a chat to social services, just to try and figure out a way forward?

Because if we can get the same provider providing the evening call, I think it will be a number of things.

**Professional/clinician**

But also then there would be more consistency with the people going in, the carers going in for (name of patient-participant) but also it would then give that little bit of extra flexibility around the times.

**Carer - lives with patient-participant**

Q Did you have to ask for that kind of continuity or is it just how it’s worked out?

A It’s just how it’s worked out. I don’t know if it does it does for everybody, but I think if you’re under a main consultant, they generally tend to continue your care

Q I’m glad that’s worked out

A That doesn’t account for GP services because you can never see the same person if you can see anybody at all… it’s a lucky dip with the GP service, [patient participant] is always nervous when seeing a GP

**Carer - lives with patient-participant**

Q I think it has to be the nurse at her GP practice that takes [patient participant]’s bloods. She’s know [patient participant] for a long time, I think she knows her family as well, she is always very personal to [patient participant]. Over the years, she knows [patient participant]’s life. She remembers things, she remembers… we went for her bloods around [date], and she remembered the time before we told her we were taking [patient participant] on holiday, she was very excited, “So! Tell me [patient participant], how was your holiday?” It was really important; she remembered something [patient participant] had told her. She is a continuous person, unless she is on holiday or sick, we always see this particular nurse for [patient participant]’s bloods. [patient participant] doesn’t particularly like having needles stuck in her, but she likes to see this lady. She has sort of got a bond with her and it is worth having a needle stuck in your arm to be able to go and see this particular nurse. I won’t say it is something she looks particularly forward to, but it doesn’t hold any fear for her. She’s always “Oh! We’ll see….” I think for me and for [patient participant] this is a really good experience because it’s taking something that isn’t very nice, but because of the continuity of that care and that person making an effort… I don’t think it’s an effort for her, she’s just a lovely person who now knows [patient participant], she has been seeing her even before she came to live with me, she’s been at the same surgery taking her bloods for a long time. So, it’s just a really positive experience and they have a laugh and a banter, she knows [patient participant] and she knows what she likes, so they can have a little joke about something. [patient participant] comes out feeling on top of the world, like she’s just seen her best friend.

**Carer - lives with patient-participant**

Generally… if you can access the service, it used to be really good if you could access the service, you were in and you had a continuity of somebody keeping in touch with you.

**Carer - lives with patient-participant**

…doctors used to… you know, you knew your doctor, you saw the same doctor every time, and they knew you, so they didn’t necessarily have to look back because they knew you… If you were with a doctor practice, unless you moved away… I was with the same doctor for [decades], now you can’t even see the same doctor, so it’s very difficult. They just need to be more aware of the person they are seeing and know a little bit about them before they walk through the door.

**Carer**

And that's what I'm talking about with the mutual trust, that comes with time, and I know that (name of patient-participant) trusts (name of carer 1) and I'm pleased for (name of patient-participant) that he does.

**Family member**

And he’s had his ups and downs up there mind, it hasn’t all been plain sailing. The change of staff, that confuses him, do you know what I mean? And they do have a change of staff a lot. But then I don’t understand what goes on there. But staff that’s there now are good, I feel more at rest now that he’s….I just hope the staff will stay there then, you know not keep changing them all the time. Because obviously the choice of people want to stay there or go ???

**Carer - lives with patient-participant**

Q So, you and (patient-participant) have known each other for over 10 years now?

A Yes

Q Oh, wow. That’s really significant. And all the time he’s lived with you?

A Yes, the whole time

Q Oh, wow. I didn’t assume that placements could last that long

A Well, they can last donkey years!

Q Oh, amazing

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

Q And what does having more time to go to the doctors mean to you?

A No I mean I will get to see my own doctor, I don’t get to see my own doctor, where I was before in (name of town 2) I always see my doctor always, here I don’t see my doctor, I see any doctor

Q I see right, so you make an appointment and-

A ??? someone else, I don’t see my own doctor ever when we’re in there, I should, cos yeah, I don’t see him

Q So why would you always like to see the same doctor?

