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

Q How do you find going to the hospital with (name of participant’s wife/patient-participant)? Is it something you are happy about, sad about, or unsure about?

A Well put it in that because….

Q You’re unsure.

A When we’ve been down the hospital we’ve had to wait about, say 7 hours when I went down with her. And I get a bit ??? She says “now calm down”. And I says “aye”, I’d say “we need to be hanging about” ???

Q Yeah. So waiting around makes it more stressful by the sounds of it.

A Yeah.

Q I think I’ve got a symbol for waiting – I think. OK so the waiting room, the waiting area, how do you find that? Is it something that you are happy about, sad about, unsure about?

A Well I’ll put it there, I’m unsure about that.

Q You’re unsure about it, and that’s because of the waiting times?

A Yeah.

Q What’s good about the waiting area?

A I think it’s when….like say if when she has a seizure ??? and if they check her over that’s a good thing.

Q OK. So it’s like you’re waiting for something that’s good but the wait can be too long.

A Aha.

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

NB: A = patient-participant’s family member; B = patient-participant

Q In the waiting room, your mum talked about you know the waiting area having toys and games and things. How do you find that kind of waiting room compared to the waiting room at the (name of clinic)? What do you think (Name of patient-participant)?

A That same waiting room is for actually children, all age you know.

B Yes.

A It is a lovely ??? of busy. The timing and waiting because they realise they’re going to get busy playing or drawing or whatever. I quite like that. Compared to the (name of hospital) hospital, the adult one, you just have to sit there and look at the telly you know. And it’s a long wait, the more you wait and look at each other it takes more longer you know.

B Depression.

Q How do you find it (Name of patient-participant)?

A ??? stop it. I notice (Name of patient-participant), if he waits more than half an hour he gets nervous and angry.

Q So you get nervous about the appointment?

A Yeah, nervous. He’s going “when are they calling”, “when are they calling me now”. It can go up to an hour waiting, sitting around at the (name of hospital) hospital.

B So I’m like ??? like “which doctor, which door?”

A Where we’re all adult, if there’s other adults coming in for different clinics, looking at each other you know. Very hard, especially for (Name of patient-participant) who can get a bit nervous because he’s sitting there and nobody is calling him.

B True.

A But at the (name of clinic), like I say it’s a big area with the children’s stuff, that is at the children’s. Now (Name of patient-participant) is an adult and everything, but it would be nice…

Q Still wants to play as an adult.

A Yeah, it would be nice if they had, at the (name of hospital), I’m suggesting and maybe a small area where they put some books for….

B Adults.

A …you know other people who can just slip into that room and not worrying about those people walking in and out.

Q Yeah. I think a Counselling Service is for the adults, the adults go where they have a calm waiting area with like colouring and stuff like that.

A Yeah that would have been really nice if there was one at the (name of hospital) hospital, you know other than just waiting “when are they going to call, when are they going to call” you know. And sometimes the calling can be long.

B Yeah very so.

A I as a mother get worried if it’s more than half an hour or more you know, I start panicking. Where (Name of patient-participant) is getting a bit nervous.

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

NB: A = patient-participant’s family member; B = patient-participant

A But if she’s passing “oh sorry I’m running a bit late” you know.

B It’s a good thing she tells us.

A Yes, she just….walking down yeah.

B She tells us before we go in.

A Yeah.

Q She sort of acknowledges you when you are in the waiting room?

A Yeah.

B Yeah, sometimes when she does see us.

A Because when you’re waiting the time doesn’t seem to go, it feels more longer and that makes you a bit more nervous.

B Panicking.

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

A (Name of son/patient-participant) was born with epilepsy. Around the age of two and a half that’s when it got complicated, he was having all these episodes. But I didn’t understand. We’d been to the GPs, we’d been to the hospital. It took a while for them to diagnose what was wrong with him. And after that, once he was set into the diagnose they gave him medication and it went from there. But it is very difficult if you don’t know what’s wrong with your child. And there’s no epilepsy in my side of my family or my husband’s side of the family so we wasn’t….we didn’t know what it was. It was really scary at the beginning. It is still scary when he has a big episode but I’m used to it now, all these years now.

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

A Yeah I think with all of our healthcare ??? they’re like doctors. I don’t think I had any bad experience with any doctors. The only bad experience we have is the waiting area.

Q Yeah, tell me more about that.

A Because (Name of son/patient-participant) has moved to the adults and there there’s other patients, different kinds of patients, sometimes it’s never on the time they have given the appointment. So we wait an hour, half an hour, 45 minutes after the actual appointment. With (Name of son/patient-participant) he can get very anxiety. I get ??? and watching the time “oh when are they going to call us” or “when are we next” you know. That makes him anxious and anxiety.

Q (Name of son/patient-participant) there pointing to an imaginary watch. [Said for the benefit of the recording, patient-participant is sat with his mum as she talks about waiting too long for appointments and is tapping his wrist, as if pointing to a watch face, exaggerating an expression of being unimpressed].

A Yeah, yeah and looking at the time, or people coming past and going by you know. I get ??? as well. And for (Name of son/patient-participant) not to get worried or anything I keep saying “are you alright” or “are you OK”. Just the waiting is longer than…but seeing the doctor can fix him, so that’s it, you know that’s finished then.

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

NB: A = patient-participant’s family member; B = patient-participant

B So my mum mentioned before about expanding the waiting area. So you could put them in specific ages so you don’t mix yourself with the younger children but older children. So like some….remember I mentioned the drawing?

Q Yeah.

B Yeah. So you could make one area for others, like for people that like loud noises, then the other side can be a quiet area for all the younger ??? their brains are fully adapted.

Q Which would you go in, the quiet area or the loud area?

B So it depends how loud it goes.

A You don’t want a loud area, you would want a quiet area.

B Yeah that’s true. Yeah mum wants a quiet house.

Q Yeah, that’s what you’re used to, huh?

B Pretty much.

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

NB: A = patient-participant’s family member; B = patient-participant

Q Do you have any advice for doctors and nurses about how they can treat their patients in a way that is more humanising?

A To be honest, I know time is very valuable, time is very valuable for normal people and the doctors. The doctors sometimes can keep you waiting for hours for them to be seen, you know. The doctors know the patient is in that….

B Waiting room.

A Yeah. Sometimes the patient could be so sensitive it would be nice if they would just call straightaway, do you know what I mean?

