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

Q So how can doctors be the best doctors for patients who are Muslim like you?

B It doesn’t matter if they’re perfect or not, they can still take the information and research in them to get an idea. That’s how I got with dumb doctors, the same advice. And I picked up in high school other methods and that. And here I am now talking to you.

**Professional/clinician**

Q What was the training like…taking you from a general nurse to an LD nurse what was the difference in training do you think?

A I think we focused more on sort of people with learning disabilities sort of right throughout their lifespan. So obviously I know there are lots of different things that can affect people, but you know sort of the common syndromes and things that can sort of lead to a learning disability, how they can affect people. So there would be sort of like the background around that, the background around medication, and then a lot of focus on sort of co-morbidities and the diagnostic overshadowing element. We would talk a lot about communication difficulties, the complex needs, the behavioural side of things, the challenging behaviour. So yeah really, really good. (University name), really fabulous team there of lecturers who know so much, really knowledgeable and really passionate about it. Met some amazing people. So yeah really good sort of grounding. So I feel like the skills they gave the learning disability cohort is that we can do the regular nursing things but we can also then look for simple things sometimes that other people perhaps wouldn’t look at in terms of environment and, you know triggers communication, you know complex needs and things, we’ve got that extra skill which is really important. And from one or two of the placements that I have done that have been slightly more clinically based, it helped transferable ??? And yet I feel more transferable from a learning disability nurse transferring across, rather than people with the more general training transferring across into learning disabilities.

**Professional/clinician**

And I just stood at the door and I just thought if these people had had the training potentially that I’ve been having I think they perhaps would have done things a little differently, that I think may or may not have had a more positive outcome, but I feel it perhaps potentially could have calmed the situation, you know and reassured the patient a lot more than the tactics they were….yeah.

**Carer - lives with patient-participant**

A With (name of doctor), she was my son’s childhood doctor. She is a very good experience in epilepsy with the children with epilepsy. She knew what’s coming and what’s going. She knows exactly because she deals with all these people with epilepsy. She’s been very good to (Name of son/patient-participant) and very good to me as well in that she always explained and she always made sure that she’s here whenever we need her, you know available if there’s anything happen or if there’s anything worrying us, you know. But that’s with (name of doctor). Same again with Dr (name of consultant doctor), I think she’s a lovely lady as well, she understood what I’m trying to say and she knows about the epilepsy people, all these kind of different moods and behaviour and everything. So whenever I’m saying something about (Name of son/patient-participant) she knows exactly what I’m saying. And I’m really happy about that as a doctor who I am seeing with (Name of son/patient-participant) she knows what she is dealing.

**Professional/clinician**

Family members of mine had learning disability nurses, one has retired now and sort of would regularly say to me, “oh do you training, do your training, do your training”. And then as I said it was a sort of ‘now or never’ moment. So I made some enquiries and…yeah, did my training. Best thing I’ve ever done. And absolutely love my job, yeah.

**Professional/clinician**

A Yeah. And I think in a way it sort of links in a little bit with one of the questions I saw about where I’ve seen sort of a good nurse. I’ve seen lots of really good nurses but I’ve also seen ones that I think I don’t want my practice to be quite like theirs, you know. Rather than sort of name like one specific nurse who has been inspirational and that I’ve taken from good practice and practice that I’ve seen that has helped me to decide how I want to be in practice and the sort of nurse that I want to be.

**Professional/clinician**

I forget what they’re called now, the emergency medication plan for epilepsy I think it’s called, and we will do the SUDEP risk assessment in community. So generally medication things are managed I believe elsewhere, but we make sure that everybody else knows what they’re doing. And we will also, if somebody’s having rescue medication we will deliver the practical element of the training as well for support staff and carers.

**Professional/clinician**

But it seemed to have been perhaps some of the confusion for her came from around had she taken it at the right time, or had she taken it or hadn’t, you know did she need to take it again. So I think it was obviously the decision was made prior to me being back in the team that this was sort of the best option for her.

**Carer**

Q So you have to think about….everyone has their way of communicating and you have to find a way of connecting.

A Connecting with people, yeah.