A Because I know they know me and understand me, other doctors don’t really.

Q Right I understand, and is doctor (name redacted) somebody who works here but you never get to see them

A (name redacted) I don’t see them ??? in (name of town 2) used to have a doctor I know and he always helpful, they know me, over there they don’t really know me only my doctor but yeah

Q Yeah sure I can totally understand that how important it is to see the same doctor who knows you.

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

A It’s just annoying cos like, it’s really annoying because I want to see my own doctor because my own doctor knows me, the one person I know in there is (name of learning disability nurse) but I don’t normally see her hardly.

Q Is (name of learning disability nurse) a doctor?

A No a nurse but like a special needs lady, I saw her once to talk about my contraception but since then I haven’t seen her, it’s all gone downhill.

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

A Yeah and I know because lockdown they changed everything but its not fair on people that need to see their own doctor, and not see any doctors, any doctors don’t know you and you’ve got to explain.

Q And do you think that for people with learning disabilities it’s more important to see their own doctor .

A Yeah cos otherwise they understand the person, not someone that doesn’t understand.

**Carer**

A No, I think it was actually the first time. I think [name of psychologist] actually had to look into her learning disability because there was nothing written anywhere about it. I’m sure… don’t quote me on that! It’s like… this happened over a good couple of years as well, so we were looking into so much stuff with her throughout those two years. Yeah, I’m sure something like that she had to look into.

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

A Yeah you never see your own doctor.

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

Q So you know your other doctor Dr (name of psychologist), because I met her and I was in the meeting, how do find, because she is a different service, she’s the LD service-

A No she’s alright cos she’s in a different place.

Q So what do you think about the LD service, is that better? The healthcare you get there?

A Yeah, cos they know me.

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

Q So tell me a little more about that, because I wonder if we can learn something from the LD service, do you think your GP should be like the LD service?

A Yeah

Q Right, tell me about that

A Needs to be like that, because they need to know people with special needs, they need to know how to handle somebody’s needs, so many doctors ?? not a clue. Somebody who I know goes in there and they have a difficult time because they don’t understand them, ?????

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

Q I’m wondering, these things that are happening at the GP and the tablets and things, is there somebody in the LD team that you could tell about this that might help you or is it very-

A I normally tell whoever is supporting me here, I tell them normally, I always tell my team members, my team, and you.

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

A They was with me but they’ve stepped back a bit now, they done what they needed to do.

**Carer - lives with patient-participant**

A She listens to [patient participant]. After a few sessions she was able to… because [patient participant] jumped from one moment of thought to another… became good at guiding [patient participant] to the crux of what she was saying. She just got to know her really well. But I think it was the fact that [patient participant] had ongoing counselling, she was able to get through the layers of her complexities and anxieties. I think it was really, really important that she had ongoing counselling for well over a year to get to the layers of perhaps the best way reach, and for her to understand triggers that caused anxieties within her and things to do where she was in control of her life and mood swings, to the point now that I would say that [patient-participant] life has become enrichened where she is not as distressed as she used to be, and in a way that ongoing care has paid off because her life is so smooth she hopefully doesn’t need long going, intense NHS care because, myself and [participant’s partner] can support her to have a good life and avoid the anxieties and triggers that she was constantly feeling before. That was longwinded, sorry.

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

Q Oh yeah and actually when you are with someone who knows you, do you feel different?

A Sometimes, depends on who they are

Q Of course yeah, but if there is somebody, when you see a doctor in (name of town 2), how do you feel when you see them?

A Fine because they know me, they know me when mum used to come with me, and mum explained and yeah they know me quite well over there

Q And how does that make you feel?

A Better there because there’s more space there and your always, always, not always see your doctor but you’ll see somebody who’s similar to your doctor but you’ll always see somebody and they know me because they’ve read my notes before

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

Q So your doctor in (name of town 2) you’re mentioning, that doctor, did you see the same doctor when you were a little kid also?