Q So (there’s a wait?) for patients.

A Yeah, especially sensitive people. Like if it was normal people, like I’m going to the GP I can wait hours in this time. But like for (Name of son/patient-participant) it’s too much for him. He is not…if he went to the doc he needs to be seen by a doc he wants to be seen straightaway, that kind of thing.

B That’s why I ??? make a story before so I can draw and ???

Q Yeah, so a different way of doing things that works for you.

B Yeah. So that needs to….

A Well I would suggest, people with a learning difficulty or whatever, they need their own small space and not with a crowd, with a big crowd you know. With a big crowd they get nervous, all these people coming in and out, in and out, you know.

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

A Well we did have a bad experience when (name of daughter/patient-participant) got ill at [hospital] and we waited a long time to get seen. And we ended up walking out but the doctor came chasing after us and brought us back in. I think we were 10 hours. It was a long time. But that’s certainly not a criticism because it was rammed in there.

Q And the doctor cared enough to….thought it was important enough to kind of grab you back.

A Yeah he did. But that was ridiculous. I mean there were people in there with headaches you know, and it was ridiculous. But that’s not a sort of detriment to the NHS, it was just…it must have been a bad day. Well they were out the door, we couldn’t even sit. You’ve been up to [hospital] haven’t you?

Q I have yeah.

A Right, well you’ve been in the waiting room of the A & E?

Q I’ve not. I’ve been in the new building once and that was just the coffee shop. And then I’ve only ever…I now know the psychiatrist is that way so…

A Well the A & E is round the back, and it has got rows and rows of seats and they were all full. There’s a machine there, there were people out the door. Apparently it was a hot day or evening. Thankfully (name of daughter/patient-participant) was OK in the end. But that wasn’t a great experience. But that’s nobody’s fault, that’s not their fault, it was a lot of people’s fault.

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

Q (Name of son/patient-participant) do you have any thoughts, any advice for doctors and nurses how they treat people like you and your brother?

B Besides co-operation, time is valuable things for many people you know. Everyone needs that time.

A It would be nice for nurses or doctors to realise that that patient is very sensitive that needs to be quickly dealt, or quickly seen and let them go off, you know that kind of thing would be nice. With a normal, “OK then this one that’s a normal, not a big issue, can wait another 5 or 10 minutes” you know.

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

Q That’s OK. OK so how do you feel about sitting in the waiting room in your healthcare appointments?

A I like it.

Q Yeah? Tell me about that. What’s it like waiting in the waiting room?

A You’ve got to be patient.

Q You have got to be patient.

A Yeah.

Q Does that mean that you have to usually wait a little while?

A Yeah.

Q And you don’t mind that?

A No I don’t. But (name of patient-participant’s husband) does.

Q (Name of patient-participant’s husband) does but you don’t because you’re more patient.

A Yeah.

Q Do you also get to talk to people when you’re waiting?

A Yeah.

Q What are the people like that you talk to?

A They can be nice, and they talk back to you. You can get friendly and….you can get friends.

Q So you like that bit of it when you get to be friendly with people.

A Yeah.

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

Q So why don’t you talk to me a bit about….how do you feel about that? So you put that you’re happy with the way that they help you. What do they do?

A Well they try and come and be happy. But they’re not as….the emergency, they come as quick as possible but they’re not as quick as the paramedics, they’re not as quick as….

Q They should be.

A They should be. The paramedics would come about 4 hours after or 8 hours after and not as quick as they should be.

Q Did they used to be faster than this?

A Yeah.

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

Q With the emergency help when they get here, what do they do when they arrive, how do they help you?

A They try and get the wheal? tears? and things like that as quick as possible.

Q Let me see if I’ve got some of these….

A But you can’t be unhappy with….because you can’t be unhappy with the ambulance because you don’t know when they’re going to come with that.

Q Yes, so you’re putting it as a sad one because you don’t know when the ambulance is going to come.

A No, because you don’t know when there is….when you phone them up they could be with another person or another patient.

Q Yeah. Are you happy where you’ve put the ambulance symbol, do you think that’s….

A Oh….

Q There’s some good stuff about them and some bad stuff.

A Yeah.

Q So you’ve just moved it now to the sad side.

A Well sometimes it can be unhappy.

Q Yeah. Well we’ve got this middle symbol as well where you can be that in-between, sometimes it’s good, sometimes it’s not good. Are you happy with putting in under Sad?

A Yeah.

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

I don’t know if I want to stay with that GP because they got big queues to the chemist, big queues to wait to go in, big queues to wait for medication and then big queues when you get in then to wait to see a doctor, takes hours to get in to see a doctor, it’s getting worse over there.

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

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, its all gone downhill, cos its not even been helping and then when I, I know there supposed to be a good doctors surgery but they’ve gone downhill because I know when you go over there and say your name at the counter then you’re sat there for hours waiting for someone to come out to you, to call you in, and sometimes you wait there for hours sometimes and I get there bang on time.

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

Q I’m trying to think what I’ve got….where are my symbols? I don’t have what I wanted. What do you think about Dr (Name of neurologist) who you go to for your appointments?

A I like her.

Q Will you talk to me about how come you like her?

A Well she talks to be nicely. And she asks. And she writes to me. And she asks how I’m getting on and….And she asks how my tablets are. And she doesn’t write every 6 months, she writes every 3 or 4 months.

Q Yeah, so it’s a bit sooner, a bit quicker.

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

A I’m not going! I will not go to the (name of hospital). Would you go? They say “we’ll take you to the (name of hospital)” for 5 hours and they keep you there for a day, 5 hours and for a day, and then 5 days, 4 hours. And then they bring you home.

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

Q And, you know when that happens (Name of patient-participant’s husband), how do you react?

B Oh when she has the seizures I go to bed and go get the phone and give the paramedics a ring. One day this week I give them a ring and they said they couldn’t send out an ambulance, they said “oh we’re too busy”. So I thought “oh I won’t ask them again. I’ll do what I can when they can’t come down and check her over”. They can’t think much really of her.

Q Is that what you think when they say they don’t have time?

B Yeah. Makes you think it wouldn’t hurt them to come down and just check her over like and see how she is.

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

Q Have you got any stories of a time when the paramedics really helped after a seizure?

B When they have come out I think there was a few times when she has gone to the hospital. And I think one time when we’d done it I think ??? we were there for about 7 hours before they could see her. I thought blimey, I thought somebody ought to come in and see her and that like.