**Carer - lives with patient-participant**

I think going back to what I said about there are some really good caregivers with natural abilities, at the same time, even though you have natural abilities you still need a level of formal training. There are certain things that might need looking at or might need investigated, and I don’t always think that the right people are in the right places to do that. I think there could be a lot more done in the health and social care setting and the people that are working in that might need a boost of training and a bit of wellbeing help themselves because it is a very challenging role. I think it is moving in the right direction regarding the health and social care setting, but I still think there is room for improvement in the training and the support the caregiver gets… not every company, not every person, gets the support like we do in shared lives. I think something that needs to be tackled in the level of support for the caregiver, because like I say, it can be really challenging.

**Carer**

I've always put it down to they're doctors because they're more intelligent than I am and they've got medical degrees and they just kind of function at a bit higher level if you know what I mean. I don't mean they're better than me because I’m very much ‘nobody's better than me’ it's just that people know different stuff at different levels.

**Professional/clinician**

And I had a placement in learning disabilities team. I actually had two placements in the same learning disabilities team and that was just eye opening. The practice educator that I had was really great in telling me a lot about the history and some of the context that some of our guys who have a learning disability have faced, and so seeing some of the disadvantages and some of the barriers and struggles that they've been through it was just really eye-opening and just made me think “oh I’d love to work and support somebody to just live their best life, without sounding too cliché. Yeah.

**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.

Q That's OK. I suppose it's just like your first thought went to ‘is there a device that can do this?’ so I wondered whether you've seen devices used elsewhere. I think there is a device that would do that but it's the training that perhaps people… there isn't a budget for that or a resource for that and so it's not clear whose responsibility that is so it doesn't get done it sounds like. Anyway I'll go back to my list of questions.

A No, sorry actually I’m just reflecting. I think the technology part came from a bit of a personal reflection on my own values as technology is a huge part of my everyday life in terms of accessing what I need to and everyone else is able to due to my own limitations. So I've seen the power of technology and how much it can change and just open up a world. And I think it would be good if everyone were to have access to it, especially our guys who have a learning disability. (name of patient-participant), you know it would open up so many more doors for her. So yeah, I think that's where it's really come from and stemmed from.

**Carer**

Q Is there anything you need to do to train new staff in the way that [name of psychologist] has trained you?

A We do a lot of talking… someone might come in or I might see something and sort of pull somebody to the side and say this might be happening because of A, B, C and D or if you change your approach and do it this way, you might get a better result, and the reasons why.

**Carer - lives with patient-participant**

A I think if you’re a carer and you have the natural ability to be a carer, then you’re humanising it anyway. I think if you’re just trying to read from a script instead of being humanising… that is giving a false impression of what it is to be human and compassionate, understanding and caring.

Q Interesting. So, when you say… there are so many things you said there, but a second ago you said if you are a natural carer, I believe that is what you said… can you tell me a little bit about the qualities that define a natural carer?

A I think, like I said, the element of having life experiences can play a large role in being a natural carer. I think, you know, alongside that you have to have some sort of formal training, but if you have got the ability to be a natural carer… caring is not just a job, it’s a vocation, it’s something that’s within us all, but you look around and sometimes it isn’t. We all have this ability, it’s how it’s brought out. I think natural care is within us all, it just has to be brought out by… you know, doing what I’ve been doing since [redacted year, about two decades]. As we’ve gone on, we’ve got more and more experiences and we’ve used our past experiences to use what we’ve got now, which is a terrific bond with the people we look after.

**Carer**

A I think the other thing that happens in the NHS, and this has always been true back in my day, and that’s that the little guys follow the big guys. So the role modeling is wrong. And it’s as though it's kind of okay to provide less for people who need more but don't know it.

Q Can you explain that a little bit.

A Yeah. So for instance, perhaps it's because they're not trained or have no experience. So I think right from being student nurses, if we're just talking about nurses, there's something fundamentally lacking in their training when it comes to people with learning difficulties learning disability. I think they're not so bad when it comes to people with a physical disability perhaps,…

Q Right.