A Yeah.

Q Wow that’s amazing, so they’ve seen you basically grow up.

A Yeah, its really helpful, mum rang up ages ago about my tonsilitis they saw me the same day cos they know me and they used to be really helpful cos I ring up.

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

Once a month she holds a Zoom call for everybody that’s involved with (name of daughter/patient-participant) i.e. the staff; the manager from (name of respite home); the carers that are with (name of daughter/patient-participant) from a (day) to a (day); herself obviously; and myself. And every month we’ll just talk about if there’s been any changes with medication, any changes in behaviour. If there’s any issues with certain things it will all be brought up. And obviously the main one is (name of daughter/patient-participant)’s eating, she will come up with different suggestions to try and prompt, and different places for staff to take her where she can sit, having something to eat and be distracted by people watching to encourage her that way. There’s loads of different ideas that she’s come up with. And it’s usually once a month or she’ll make a house visit and we’ll talk about it then, or if there’s an issue there’s always texts. We keep in contact regular most weeks or every fortnight, there’s always that information being passed over. And also we have a handover twice a day with carers when I’m handing (name of daughter/patient-participant) over to the carers, I’ll tell them whether she’s had any seizures, whether any rescue meds have been used, and obviously it’s all being recorded. But we’re all singing off the same hymn sheet and that is the way forward, communication is the key.

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

But that’s the best part of (name of LD community nurse), (name of LD community nurse) has really shone amongst all of this. And all the way through. She’s been with (Name of daughter/patient-participant) for a lot of years. So she knows (Name of daughter/patient-participant) well as well you know.

Q Yeah. Roughly how long do you think she’s been with you?

A [Redacted - over a decade].

Q Oh ages.

A Yeah, yeah, yeah a long time, yeah. And she’s ??? at the National ??? which is, if you go over the mountain it’s [redacted] away, if you go round it’s [redacted] away.

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

A All I can say is about (name of LD community nurse) is that she’s been for (Name of daughter/patient-participant) from day one. Very professional person.

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

And over the years we’ve got to see what (name of LD community nurse) is about, and she’s all for (Name of daughter/patient-participant) and others, you know.

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

Q Do you want to talk to me about your pharmacist and how they’ve helped your family.

A My pharmacist is quite good. They’re just literally round the corner where I live. We know them from years you know and they know (Name of son/patient-participant) because he had all these bad illness, they’ve got records of all his medication. So they knew, when I walk in they know who am I and my son (Name of son/patient-participant), especially in charge of the pharmacy, he knows that my son is (Name of son/patient-participant) you know he’s got a lot of problems. They’ve been quite good, the pharmacist has been good. They just get in the medication when they order it. Sometimes they have to order it again for it to come, otherwise it’s not here.

**Professional/clinician**

A No that’s fine. I’ve known (Name of patient-participant) since she was [redacted, older adolescent], I picked it up in transition. So I’ve worked with her for a good [years redacted] now – maybe a bit longer than that, I think she’s [age of partient-participant] coming up so it’s [redacted years they have been working together - over 20 years]. I’ve gone off and had children in between and fortunately I’ve been able to pick her back up when I’ve come back. And she is such a lovely young woman, got such a character about her and so many skills, but it also extremely hard work. I really take my hat off to her parents, the amount of effort and support that they have to provide for her on a daily basis. I don’t know if I could be able to do that as long as they’ve maintained that. And the last 3 or 4 years her health needs, especially around her epilepsy have increased significantly you know, to the point where she’s hardly eating now, and the amount of work that has been needed to try and keep her well and healthy. It’s quite pitiful at times to see how much she is struggling and subsequently how the family is struggling, because they are working as hard as they can to give her the best that they can.