Q That’s a long time to wait. It sounds like you have….

B I’ve gone “when is someone going to come and see her” and they said “oh it will only be a few minutes”.

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

Q Can you think of any examples of people being kind to yourself or to (name of patient-participant) when you go to the doctors or the nurses?

A Well if we’re poorly they should see us straightaway.

Q Do you think that’s particularly important because you have a learning disability and epilepsy?

A Yeah.

Q So why do you think that it’s important that people with learning disabilities get seen fast?

A Well they shouldn’t just leave us there in the chair or….

Q Yeah, you were saying that you were at the hospital and they didn’t put you in a bed for a long time and they just put you in a chair.

A Yeah.

Q How did it make you feel if you’re sort of left in a chair when you were there for so long?

A Awful.

Q Yeah, why did it make you feel awful?

A Because my back was hurting and…. I mean they could have put me in a chair…in a bed or something.

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

A Yeah but how long was you there for (Name of patient-participant’s husband) before you knew ???

B Oh I think just for a few minutes I think I was there for.

Q So the GP saw you quickly and they asked how you were and they listened to what you had to say.

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

A Because sometimes they usually like perhaps a bit late in coming and (name of participant’s wife/patient-participant) says “oh they’re not coming”. So I think “well if they’d give us the code number I’d be able to do it”.

Q OK. So you want to be able to do it on the days they don’t manage to come.

A Aha.

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

A When I do take my own I don’t have to wait for them.

**Professional/clinician**

Q Yeah. So obviously she was sort of saying for a long time that [redacted time, very early] was too early and it did take quite a while to get it to [time redacted - early morning, not unreasonably early]. So can you give me a sense of what’s happening in the background – and I expect it’s a lot of bureaucracy that’s happening that makes it really hard to make that change – so can you help me understand why it took so long and how you managed to get that win. Because some people get stuck for years and….

A If I’m honest I think…. I think a lot of it is…. unfortunately a lot of it comes down to funding and whose responsibility certain things are. If there were other things happening on the call, if she needed more support with personal care then it would have been easier to get a provider in to do that. But unfortunately, for me I think a lot of it comes down to sort of funding. I think everybody’s got to be so careful with their budgets and are really not in a position to sort of commission anything that isn’t strictly something that they’re responsible for doing. And sadly I do think that that’s been a little bit of the case here. Because I know that that is….yeah. So it’s been sort of looking, trying to contact Commissioning and asking them to look for a private provider. They’ve not been able to source one, they’ve been looking sort of periodically. Yeah.

And I don’t know if there might be a difficult now going forward because the provider that we’ve got going in the morning we were hoping could do the evening call, but I know that I’ve been back and forward with Commissioning and the social worker now because it’s not a provider that we as a Health Board are commissioning with at the moment. I know that I was asked to explore the possibility with the social worker of social services funding it and invoicing the Health Board for it, which has I believe has happened I don’t know in this team but I am aware that that sort of thing has happened. But at the moment we’ve had a ‘no’ for that so I need to sort of have a little look into ‘we; why no?’ You know ultimately it’s about getting this medication prompted at an appropriate and safer time in a consistent way for (name of patient-participant) to help her to sort of, you know manage her medication and keep her independence at home.

Q It’s saving social care a fortune to have medicine prompters coming in to help her live independently so they should really want to make it work.

A And it should be about what (name of patient-participant) needs and wants. Yeah.

Q What made it possible to finally go from [redacted time - very early call] to [redacted time - early call but not unreasonably so], what did that conversation look like, what pushed it to….

A That was quite straightforward as it was in the end. I know there had been a couple of other concerns around hygiene and things, so yeah that was quite…. When we’d sort of thought about it and I know a social worker had discussed it to ask if that was something that she could arrange I guess with her manager, and we’d spoken obviously to (name of patient-participant) about it to make sure that he was happy with it, that was actually something that was really quite straightforward to put in because the call was already being commissioned anyway, just later in the day. So it was just moving it and adding to the care plan to ??? the lock box and prompt with the medication. So it actually wasn’t….it wasn’t that….

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

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.

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

NB: A = patient-participant’s family member; B = patient-participant

A We used to be on the first floor, but so what. Coming down the stairs. And in this block there’s a waiting area.

Q OK. So what’s the waiting area like in a perfect hospital?

B Similar towards the one in (name of hospital) where we met the first time. But over the years I can imagine they change a lot.

Q So it would have things to do.

B Yes.

Q Would it be a busy room or a quiet room?

B It depends on the child.

Q Well maybe thinking about you as a grown up now, what do you want now from your doctors in a hospital?

B Mainly peace and understand.

Q Do you still want things to do as an adult in the waiting area?

B Chair.

Q What things would they have? They probably wouldn’t have building blocks would they like when you are in the kids area.

B No because this is going to be separate.

Q Yeah. Now you’re grown up what things would you want to do in a waiting room?

B Basically like given….it will obviously be loud and because you’re qualified enough to play instruments and ??? blinking loud.

Q Yeah, you wouldn’t want to be loud for the other patients, because some people have things like autism and those loud noises might upset them.

B True, and hearing aids.

Q Yeah that’s true as well.

B I do have a few friends at college that have hearing aids. And one of them is deaf completely.

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

Q Oh, that’s great! What about the waiting room?

A Sit and wait for your turn to go in.

Q What is the comfort in the waiting room like?

A Soft and comfy.

Q How about the noise?

A I don’t mind the noise.

Q Is it noisy there?

A No, it’s quiet.

Q What do you think about that?

A It’s good.

Q How about the lights?

A The lights good, helps people see what’s on the door if the fire alarm goes off and the light goes on for deaf people.

Q Oh, it helps deaf people when they can’t hear?

A That’s right.

Q And how about the temperature? Is it warm, too hot, cold?

A It’s warm.

Q Is that a good thing?

A Yeah, it’s good.