A But learning disabilities is something that's kind of alien to them. I don't even know that they know the difference between having a mental health issue and a learning difficulty, and a combination of both just fools them completely. So it's “yes, yes sit down dear” you know that kind of thing, and there's that lack of humanity again. It's funny they should call your research humanizing healthcare. It's hard to explain, but it's just like this lack of awareness, lack of…I'd love to get them in a room and say…..do you see what I mean, just for a couple of hours and say, "Come on, you can do this, if you understood the difference that when you meet someone who has a learning difficulty you can make”.

**Carer**

And on that occasion, right through to the radiographer, they let us within a little do it all ourselves, if you know what I mean. “You know her, you do that, I'm just going to be in charge of the machine. Just stick one of these things on”, you know the lead vest. And we got the result. And that was the kindness, understanding, respect, communication, listening.

**Professional/clinician**

Q And for you was it like a no-brainer that you’d be an LD nurse?

A Yeah, yeah, never even considered. And I mean the good thing for me with the curriculum that I was studying is we do all the same training anyway alongside adult nurses and then we break off then for sort of field specific training then around learning disabilities, which is really good. So I do have all the same training as a general nurse as it were in terms of clinical things, admittedly less experience of doing it on placements because my placements have been predominantly sort of learning disability placements. But yeah so fully trained but with that extra knowledge I think and skill that comes with it.

**Carer**

A Yeah. I'm there because I need help from them because they know more than me about that particular problem. They need me there if you like, because I know that person and I know what will keep her or him calm and safe, happy to a degree even though they're unwell, and familiarity. So working together. In other instances we've had nurses say to us, "God, you're amazing. nobody else leaves their staff here all the time." Or, “we're so grateful because we don't really know what we're doing, other than the clinical side of stuff and the nursing part, how do you feel about working together” you know that kind of thing.

**Carer**

A It's not only me that thinks that, other people have said it to me, “oh you're just a carer, shut up”. They didn't say that, but “what do you know?” Actually we know a fair bit, you know.

Q Do you think that happens? Do you get that by doctors, nurses, or is it like the…

A It's not all of them, it’s not all of them but…. I think it's everybody now and again. I think they work in a hospital situation. Our guys work in a care home. And they just see it as being more lowly.

**Carer**

A I suppose the majority of people would say money. I don't think it's all about resources and money. I don't think it matters, if somebody come along, waved a magic wand and suddenly you've got all the perfect hospitals built and everything else. I think it would make it easier but I don't think money can change making the health service more humanized in particular. First of all the people have got to change. In fact I'll give you an example. Systems drive me nuts. So I'm quite autonomous and I'm very lucky I can make decisions and they happen two hours later. I’ve had need to…and this is the NHS, I've had need to contact the bladder and bowel service over the last six weeks. I know one of our residents needs to have an increased level absorbency in her incontinent pads. One level, one level, that's all. Been caring for this lady for 21 years. She's changed a lot in age so her needs are changing. Cut a long story short, I did everything by the book. I completed the assessment I kept a two-week assessment form that gives a clear picture of her bladder and bowel habits, her intake of fluid. We're now six weeks down the road and I still haven't had an assessment for her. They won't give me the OK or they won't approve the higher level of pads. I can't bear to see her wet so I've been purchasing a higher level of pads from the same place that they provide them from. So at great expense we've been buying them. She's now dry. She's been dry since I started to purchase the pants.

I emailed them a week ago. We're about to run out. We're going to have our new delivery of the NHS stock on Friday, but they will not provide me with the higher level of pads. So today I phoned them again “Please do this. It's the most common sense approach. She's dry”. Her skin integrity is good. Why would we want that to not be good? Why should she have to be in wet clothing? Why? But in short they won't do it because she has to have a home visit, even though I'm saying to them “it works, these pads work”. They're not even any more expensive than the other ones, they're just higher absorbency by one level, and they will not. So they're sending out on Friday the old type, which will result in her being wet again once the pads have run out that I've now purchased that will come on Wednesday.

So today I have said to them, I asked to speak to one of the continence nurses, the one that comes out to do visits is on holiday, I said surely there must be someone else - there isn't. So in a nutshell, we either have to buy them or she has to be wet. I've said I'm really concerned that the integrity of her skin will be put at risk, so I'm not going to be party to that. And this is what I mean about I'm not a goody goody but I'm also not afraid to be counted. And I think it's bloody shocking frankly. Because they'll send out boxes and boxes of pads that are no good, yet I'm repeatedly hearing on the news that the NHS is financially in dire straits. Why do we want to waste all these pads?