And support networks are diminishing. You know I’ve been around a long time and I’ve gone from the support services being quite intense and available to all, to them being narrowed and narrowed and narrowed to (now staff, their staff now?) families literally have to beg to get services. And even then I’ve had some families that have give up their caring role and relinquished the responsibilities for their children to go into supported living. And I’m not saying that that’s not the ideal and that’s what should happen because eventually we all have to leave home you know, but it’s also been forced upon them because services are a lot less than what they used to be.

**Professional/clinician**

You know I’ve just been talking to another mother that I haven’t got a role that I’ve got to discharge, his epilepsy is now well-controlled, and I’ve said “look, I’m on the end of the phone if you need to run anything by me”. But unfortunately I can’t stay involved because there isn’t a role for me, our time is pressured as well and I can pick somebody else up instead. But I know that their needs are no less now than when I started with them, it’s just things have settled in one area. But their son’s needs are still high – and how little they have and how little support that they have.

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

A Well I find that the doctors….years ago when I was a child I mean you had a doctor who knew the whole family. Today there’s a multitude of doctors. The care is not like it used to be, it’s not as personal, especially with your own GP. I mean if we have problems concerning (name of daughter/patient-participant)’s extended learning disability that it comes under, the doctor would say ‘well you know that’s going to have to be for the learning disability team to deal with’ or ‘that will come under the professors’ you know, especially with (name of daughter/patient-participant)’s epilepsy because she’s got very complex epilepsy. He would say ‘you’re going to have to refer to the professors for that’ you know. But I mean the care is not there, it’s not humanized, it’s not personal no more. It’s very stand-off I find. Not every GP is the same, but hence like I said there’s a number of GPs in (name of daughter/patient-participant)’s surgery so…..the one doctor talks very, very slow and quite quiet and he’s very caring, the one doctor, very, very caring and he doesn’t rush you, you know and he does find time to talk to (name of daughter/patient-participant)

**Carer - lives with patient-participant**

A I look for the continuity, if possible, that we see the same person because [patient participant] likes to have a bit of an attachment with the person that is treating her. When she goes and gets her bloods taken, she sees the same nurse, she’s known her for years. She knows [patient participant] and she laughs and banters with her so [patient participant] is not frightened to go. Most of the consultants she sees, it’s been the same person, she sees the face and she remembers. She feels more happy… are we going to see the same lady… that’s important, the continuity of care so that she can feel comfortable.

**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.

**Professional/clinician**

Now I’ve always worked in that he wouldn’t go anywhere, wouldn’t go out, wouldn’t do anything, but slowly I gained his trust by visiting and saying “come for a ride with me”. “No, no I don’t want to go anywhere, no, no”. I said “come on, tell you what we’ll just go for a ride, we’ll pull up to a….” oh God, a thing on the side of the road and have a cup of tea, you know so we don’t have to go in, we don’t have to do anything. We’ll just go and have a cup of tea. He came. We went walking in his local community, called in a couple of shops, that worked. Taken me 10 years mind, it’s taken me a long time. Then it would be “right, do you want to come with me to the café” – no problem.

[CONTINUED]

They agreed that he could have a support worker. I did the introductions. I went with them for a few weeks to be able to build that relationship with them, and we went to cafes and we went for walks and we went and did things like that. And eventually then I could pull out. He is now going out every fortnight with that person.

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

A Yes. But she’s on maternity leave. She has been there a while. But before that we had a lot of changes. I think it was (name of psychiatrist) as well, so we had a lot of zoom calls. And it was quite difficult because nobody ever got to know (name of daughter/patient-participant), whereas (name of another psychiatrist) has met, come to the house and met (name of daughter/patient-participant) so she does know (name of daughter/patient-participant) so that’s good. So I think she could see and thought – and I had said about we thought (name of daughter/patient-participant) problems were down to the seizures activities. So if we can get that under control I think (name of daughter/patient-participant) would be better.