**Carer - lives with patient-participant**

Q The practice has changed, they’ve merged, there are not enough GP s… if you ring up, unless you’re dying, they put you on a waiting list. I just had to wait 13 weeks to let one of my people in to see a doctor. They requested a 4-week follow-up… I did the right application at the right time, and yesterday I had to send them a strong message to say, you know, this is 13 weeks, and you are leaving somebody with a perforated eardrum without a follow-up, which was at your request… and this is somebody with a learning difficulty as well. It’s very typical of service now, it’s a lucky dip whether you get to see somebody or not. Somebody will triage you and decide if you need to be seen. When [patient participant] had a suspected TIA and I rang the doctors, they sort of fogged us off and said they only had an appointment later in the day, which would have been fine. They send everyone to our local hospital, which is just a little hospital in [town], and I think we mentioned previously but we waited there 4 hours and got shipped off to [hospital] and we were 13 and a half hours. If that doctor would have said, I’ll see [patient participant], it would have been a different story, but it doesn’t make any difference the fact that [patient participant] is vulnerable or had a disability… she had no priority over GP care. It’s just the same of us, it’s a lucky dip, you get an appointment of you don’t.

Q Sure. And that experience in [hospital], if I remember correctly, you said that [patient participant] wanted to leave [hospital] but she couldn’t because you couldn’t discharge her and she couldn’t discharge herself

A Yes. It didn’t matter that [patient participant] had a learning disability and might have needed extra care for the 13 and a half hours we were sat there. Nobody took or had any consideration for the fact [patient participant] was there. Everybody was sick, and I get that, but [patient participant] was vulnerable, and we couldn’t even get… nothing for the whole of that time. So, she was anxious, and she was upset that we were waiting for that period of time. She wanted to come home and I want to the desk, and I said, “look, I am really sorry but I don’t think we can sit here with [patient participant] any longer, she is getting very agitated, she does have a learning disability and she wants to go home. All of a sudden, it mattered that she had a learning disability because they wanted to know if I had power of attorney and I didn’t, her family did, but it’s 3 o'clock in the morning, I couldn't wake her family up, they’re elderly. So, they wouldn’t let me take her. If I took her, they would call the police, that’s what they said. You know, you’re sent there by another medical professional in a different hospital and are there for that length of time and I end up feeling like a criminal because I want to take her home, because that’s what [patient participant] wanted.

Q Yeah… I absolutely understand your situation there but also the fact that someone like [patient participant] can’t make the decision to leave a situation that is harming them is pretty shocking.

A She is quite able to make that decision, she knows her own mind. She is allowed to make wrong decisions, she is allowed to make bad decisions, that’s up to her, that’s her choice. I suppose I get they have got a protocol they have to follow, but that protocol wasn’t brought into force the minute I booked [patient participant] in. She should have been given a learning disability nurse to be with her. As nobody is ever available anymore, she should have been able to make that choice, whether it was the right one or the wrong one. They obviously weren’t considering her case to be urgent, although a suspected stroke in my book is quite urgent, she was urgent when the doctor in the small hospital made the referral, so she should have a CT scan within minutes of her arrival in the hospital… after 13 and a half hours, [patient participant] never had a CT scan, she still had never had a CT scan. So, somebody wasn’t thinking that a mini stroke wasn’t a serious thing for [patient participant], it didn’t warrant any care. She wanted that decision to leave, she should have been allowed it. If that situation had happened again, I wouldn’t tell somebody I was leaving, I would leave. I wouldn’t give them the courtesy of saying sorry. If I didn’t think it would jeopardise [patient participant] in any way, I would just walk. Because if that was something she was adamant… she was crying and saying I want to go home… she seemed like she wasn’t showing any signs of these funny terms that she has. I wasn’t actually worried about her by then. So, next time I would walk with her rather than give somebody the courtesy of saying sorry. Other people were walking out, but because I went and say we are going to go, we got a “you can’t”.

**Carer - lives with patient-participant**

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. Now, it’s really hard to access the service, you have to go through a social worker, which is impossible, there are very few social workers available, you can ring them and put your name down and say you want a social worker and it can take a long time… it can take a year… it can take a long time to access the service now. So, that’s not so good for somebody who… somebody said to me yesterday, I had to take one of my other people to the doctors, I waited 13 weeks for this appointment, and because I had been a bit stroppy in my email saying, “this is unacceptable…” suddenly I had gotten an appointment, “can you be here by a quarter past ten?” And that was good… I have forgotten what I was going to say…

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

A As a patient ideal, especially with the children with all people with learning difficulty I would like ideal room for them, a waiting area for them away from the normal people with other problems. With disability learning people they are not used to the crowd, they are not used to the crowd, they always escape alone or by themselves or whatever they feel comfortable, you know. Some might feel comfortable in a crowd and some won’t, you know. But with my ??? they feel comfy in the crowd, they like to be away from the crowd, maybe someone they know they’ll be alright if they sit there. But as an ideal waiting room I would like, you know if it could be done, to have a small area for learning difficulty people can just stay there and wait for their appointment time when the doctor calls them. And give them something to read, or something to fiddle about, or something to, you know ???

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

A Well it would be nice to have a nurse saying every so often “oh are you alright, do you need anything” or “are you OK” you know that kind of thing, saying that “we are doing our best to get everything going”.

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

NB: A = patient-participant’s family member ; B = patient-participant

A Yeah. With the doctors, (Name of patient-participant) has been seeing Dr (name of doctor), a long time the epilepsy doctor in ???

Q Is that what they call the Child Services there?

A Yeah the Children’s Clinic. But they were brilliant down there you know. Have you been to (name of clinic) Clinic?

Q I’ve not, no just Adult Service ???

A Yeah the Children’s Clinic down there, (Name of patient-participant) has been there for a long time and he had Dr (name of doctor) was his….

B The first.

A His doctor, yeah. So brilliant. You know such a nice place, all new building. Takes a while to get to (name of hospital) but once you’ve walked in there are all these children’s toys, books, everything was there. And there was a big sitting area, if it was crowded the children could sit wherever they like, you know where they are happy, sit around. It was a really nice hospital there.

B True. And the ??? area if you remember.

A Yeah. So wherever the children were happy they can move around and sit, you know.

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

NB. A = patient-participant, C1 = Carer.

Now this is a picture of a waiting room, obviously when you go to the doctors sometimes you have to wait.

A Yeah.

Q Tell me how you feel about waiting to see the doctor or the nurse?

A I don’t mind it.

Q You don’t mind it?

A No.

Q OK. If you don’t mind it go….if you’re unsure, or happy or sad whichever one you want. Do you have to wait a long time sometimes?

A Yeah I do.

Q How often do you have to wait?

A Aha, I think 10 minutes.

C1 No real concept of the time sort of thing.