[continued]

A Yeah. I mean there are…. I'm quite knowledgeable in incontinence pads, as boring as it sounds because I've used them for so long - not personally but for other people. And it's important the absorbency is correct because it can really sort of dehydrate the skin tissue if you use pads that are too highly absorbent. But these are not, they just keep her dry. She hasn't got wet clothes. Why would anybody expect somebody to want to wear wet clothing? It's unacceptable.

**Carer**

A But I think that's the very essence of treating people as individuals. And that's why the healthcare professionals, whoever they might be, need to respect care workers because they're the people who know that person as individuals, and be guided by them in that nobody's asking them to be guided by that with any clinical outcome, just “oh, she won't like that”. “He’ll be scared if you do that”. “Perhaps you could try….” You know that kind of thing.

Q Yeah, I know exactly.

A And even to have some background history maybe, what would be wrong with that? Background information, a little chat with somebody on the phone that could save all kinds of agonies you know when you get to the appointment.

**Carer - lives with patient-participant**

…the most amazing counsellor that [patient participant] had, she was absolutely amazing with her. It took her a while to grasp all of the complexities of [patient participant]’s nature. She was able to guide her in counselling in every way.

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

Because you pick up, and when you’re in this environment with disability and everything, and me and (name of wife/patient-participant's mum) are people-watchers and reaction-watchers, which has all come from when (Name of daughter/patient-participant) was going down on the street, she’d have a seizure and it doesn’t matter, in shops, theme parks, the comments that people make are not always nice. But you get, over the last 30 years, you can pick up on someone’s reaction and words. You don’t always have to say, it’s written all over your face. Ignorance is out there large by way of disabilities. I’ve seen it for myself a few times. You know somebody who can’t get up a step, people just walking past. For fuck’s sake that’s a human being there. I’ll help when I can. I won’t see no-one struggle with a disability whether they be in a chair or a stick, it doesn’t matter. But that’s….just watching people.

And it’s a shame that they couldn’t put it into the curriculum, you know like when they got sex education or whatever they call it. They really should think about, you know like they do with religion, you could take it or leave it. Maybe put it into the education just to give these kids a bit of understanding what this is all about so as they get older there’s not such a stigma about it, you know.

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

A Yeah, yeah. And if there’s anything that I’m having issues with she suggests getting done, like I said, and maybe a full blood count man to check her levels, maybe see if she’s lacking in iron, which (name of daughter/patient-participant) was back a few weeks ago - the doctor gave her an iron tablet, so (name of community nurse) was right. She looks at something and she problem-solves. And she’s so good at doing that you know. Sometimes I can’t think outside the box because emotions take over and the stress levels and the worry and concerns is very demanding because she’s my child, she lives with me and you’re seeing a decline. I mean it’s hard to sort of step out of that box and really see what needs to be done you know, you can’t be rational at that particular time because you’re so concerned of the welfare of your daughter, you know. So when she comes in it’s like she’s so fresh and bright and she can see the grass from the mud sort of thing.

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

And all this could have been avoided if they had just taken in what’s being said, you know. I totally understand where these guys are coming from, I do, I do and I understand the pressures they’re under. For them to help us the government has got to help the NHS, they’ve got to. You know they’re humans just like us you know, overall super educated. I’ve got a cousin who has got an IQ [redacted, very high IQ], it’s all brains and no common sense, a man who can’t even change a plug.

[Redacted further details about family member]. But that’s what I seem to think here. I think they’re blinded with so much information that they can’t see through it. It’s sort of like they’re clouded. I can only imagine the pressure they’re under, but that’s not helping people like my daughter you know. What have I got to do, cry to these people to get a bit of attention out of them to get them to fucking see like you know?

**Carer - lives with patient-participant**

Q What are Dr [name of psychiatrist] qualities?

A Dr [name of psychiatrist] was amazing because [patient participant] was in quite a… Dr [name of psychiatrist] was able to diagnose [patient participant] with [mental health condition], we weren’t told that [patient participant] had [mental health condition], so this condition had been present with [patient participant] for many, many years and I’m just so surprised that no one was able to… previous practitioners were not able to diagnose [patient participant] with [mental health condition]. It has allowed [patient participant] to understand easier some of the warnings and triggers to the condition and we are able to steer her, most of the time, away from the triggers that elevate her [mental health condition].