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

And obviously – it wasn’t last year it was the year before – I don’t know what was going on with (name of daughter/patient-participant) but she wasn’t eating breakfast, she wasn’t eating lunch, she wasn’t eating tea, and she just had things…she was asking for soft cheese, so that’s all she was surviving on. Oh and she had a lot of reflux so I don’t think that was helping then. So (name of LD nurse) used to come every 4 weeks and weigh her just to make sure she wasn’t going… And (name of daughter/patient-participant) did go down to 7 and a half stone. So that was good that (name of LD nurse) was keeping an eye on…

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

I know (name of LD nurse) is off at the moment but they did phone me and said “you know where we are if (name of daughter/patient-participant) is having any moments and you need to speak to someone. So that’s good, I got their number. I know I can contact (Name of consultant) any time with queries about (name of daughter/patient-participant) seizures, so you don’t feel so cut off like people said you would be. Because people do worry about that, going from….because you have a lot of things when they’re children, and as they turn 19 and they’re leaving school people had said “oh it all stops”. But it hasn’t. It’s been positive for us, yeah.

**Family member**

A No coming back from it. No unfortunately she remembers and that’s it. So I think…. And that’s what’s difficult with professionals as well, sometimes they only meet (Name of sister/patient-participant female) once or twice – and again it’s hard to do that – but on the professionals where she sees them all the time it will be like, you know you can build that good rapport with a patient.

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

Fortunately the lady that comes in on a [day of the week redacted] is a staff member at (name of day centre) where (name of daughter/patient-participant) goes in the daytime, so she’s very familiar. So that helps because then she’s very pleased to see her. We have a lady that comes in on a [day of the week redacted] who we’ve had for quite a while now and (name of daughter/patient-participant) has accepted and she knows. So on that score, that is OK.

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

And some of the staff actually moved to (name of day centre) as well so there was a sort of continuation there.

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

Q What about staff. What makes them….

A Well the familiarity for a start. You know they know (name of daughter/patient-participant), they get to know (name of daughter/patient-participant). They’re just lovely people.

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

No they’re really good. And (name of daughter/patient-participant) knows them by name as well, it’s not as if they sort of keep swapping all the time. Like sometimes she’ll have one person for a couple of days and then….they do swap but obviously they know….

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

A Yeah. I think that was the eye opener for us. When she finished being a child into an adult it was quite a big jump. Maybe something could be done to sort of ease that jump, I don’t know, but they went from bump to bump, if you know what I mean with no in between. And everything stopped, so we had to sort of find other things to help. And I mean the council can only recommend places which they run can’t they? When you think about it, it’s not even in our borough (name of town), so we had to sort of ask…yeah the council approved it. But it was the best thing we ever done.

But that was, you know you could put that, is that from child to adult was quite an eye opener, and maybe disappointing as well to see what was around. And we have to go out. I mean really you should have a place like (name of day centre) in (name of town) shouldn’t we, in our borough.

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

But no I think generally her healthcare’s been not too bad. It’s just the changing…some of the things I’ve already said.

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

A Well I think in an ideal world she’d have more regular appointments. Also I think that resources could be improved in respect of equipment and stuff like that being more available.

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

A She was a pediatrician, she basically saw (name of daughter/patient-participant) for quite a while, and then she moved up to the (place) which is a new centre which she’s been in. But then obviously when (name of daughter/patient-participant) hit a certain age, 19, 18 or 19, then she went into adult, and things changed a bit then regarding access to….we weren’t allowed to go to the (centre) for swimming because she was too old. So a lot of things changed. And that’s when I…earlier on when I was making my point about when we went to see other places for adults, I didn’t really like them, we didn’t like them at all. And I’m not sort of belittling them, you know they probably do a great job, but we didn’t get that sort of….you know you get that – not that we got a sense put it that way.

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

A He said he’s got a meeting with another person who will be with him, a lady who is a new lead-up with him(?)

Q Oh ok, so you will have a new doctor with you?

A Yeah, a new lady from the hospital(?)

Q What is she like?

A She’s lovely!

Q Can you tell me a bit more about them?