Q Yeah. (Name of carer 1) would you say that you’re often waiting?

C1 Yes.

Q For a long time would you say?

C1 Yeah.

Q I don’t know, if you can help to remember any incident. Like (name of carer 1) is quite calm aren’t you? I’ve sat with you in the waiting room, you are quite calm (name of carer 1) aren’t you?

C1 Yeah.

Q You don’t seem to get too bothered.

C1 I do for their sake where sometimes when a certain amount of time we’ve been waiting passes you know, because they should be seen in a manageable time, you know. And yeah at the moment, it’s not ??? but the doctors ??? to get an appointment is very, very bad.

Q How do you feel about having to wait so long (name of patient-participant)?

A Niggle-y.

Q Niggle-y.

A Yeah.

Q Yeah, you get kind of ants in your pants if you have to wait.

A Yeah.

**Carer**

A No? So we arrived at A & E in a very busy A&E department. And the first positive thing which happened was that because this lady is 2:1 we supported her 2:1 to attend A&E and I was one of the two, which meant that I had to park the car and so on. And when we first got there, we were told that we couldn't park outside A&E, which would have meant that one staff was staying with the lady who required 2:1 and I would have had to go quite a long way to find a parking place, probably could have been gone for 20 to 25 minutes. That wasn't acceptable. I explained to the security staff who were absolutely fabulous – and that is not always the…. It's positive because that has not been our experience prior to that. So they made us a special place to park. We were told I didn't have to go and park the car. So it started off really positively. This enabled this lady to remain at baseline, be calm, not to become over anxious. Because as you can appreciate, walking into a very busy A&E department these days is a challenge for most of us and especially someone that doesn't understand what's going on, and she was unwell.

**[CONTINUED]**

So the second thing that happened was the reception staff were very welcoming and they were also really positive. So I thought we're on a roll here, this can't get any better. But it did because this particular lady does not like crowded places, and it was very crowded, we couldn't even sit down, it was full. The corridors were full. The staff were run ragged. And I explained to a staff nurse I think it was as privately as possible our situation and I also explained that we needed somewhere quiet to sit. If it wasn't possible to facilitate that I would probably have to go and drive this individual around in the car because this is the only place she would feel comfortable. And within 10 minutes this lovely staff nurse had found us a very small, almost a cupboard, but nonetheless quiet and away from everything.

She did try to hurry us through but we understood that her clinical sort of presentation didn't warrant to come before some other clinical presentations they already had there. But just the human part of people being kind. and the fact we were able to be accommodated in a very small room with a couple of chairs and it was quiet and there wasn't a lot of external noise or anything made an enormous difference, not only to the individual but also to us. So we felt we weren't getting stressed with trying to keep this person at baseline constantly, which is nearly impossible in a busy environment. And I did feel at the time that had that not have happened then her healthcare needs wouldn't have been met because she would have missed out on having the X-ray that she ended up having.

**Carer**

A No it's fine, don't worry. He once told me when we were sat waiting, “I wish they'd make a cup of tea” because we were waiting. And again, my one thing, we only see it from our point of view I guess, waiting for anybody I think with… who tends to be anxious doesn't help them perform well if you like when they eventually get into the appointment. And on this particular day he'd waited quite a while and he was very fidgety and we actually…. I think you were there actually because I said, "I think (name of patient-participant) would like a cup of tea." Obviously he couldn't have one but that kind of touch would humanize it more.

Q Yeah, because you are like… that was probably the one where you were waiting ages, was in like the slightly…. the building that's like 60s falling apart one, right?

A Yeah that’s it yeah.

Q And you're sat there waiting on a hard, hard, old, old bench right opposite a kitchenette.

A Yeah, yeah and there's people flying in and out and you've no idea who they are, yeah.

Q And it wouldn't be much to go and make someone a cup of tea from the kitchenette.

A No.

Q Although there's never milk in there.

A Well let us make it you know, but sit and have a cup of tea together,…

**Family member – lives with 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.

**Carer**

A Yeah, it’s will commit?, isn't it? If there were one bit of things we could change that weren't particularly gold standard, I think that kind of thing puts people's anxiety to rest a little bit you know. And just something like that with (name of patient-participant) can trigger a seizure, which is quite important really. Or the other thing might have been if somebody came out, anybody it didn't matter, “look we're going to be half an hour”.

Q “Go away, have a cup of tea”.

A Go and have a little walk round or….yeah, yeah. And I said, "Fab, come on (name of patient-participant) let's go and have a stroll”. And that way he's occupied, he's doing something.

**Carer**

A …really, that would be kinder, that would be some of this milk that I'm talking about, you know.

Q Yeah.

A And it's the little things. The big things, they don't matter. But the little things. Same as they do to us, you know just any people anywhere, if you've got information and you know it's going to be half an hour you react better. If you know it's going to be an hour or whatever and you know what's going to happen. But imagine being someone that doesn't process all the innuendos, or pick up on messages that are not spoken, but you're just sat there, it's totally different for them.

**Carer**

Yeah, for me that's important because I see that it makes a difference to that person. And we need to be more wrapped up in that kind of thing and more proactive perhaps. But I get it, everybody's busy. And I'm not saying for one minute that…. we're the people who are paid to support that person but sometimes that support is almost taken out of your hands in the environment that you're found to be in.

**Carer**

Q Have you had any experience with any other kinds of NHS healthcare, like physios or…what’s it called….you know like there’s lots of other kinds of services.

A Yeah. Well my own experience is when it comes to them they are too slow with the appointment thing.

Q OK, so waiting for lots of appointments?

**Carer**

A Waiting for long. Like I don’t expect them to wait….to take longer time to attend to them. Like for (name of resident 2), the ??? appointment that I told you for, the doctor refers to (name), I think their name is called (name) I can’t remember, to come to the house to check ??? It’s 3 years is the ??? from them. So the waiting time I feel is too long. Because I feel the disabled should be like major priority. Because the longer time it can take for you is very different from the longer time they can wait.

**Carer**

Q …can you tell me a story of what you imagine would be the best GP appointment, for (name of patient-participant) for example, like what would you like to see when you take a patient in?

A Yeah. Like what I imagine is just….so sorry why I am using (name of resident 2) is because….

Q If that is the service user that you work with the most then that makes sense.

A Yeah of course. Like I said….

Q It doesn’t matter what they want more.

