**Carer**

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, I think there are some situations where the healthcare is amazing because they put out all so much support there is so much constant research going on to make things better so you can see that they are really trying and in certain healthcare professions that’s amazing because they are putting that effort in to support individuals as individuals, 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.

**Professional/clinician**

A No I was just going to say, you know sometimes we will do things differently, like we will go out and we will take blood from somebody in their own home where they are more comfortable, rather than somebody having to be sort of dressed and taken in a car and taken into an unfamiliar environment and having to sit and wait and things like that, which can be really triggering for some of our people on our caseload. And people, particularly the ??, there might be issues around transitioning and things like that. So we think “right, well why can’t we do this, how can we….let’s reduce that” you know. And yeah.

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

NB A = patient-participant’s family member , and B = patient-participant

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.

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

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 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.

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

Q And then do you get those packets where it’s like got the dates in and you have one packet for each day?

A Aye.

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

Q You’re nodding, yeah. And what about with (name of participant’s wife/patient-participant) tablets and those people that come over to support with that, how do you find that?

A They come over like say about 6 o’clock to give her her tablets, because it’s locked away like in there but they don’t give us the code number to it. They say “oh we can’t give you the code number”.

**Professional/clinician**

It was a bit of strange one because the [home care] team who go in to prompt the medication wouldn’t normally work with a patient in this way, but there was difficulty at the time with our Commissioning team sourcing a provider to do this. And as you are probably aware, like the difficulty for us is…and this is where a little more joined up working I think would be nice sometimes, is that social services can only put in their social care element, and because (name of patient-participant) was independent with everything else at the time they couldn’t just do the medication, that needed to come to Health. So I think it was the [home care] team that picked it up as an interim measure, but it’s been a really long interim and they’re still going in now in the evening.

**Carer**

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.

**Professional/clinician**

I’ve arranged for podiatry to go out, I’ve arranged dental care for her in her own home, she’s had teeth out. I’ve arranged audiology appointments at home. I’ve arranged opticians appointments at home.

**Professional/clinician**

Q Has (name of patient-participant) talked to you about the tablet prompting a bit?

A Yeah she has.

Q And have you got any kind of views on that service?

A That service feels…. it's really supportive in terms of making sure that she gets the right medication at the right time. It's just I struggle with the rigidness of it. I think I struggle with that there's no kind of flexibility in terms of creating the package to suit her. Which I think is something big that in social services we push to do, where possible try to create something that suits the person because it should be person centred. But it almost feels the medication prompt (name of patient-participant) needs to fit in with the service, which it's not really fair. But she's getting the medication that she has been told that she needs.

Q It’s a tough one isn’t it? If you were to be able to, like money and other collaboration and people's time was no object, how would you look at that creatively - that problem? What would you do to fix it if you could do anything?

A If I could do anything I would love to look at some kind of technology that would really help her to be able to take her medication herself. If there was a box that would ring an alarm at a certain time that was convenient for her, because she needs that prompt at a certain time so she could go and take her medication, that would be fantastic. If not, if a person did have to go in and actually prompt her with the medication, simply asking what time would you like them to come? What time would work well for you?

**Professional/clinician**

Q Yeah. Have you seen improvements based on technology in the last five or 10 years?

A I'm not sure I can answer that question.

Q We know technology's gone like this, but I don't know whether I've seen it really be employed to help people with learning disabilities very much.

A I don't think it's one of the things that people think about first, because potentially there will be the need to then skill build and support somebody for a period of time to learn how to use the technology. Which in my opinion is fine, it’s what needs to be done but I suppose it's a bit more than just putting in. I don't know, I can't comment on seeing a improvement in technology.

**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.

**Carer**

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.

**Carer**

So yeah, as you can tell it says quite a lot about the GP surgery. The NHS, like hospitals themselves, I can’t say too much about because we don’t take these residents there too often and when we do, I mean that’s just….it’s all over the country it’s the same isn’t it? But yeah, so me speaking is just about the GP surgery and about learning disability, them or even… I mean them or regular people. I think it’s a terrible service over there. But for learning disabilities and that, I mean I suppose they could, or they should, do exactly what like I just said about the other surgery and that’s give like a….not a priority line but a different number that’s not out to the regular public. Because there’s so much care to be given and then they can’t get the appointments they need because of this, which could then lead to detrimental health problems going down the line a bit at a time you know.

**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….

Q This priority because your service users can’t necessarily state how serious things are.

A State how serious things are. Like you….

Q The doctors take it seriously ??? as well.