A We’ve met her on the camera about five months ago and he’s come up to see us at [time] last week. It was good!

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

So we learned about her personal life and so on and I think that helped. I think that helped because we felt she wasn’t just a consultant, we like to think of her as a friend, and (Name of daughter/patient-participant) did too. I think that is important with a relationship, a medical relationship, if you actually think of somebody as a friend. We’ve never really had that with a GP. They seem they are not want to be…. At one time we felt we had a GP that we could ring up and ask for an appointment with Dr Who – not Doctor Who!

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

Q What do you think it means to be treated like a human being?

A Well I don’t know, it seems to me it’s more of a quality. You know if you were talking to me, talk the same to (name of daughter/patient-participant) and be familiar as well, not just another person. Because a lot of people tend to bring sort of students with them, which I know they’ve got to learn and all that but sometimes it can be a bit disconcerting. I think that if (name of daughter/patient-participant) can be on first name terms with…and in most of the cases they are, it’s just this one, obviously one of them is off on the sick now and when she had a couple of those. But by and large they do know (name of daughter/patient-participant) but I don’t want to keep….I mean the worst one is the GP.

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

But all I wish that, all we can wish for with (name of daughter/patient-participant) is that everybody who looks after (name of daughter/patient-participant) knows (name of daughter/patient-participant) you know not keep swapping and changing different people. And I know sometimes you’ve got to see different experts and all that, but I think now we’re pretty much sort of fixed into people we see. I mean even people like you, you know she knows you now. But she didn’t before did she? But then maybe now over these next couple of visits, you walk in and she’ll be like “oh (name of researcher)”.

**Carer**

Participant – Exactly, and I think that is the difference because if you are a just a person phoning in the doctor, they are just looking at you on the screen and it’s bringing up your problems, your issues, your diagnosis etc is, whereas if it someone like we have Dr (name of doctor) who knows our clients so well, our clients aren’t just someone on a screen, she knows who they are and she knows that if we are saying we need something, she knows that that means they need it, I do think that works really really well, I know it’s a little bit different in hospital, I know that when I go and see my physician at the hospital I always go and see the same one. That’s better for someone who is not in a care home as such, so I hope that’s the same for everybody else. That’s my experience really.

**Carer**

A So (patient participant), was seen by the learning disabilities team a long long time ago, she has been her for some time, when she first joined us there was a little bit of support being put in there and they felt that (patient participant) was doing really well and no longer needed that support but all obviously know that if (patient participant) does has a dip or she is not feeling herself or anything like that we can back in contact if needed.

Q And how are you finding that easy, that getting in contact with and getting a referral and that, because I know in some services that what some people struggle with like the service is there but accessing it, so how are you finding accessing that specific learning disabilities service?

A I personally haven’t had any problems with it, we did have a very good relationship with the learning disabilities nurses and the whole team, so I do find that if I send an email, it may be a week or two but someone will come back to me and they are always open to suggestions and I think that is the thing to be open and honest with each other we have got a good relationship so.

**Carer**

I don’t think we have had any bad experiences that have been terrible in this house for a long time, the team that we have, I think when you have a solid team in the healthcare system and they are not just constantly changing people, you are seeing regular people and building up that relationships to be able to communicate what it is that’s actually going wrong for that person and how that is going to be supported and what they need and how they want to be supported, it works really well but when you are going to see someone and it’s for the same thing but seeing different people constantly, it’s like catch up so you are having to go over all the old ground to get to where you need to be and it’s not necessarily productive.

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

A Which Doctor Who! And we always used to…but we can’t do that now, it’s just ‘a doctor’, and I don’t think that’s very good. But that’s another subject. I think the doctor/patient relationship is important to the patient and I think it helps the doctor understand. Because if it’s the same doctor, the doctor will remember and notice differences in a person, but you see one doctor, the next time you go a month or two later you see somebody else. And it’s not very good. So the fact that we saw the same person with (Name of consultant) each time I think built up a relationship. And she was able….she would hold (Name of daughter/patient-participant) hand and look at her and talk to her, and look at her eyes, you know she would be examining her without (Name of daughter/patient-participant) thinking she was examining her. It’s clever. It’s an in-borne skill that she’s got I think. Certainly she was able to be close….(Name of daughter/patient-participant) felt comfortable with her, she was always happy to see her, always liked to see her.