A Yeah because on like that day that I said about the ??? I imagine there would just be something to check the microscope immediately. Like the team being around to check, to know, instead of just saying “oh I’m referring you to this”. Or probably after checking and saying “I’m referring you to this” in the next day or two days time they are already at the house to come and check what the thing is and giving a solution for that. Instead of waiting on the waiting list. So that’s the kind of scenario, like that is the kind of….

**Carer**

A A bad story… I can only think… this is based on somebody else we support… we normally get this support with [patient-participant], but we are struggling to get it with someone else who is actually in a very similar situation… so, I think… I don’t understand why we can get that support for one person but not for another. I know there are lots of people out there who need support, and I understand all of that, but when we are struggling and crying out and screaming out, even down to the social workers saying there is nothing else we can do… what do you mean there is nothing else you can do? We need help but you just don’t know where to look for it anymore. I think that is probably a bit of… I hate to say it but it has really gone downhill… I’m not saying it was perfect before because we all know it wasn’t, it was already declining… I just feel that our services are being cut and cut and cut so much that there is nowhere to turn to. Even if the service is there, there is only one person dealing with it… which they can’t, can they? Yeah, I think for the minute, our bad story is the fact that there is nobody at the other end sometimes.

Q Yeah. So, was [patient-participant] referred to the psychologist before COVID?

A No, it was during all of it

Q It’s so strange that then the other person you mentioned isn’t getting similar support. Would it be possible to ask [name of psychologist] herself?

A Yeah, I did that. Her support is actually in the building, and we have actually done all that sort of stuff. So, things are moving slowly but nowhere near as they were with [patient-participant] and what we got with her, really. I don’t know if we’re doing something different because obviously there was a different team here at that point as well. We had a different manager… and I don’t know because she’s the one that instigated a lot of it so yeah, I don’t know where it all started really, I just know one day we had [name of psychologist] onboard and she’s almost like a little miracle worker.

**Carer - lives with patient-participant**

A Yeah, I think that sometimes things move a bit slowly, but I understand that is due to severe pressures within the NHS. We expect sometimes that things should move along a lot quicker than they do but there are an awful lot of people out there who are trying to seek help in the same way that [patient-participant] is, so there is only so many specialists who can help [patient-participant]. On the whole, the NHS do a fantastic job.

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

So when you get to the hospital – we’ll use this one, this looks like the outside of a hospital doesn’t it, the Health Service symbol here – what’s it like being at hospital after you’ve had a seizure? Are you happy about that?

A No I’m not.

Q Shall we put that under Sad then?

A Yeah.

Q OK, so what happens when you get to the hospital and you’ve had a seizure? You know the ambulance has driven you there, what’s your experiences like?

A Well you don’t know how long you’re going to be. And you don’t know how many patients are going to be there. And you don’t know how long you’re going to wait.

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

Q Do you like sitting there a long time?

A No! My bum was aching.

Q I bet… 13 hours… I’ve never heard anything like it. That’s too much. Well, the doctors must be nice if you remember them as nice even after sitting there for 13 hours waiting.

A Mhm.

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

Q Ok, good. How do you feel about how the doctors and nurses keep in touch with you?

A It can be a little worrying because you don’t know if they’re going to ring you or not.

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

Q What do you think about the comfort at the waiting room?

A Very good. You’ve got your own space, and they say you can sit where suits you best, and that’s it.

Q How about the noise in the waiting room?

A Not very good because it needs to be quiet.

**Carer - lives with patient participant**

Q Is Dr (name of clinician) part of the learning disability team?

A No. He is just a GP, a really good GP.

Q That’s brilliant because a good GP is just the best thing, isn’t it?

A Yeah, you can’t get a hold of him though because he’s just so popular!

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

Q I used to be in (name of town 2) doctors surgery, I used to feel really comfortable there because I know if I ring up, or mum rings up, or someone rings up at 8:30 or whatever time you’ve got to ring in and I always get to, if I got an appointment I’ve only got to wait like 10 / 15 minutes then I can go in, there I’ve got to wait like an hour.

A Yeah

Q When you put your prescription in and you go in next day, couples days, 7 days, to get your tablets you’ve got to wait an hour for it, you cant just go in there and pick it up you’ve got to wait in the queue and then wait for them to be ready and then wait again.

Q It’s a lot of waiting.

A And then when we’re out the other chemist, you wait 10 / 15 minutes and you’ve got it, there you’ve got to wait an hour in queues.

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

NB. A = patient-participant; B = Carer

A Yeah I hate queues.

Q Yeah totally.

A Somebody needs to get medication and go.

Q So what do you hate about queues?

A Too many people in there, always out through the door normally, you know what chemists can be like.

B Yeah and you’re a very friendly person aren’t you so it’s probably quite hard for you to be in a queue as a friendly person and nobody else is chatting.

A Yeah.

B Oh I see, okay.

A No one talks.

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

NB. A = patient-participant; B = Carer

A Small building but it’s got upstairs and downstairs.

Q So why is upstairs and downstairs important to you?

A Doctors upstairs, and no doors, and not too big a waiting room, maybe a fish tank or something to make it look lively, there’s nothing lively in doctors surgeries do you agree, nothing there to make it.

B There’s a few canvasses on the wall.

A But yeah nothing to make it more.

B Certainly for LD, something you can watch and is calming.

A Yeah and fishes and something there for someone that’s got needs and music

????

A Music and fish and anything calming, or toy corner, your place has a toy corner, something for kids something for them to do because they haven’t got it.

Q Toy corners used to be, every doctors had a toy corner.

A That one hasn’t got one at all, and they should because kids go in there quite a lot for appointments and there’s nothing for them to do and they climb over the chairs, they should play not just climb over the chairs, they should.

Q So when you wait there at the doctors, what do you do?

A Sit there.

Q Just sit there, yeah that gets boring quickly. Do you go on your phone or anything?

A Yeah, the other place got fishes and things to look at, you got toy corner, music, you got things to see, books to look at, haven’t got books either the other one has.

Q They don’t even have books?

A ??? read either.

B ?? hands and germs.

A Yeah but they can, they should, the (name of town 2) one does, did, or still do, they still need something to do when they’re waiting because otherwise they’re sit in there doing.

Q Yeah so it sounds to me you go on your phone because there’s nothing else to do but you’d prefer not to.

A Yeah.

Q You get Wi-Fi there?