A Yeah. Like you being able to say “oh this is very serious”, like you can’t expect them to say “I have a headache” for example, they will only tell you “my head hurts”. And you as an adult can be able to differentiate a normal headache to a migraine headache, but for them if they are having a migraine, if they are not being tested on tablets say for example, they would not be able to say like “oh this is a migraine, not a minor headache”. So that is my own example.

**Carer**

A No, you’ve really touched….the question was nice, you’ve really touched ??? So if they are taking them to be important, to be very important like a priority, I believe that would be quite important, there would be a difference in the way they give them care. Just taking them to be a priority. Though we have a waiting list, but when disabled people are like priority they tend to stay longer in the waiting lists. And it hurts them because you, someone that is not disabled can be able to tell when it is getting to an emergency, and someone that is disabled. So that’s the thing I feel with it.

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

Participant – MRI, it was not nice, I hate it, too claustrophobic in the machine, you lie still

Carer (?) - I came in with you

Participant – Yeah she came in with me

Researcher - How did you-?

Carer (?) - I had a chair at the end

**Family member**

We waited in the ambulance rather than take her into the hospital, which would again, more in and out, more exposure to light which would have been more uncomfortable for (name of sister-in-law/patient-participant). They brought the doctors to her in the ambulance, the nurses came, they were all wonderful. And as I said, we knew (name of sister-in-law/patient-participant) better so it was safer for her to come home to us and if she needed medication we could take her straight back in because we couldn’t give any more, but the hospital could, rather than her sat in bed in the hospital, again over exposure to sensitivity with the lights, people.

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

Participant – And they said ??? able to walk after it, and I said not really, they let me have wheelchair to the entrance and (carer 1) brought the car down to me.

**Family member**

A Yes it was, yeah it was. It was very private. They thought about again (name of sister-in-law/patient-participant) health by bringing her in and out of that ambulance and that would potentially cause more sensory overload for (name of sister-in-law/patient-participant) and that may again create more seizures. As I said, the nurse came, the doctor came, everything was done at the ambulance. The ambulance service while at the hospital treated (name of sister-in-law/patient-participant) with respect, spoke with (name of sister-in-law/patient-participant), tried to help (name of sister-in-law/patient-participant). As I said in my auntie’s case it wasn’t quite the same.

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

A I think treated like the same no matter their disability or anything like that. Treated like a human? Yeah I just think treat everyone the same. And given the same options as everyone would get. Yeah.

Q Have you got any examples of times when you think that (Name of sister/patient-participant) was given options or wasn’t given options?

A I think my mum had someone….yeah, when she rang for (Name of sister/patient-participant) to have a blood test and my mum said they need to come to the house. And she said that they didn’t have anyone and why should we have someone come to the house to get bloods done. But obviously they ignored the needs of (Name of sister/patient-participant) I’d say. So yeah I feel like some people are unaware what they’re saying until they’ve said it. Yeah.

Q It’s the GP receptionist thing isn’t it?

A Oh God. Hell.

**Family member**

One appointment which I know is really good is like her dental care, and I don’t know whether they’re more tuned into like disabled children or they know how to speak to them a little bit different, but she’s always quite relaxed when she goes there, they talk to her, they have the right equipment there for her to like go into the chair. So she always has a good experience with them.

**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 Well 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**

A So everything he was saying I recorded it on my phone so I could go back over it and I could actually write the medication down, it was like twice a day every day, how much the medication was. So I could actually go back to it and look over it even when the prescription is being dropped off by the pharmacy. So that’s been helpful. And even if (name of associate) was actually….oh what did he say….he allowed me to actually do that to be honest, because I didn’t think most people would. But I had my kind of like safety nets to give it to my mum to go over, even though she was on schools at the time anyway, to listen to to actually hear what he was saying throughout the whole of the assessment. It was a really good fallback for me. Because if I was trying to explain it I wouldn’t have explained it tidy or better like (name of associate) did. And she was very grateful for me to play it back for her, so she was listening to it. And she actually agreed with everything that (name of associate) said.

**Carer**

Participant – I think that it is to do again with that relationship building so we have across site 1 particular doctor that we would go to at the doctors surgery and she knows all our clients so well, so she knows their needs and they need it now whereas if you are Joe Bloggs phoning in, I don’t know about you but I think I have only met my doctor about once and I see hundreds of different doctors.

**Carer**

Researcher – …there is also this question on how you think patients with learning disabilities are treated by the NHS, I know it sounds like a mixed bag, is there something you would like to say about that

Participant – 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