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

A [name of female clinician]? But I’m not sure, I can’t remember. But they’ve changed again.

Q Oh have they?

A Yeah because one of them is on the sick.

Q Oh no.

A I don’t know. That’s what I’m saying, that particular person’s changed twice since.

Q OK, not ideal.

A Because at the end of the day they’ve been ringing (name of female) up saying “can we do anything”, but they don’t know (name of daughter/patient-participant). So we’ve said “look, if there’s something wrong we’ll ring you”, otherwise just don’t bother. Because it’s the resources like. Because they don’t know (name of daughter/patient-participant) as much as we do.

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

Q And how do they treat her, how do they chat with her?

A Oh well they know her, (name of daughter/patient-participant) has been seeing them for quite a long time so they’re on first name terms and (name of daughter/patient-participant) knows (name of physio 1) and (name of physio 2) and (name of physio 1), and so yeah she loves it. But she does love swimming full stop.

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

A Yeah. Well when she first started she was a little bit nervous if you like, but it didn’t take long for her to sort of adapt. And she does like doing things. And if she likes you she’ll get on, and she does like them. So yeah she’s gone on really well.

Joint interview: **Patient-participant – person with learning disability and Family member – lives with patient-participant**

NB. A = family member of patient-participant; B = patient-participant;

Q But how did you find not having epilepsy doctors for years during COVID and after COVID? Anything you want to say about that?

A Well to be honest it didn’t bother him. It did not bother him because I was looking after his medication and his health. It didn’t bother him it was a doctor or not a doctor but it worried me. I was worried. I just thought all that time. Before Dr (Name of epilepsy consultant) he had Dr (name of consultant). He only seen him once or twice and that’s it, and then COVID came and all these.

Q Yeah I think I’ve met Dr (name of consultant).

A Yeah, he only seen once or twice with you, then not much. And whatever (name of consultant) has given (Name of patient-participant), (Name of patient-participant) has taken that dose all that time. And now Dr (Name of epilepsy consultant) came in so she’s changing the medication.

Q How have you found those changes?

A The change was a bit difficult.

B Confusing.

A Confusing, because he’s used to having this and that, and now suddenly one is stopped and another one was introduced. So it was a bit…was introduced for like small, then higher, then higher and ???

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

From thereon we didn’t see evidence did we, then we moved on to the other doctors.

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

Q Oh yeah, so there is an LD team there at (name of hospital) and they are there when you have your injections in your hip, which sounds like a big thing.

A They’re there if anything happens, they’re there, I know most of them anyway and they know me.

Q So when you say they are there, what does that mean to you?

A I mean they’re there like if I need help understanding something, they’re there

Q And they’re there literally in the room with you?

A Yeah.

Q Oh that’s so good.

Carer We book them.

Q Oh okay.

Carer To any procedure or appointment.

Q I see, so the doctor or nurse, whoever does the injection, is just a bog standard doctor / nurse.

Carer Yes.

Q But the LD team they come and meet you there, that’s so cool.

A They even let me, they’re helpful, they let me have wheelchair because I can’t walk properly after my injection, I was brave ????

Carer You were amazing, incredible.

Q Yeah last time I saw you, you had had one, having an injection in your hip, you’re so brave (patient participant).

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

A Yeah. So yeah and I think (name of psychiatrist) organized the meeting with (Name of consultant), a joint one, so I think that helped as well. Yeah. But up until then there was a lot of changes and a lot of diagnosis for (name of daughter/patient-participant). So I’m glad it’s settled down a little bit now, you feel like you know where you are.