A Sometimes, it depends on what area ??, have you found that?

B I tend to read my book on my phone, so I don’t need Wi-Fi to read my book.

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

Better there because there’s more space there

**Family member**

A (Sister/patient-participant) was in respite, my parents were out of the country so I was guarantor for (Sister/patient-participant), I was her main guardian whilst my parents were away. And I was house sitting and going to work. And I had a call in the evening and (Sister/patient-participant) was having a seizure and the staff were a little bit scared because they’re not used to the tonic clonics, the tonic seizure that she was having. The paramedics were called, they took about half an hour, 40 minutes to get there. Once they were there I was getting there roughly the same time.

**Professional/clinician**

I am renowned for not discharging when people should be discharged because I regularly think it might be not now that they need the support but in a month’s time they might. And I feel it is hard then for them to have to go all the way back through the system to be able to get their needs met. You know once they’re discharged it’s not necessarily me they will come back to, it might be that they’ll be put on a waiting list, because that’s the way the service is, so I tend to hold a lot more clients than I should.

**Professional/clinician**

But like I said, I campaign for get through to the GP because sometimes you can be on the phone for hours. Mum hasn’t got the option of doing that because she’s so ??? So I say “right, I’ll ring them, I’ll pass that information on”. And GPs are better, they are more open now, and sometimes we’ve got an email that we can email that query to, whereas families can’t, so doing things like that just to lessen the stress on them if that’s at all possible.

**Family member**

The ambulance, they are really busy, it had taken around 4 hours for them to get to her.

**Family member**

Waiting for 6 hours. I’m not a good patient, I’m really not, my patience is zero for myself. In work, all the patience in the world. For my own life I could not sit there for 6 hours, I’d be thinking of all the things I could be doing and should have done. So for me I can communicate that. Like “where are you, I’ve been here 6 hours now and nothing’s moved”. For somebody with learning disabilities with non-communicate who couldn’t communicate verbally, this would potentially be hitting out at chairs, rocking back and forth, making noises for example screeching. Whereas to somebody else that may look angry, aggressive, all she or he is, is trying to communicate “I’m frustrated”. “I’m bored, I’m frustrated, where is somebody”.

So I would say “right, OK, 2 seconds we’re going to…” again I’m just going to say a name, a random one, “2 seconds [name] I’m just going to find out where everybody is, what’s happening, I’ll go and check where the doctor is”. So again, because I know that this is frustration, he would calm, he would relax and “right OK”. So we’re back now and she will go and find out what. So then I can come back and say “right [name], the doctor said now we’re in a list, we’re 7 in the list, there’s 7 people in front of us and we’ve got to wait for these 7”. So then [name] would also concentrate on counting 7 people when the names were called, so that’s one, that’s two, that’s also something to help with the wait. OK it might not be 7 and we might get a little bit more frustrated then when the eighth person has got called and it’s not [name]. So then I can go back to the reception and say. And again it’s that aspect of communication where it would come across aggressive to anyone else, whereas somebody who would know him it’s just frustration of that anybody else would normally feel while visiting the hospital.

**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 And even like the mobility cars and stuff like that, it’s a good service. We’ve been waiting over a year now for a different car. There does just seem to be, even with everything connected with disability equipment there does seem to be a bigger delay than there would be if you were just going out to buy a computer, you could buy one at Curry’s just like that, do you know what I mean?

Q Yeah, you’re waiting for stuff that’s urgent.

A That’s right, yeah. And not that we’re waiting for anything at all – we are waiting for…

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

A I don’t know. We’ve had temporary cars in the past when it’s broken down, but even so like we still have to wait for [car company redacted] to sort of book an appointment in and stuff like that. So there is a general – and I’m not complaining, don’t get me wrong, it’s just I think that could improved. And more accessible disabilities people to get more equipment and stuff, at least at the same response as you would if you were just a normal guy.

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

A Well in fairness to them, when (name of daughter/patient-participant) got sick she went straight into the…but then there was a lot of waiting then. They took us out of that scenario. But we had to wait to get served, if you want to call it that, and seen to. But as soon as – I can’t even remember what the problem was to be honest, was it breathing….I can’t remember. But they took her straightaway into a room and got us somewhere to sit. But then the waiting time for that was for a long time. In fact it got so bad that she didn’t have her meds, it was late, really late. We said we need to take her home otherwise it will be worse. So we…well we were in the car park and the doctor came out and said “look….” you know. So we went back in, got sorted. But yeah that was….

Q Well little things like that, putting you in your own room, I mean if that’s something that gets offered to you…. you know.

A Yeah that was nice. But it wasn’t a great experience. Nobody’s fault though, it was just a bad…wrong time, wrong day. You see we could have been there the next day and nobody would have been in there. It was just that. Just the wrong day. Yeah, I can’t think of anything else really. Probably when you go I’ll think of loads, but…

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

Or like to be more humanising, I feel like things like A & E, I think rules need to be put in place more. Like my mum took (Name of sister/patient-participant) because she fainted, and they didn’t offer her a bed until they were leaving. But like she should have been offered that. Like she’s been in her chair, she needs to distract, I think needs need to be accommodated more. Because even like (Name of sister/patient-participant) behavioural thing, I think it needs to be taken into more consideration because it can be very distressing for her. It’s like she doesn’t want to be there anyway so if she’s not given like a comfortable environment she definitely doesn’t want to be there. Or want people to come here or like take bloods or something like that, it just makes the whole thing more difficult.

Q Will you speak about that trip to the A & E. Can you turn that story of your sister going to A & E because she fainted into like an ideal story? How would you ideally have wanted everyone to have treated her and your family when they went to the hospital?

A Well obviously I know A & E is really busy but I would have wanted her to be offered it when she needed it, when she first came in, not when everything was done and they were going home. I feel like she needed to like lie down, or stretch her legs, or accommodate to the situation when they first got there or like an hour in, not when they’d been there for like…I don’t know how long and she was fed up.

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

Q Because I do want to go back to the kind of positive examples, because you said a lot and I want to just pull it apart a bit more because I think you’ve got some really good stuff there that’s really interesting. So let’s start off by just thinking about this autism kind of stuff. Had you ever really heard or thought about autism for yourself before you met (Name of consultant)?

A No I didn’t actually. I know I’ve looked…when she mentioned autism at the end of the session I remember going home, looking up all the autistic traits and I’m like ‘oh my God that actually fits me, all of this stuff, maybe I am autistic’. And then when I actually got the referral and we were doing all these tests and that. And then it was the waiting which was frightening because there was a long period of waiting. And then actually getting that diagnosis I was autistic, which helps me a lot because I’ve had more support in school – not school, yeah more support in college, in university because of the diagnosis. I’ve had support when I was on Universal Credit as well because of this. So yeah, that diagnosis was the best thing of my life.

**Family member**

A Well it’s just the fact that the doctors are not doing anything. He was supposed to be arranging things, a scan on my tummy, an MRI scan. The bladder and bowel people phoned me up to find out when it was and I said….oh no I phoned them up to find out, we were talking, should phone ??? so I phoned. “Oh no he discharged you”. I wasn’t even told. And that’s it. That is my life. So yeah I haven’t got…

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

And so we always believed that and (Name of daughter/patient-participant) always believed that and so when we went to see her, even if we had to wait a long, long time – we usually did have and the nurse would come round and say “I’m sorry”. But we’d say “no, (Name of consultant) is never in a hurry to get rid of us either, so the fact that we’ve got to wait a long time because she’s running behindhand is exactly what we know she does. She will spend as long as she needs to be with somebody and if that makes her unpopular, well tough. And we never complained, we never said “oh gosh we’ve been waiting for an hour and a half to see you” – she knew we had. But we were just pleased to see her. And I think she often saw us at the end of her clinic, so often when we came out the place was closed, they had to unlock the doors for us to let us out, you know.

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

NB. A = patient-participant; B = Carer

A Looking forward to my boots and calliper if they fit again.

B It’s been a tricky one hasn’t it.

A Yeah, my callipers are too big for my legs.

Q Yeah and why is that?

A Because I’ve lost loads of weight

**[CONTINUED]**

B What happened when you went last?

A They had to measure me up again, and I’m getting sick and tired of it.

Q I go away ???

A I said I am doing it for my health.

Q Totally and that is their job to give you your callipers. But I think since I have met up, you have had one set already and I only met you just before [month].

A Yeah.

Q It’s crazy.

B It got too big, so you had another appointment to get your new ones fitted but when you got there they were still too big as you lost even more weight.

Q So between measuring and them being ready.

A They muck up my [colour] boots up as well.

Q How do you mean mark them up.

A No muck them up.

B They messed them up, mucked.

Q What did they do?

A ??? to hard on the left boot, no strap just too old, I might need a new pair second one.

Q And the boots, you have [colour] ones? They are the ones that were mucked up, you had a spare pair.

A Yeah.

Q Well that’s something, and who makes the boots and the callipers for you?

A I don’t know that one, I just go on my lovely walk and wait patiently,

**[CONTINUED}**

A Now they should get my boots right, my boots and calliper.

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

Q And can you remember a story that happened when you went, for example for your Doppler?

A I haven’t had one yet as it has been cancelled twice and I am still waiting.

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

Q How does that make you feel to wait for an appointment?

A I don’t mind.

**Carer**

Overall (patient-participant) has always said that she has found it easy to talk to in other professions, I know that she can get frustrated in not understanding, for instance the boot situation she’s got at the moment how long things take to make and if I was in (patient participant's) position I would be quite cross too as things are taking too long and it’s a need, she needs these boots to continue living the life she is living and I think she feels a little unheard sometimes when she is saying 'I need these now and they are not understanding that' because it’s just another person rather than saying I do understand what you are saying and I’m sorry you have to wait but this is what’s going on, it’s kind of this is what’s happening rather than this is what we are trying to do to support what’s happening. I think she can be a little bit frustrated sometimes with the information that comes across.

**Carer**

A I think in personal experience, I think what doesn’t go so well is the time restraints and how long everything takes, when you get to it, it can be amazing but the waiting list is so many things, is just.

**Carer**

A So obviously when there is a need, that need is now and that need can develop and change into something more or it can be dealt with and just go but if that need is now, you need that support service and you don’t necessarily get that, I think that could be a little bit of an issue, here I don’t think we have had that issue particularly, it can be tricky sometimes with the new way the doctors have done the online clinics, so now you have to do an online clinic before you can speak to anybody, which in theory would work really well but you are not getting an answer for when they are going to contact you so you are just on a constant waiting.

**Carer**

I think again this needs to be individualised so for instance, one situation that happened the other day is we had a client that needed to go for an ECG and this particular client has behavioural issues, she had a learning disability and waiting around is something that is not possible for her, she really struggles with that, the hospital had all her information and they still had her hanging around for (time redacted; 2-5 hours) hours which of course caused upset, that I find really difficult as you are in a hospital and of all places they should understand that sort of thing, so that’s not great, but then on other days they are fantastic with people’s learning disabilities because you get doctors like I was just talking about, you build relationships so you do see them, doctors surgery know who they are real people and will speak to them about what’s going on quicker, you know people will make the effort to come out to see them, I think that’s amazing you don’t get that everywhere, a lot of people have to go to them, to the hospital or the clinics whatever, so I think there are swings and roundabouts.

**Carer**

…sometimes it lacks like that situations where people are having to wait in inappropriate situations, I would say overall the healthcare care or care is very good, it does try to be individualised especially with residential homes where they will come out and make exceptions, you know someone that has bloods done at the doctors, that nurse might come out and try to do the bloods here or we have had people do it in cars, we have gone the extra mile, but then you get that little bit that’s just not quite there, it will get there I am sure

**Carer**

Q So what are your worries and hopes about healthcare in this country, particularly for people with learning difficulties.

A I think my biggest worry is that learning disabilities is so vast and more and more disabilities are being recognised, which is amazing, that’s the good part that things are being recognised for what they are, not as something else being misdiagnosed and things but along comes with that lots more people have that problem which means longer waiting times.

Q Interesting.

A I think that’s the biggest thing I would say, the understanding taking longer, times are taking longer as more people are being recognised as a particular need.

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

Q So, tell me a little bit more about [name of hospital 1]?

A [Name of hospital 1] was very nice. They had sweet machines, and they didn’t give me no hot chocolate, only water.

Q Is it important for you to have a hot drink when you’re waiting and things like that?

A Yes.

Q Sure, that’s understandable. What time did you arrive at that hospital?

A I can’t remember.

Q So you stayed well into the night there?

A 3 o’ clock in the morning.