**Family member**

A Don’t get me wrong, there are downs but there are amazing highs as well you know. And that is across the board. I think as a manager….we’ll go managerials this way, right. I think a young team is always a failure, because unless you live and breathe it right – and you mustn’t take of what I next say now to heart or anything like that right – but there’s a big difference between reading out of a book and actually living it, right you know. So when I was [age redacted, adolescent], working in care, I had [years redacted, almost two decades] years of every day of every minute. These people have got 6 hours a day. You’ll never compare to me. I’ve got, without knowing….

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

Q And I hope they take a bit of notice of this stomach examination that she had with the camera. Was she in here just now?

[redacted discussion about pet]

A I’ve forgot what I was talking about to be honest.

Q You were talking about how you hope that the examination of her stomach and them not finding anything they’ll pay attention to that.

A Oh yeah, I really do, I really do. Because as me and (name of wife/patient-participant's mum) said, they’re looking for something that’s not there. It’s staring you in the face mate, you know. And how they haven’t seen that I will never know. No. We’re not experts but it’s plain as the writing on that piece of paper there.

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

Q What does it mean to be professional to you?

A Know your shit. Excuse my language. But know your shit, don’t feed people waffle who are desperate to see some signs of success in the meds, the condition, everything. And just to have someone, just suggestions by way of just simple things but they make a big difference. She does know her stuff she does. Even with the meds, she knows what the meds do and all the rest of it. She explains that to us. Not like the professors and everybody else.

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

She’s very informative.

**Professional/clinician**

I don’t type very quickly and technology isn’t my forte. The youngsters that are working with us now I take my hat off to them, they’ve grown up with it and they are, you know way, way in advance and quicker than I am. In fact they can type quicker than I can write some of them you know. So they are equipped to do a lot of that. They’re still tied up with an awful lot of it, it still is you’ve got to write about this. And when we had the new system I was quite excited because it was supposedly you could dictate into it and it would type it for you. That never came to fruition. But I was like “great, all I’ve got to do is come out of a visit, I can say what has just happened and then I don’t have to type it and it’s done and dusted”. But that didn’t materialize. But you know that is a frustration for me.

Q I mean that sounds awful that your job is meant to be this and yet it’s now 60% paperwork and administration.

A And the systems, the systems are not always user-friendly either. You know we had a new system come in 2 years ago and it frustrates me every single day. Every day there is something. I did an assessment yesterday, went to send it to the person and it was like “no”. And I’m like “well what happens here now”. All it had saved was my signature. Well why did my signature save and nothing else? Why was that? So it’s like “argh…”. It’s most probably I’d done something but I don’t know what I’d done to be able to rectify it. It just means I’ve got to repeat all that task again now. And you know again that’s another time away from spending time with people.

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

Q I was thinking about that knowledge thing again. And I’m just thinking out loud, but the nurse is great because she knows her shit and she obviously conveys it in a way that’s useful to you.

A It helps us understand.

Q Yeah. And then the professors are like they know what they know and they’ve already made up their mind, that was the impression….

A That’s my impression, yeah.

Q So like what is it about what the nurse knows, how the nurse uses what she knows, how the nurse conveys what she knows that makes her being so knowl….like what makes her knowledge more powerful than the doctor’s knowledge?

A Because she takes the time to explain it all to us, it’s not rushed. She’ll sit down and have a cup of tea and explain it to you “this does this, this does that, this is why this is doing that and this is why this is happening”. She’s just repeating what they have said but with a bit more detail and information for us. And it helps us understand what’s going on. Just simple things, simple things. With the professors, it all seems a bit rushed for me. No sooner are you in you’re back out. And there’s not enough time to get them to see the picture. Very hard to get them to see the picture. And that’s where (name of LD community nurse) has given us a bit of piece of mind, just explaining things to us.

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

A Everything. You’re not singled out. And most disabled people are singled out because of their conditions, whether they be mentally, physically, they are singled out. There’s a statement about it all, there still fucking is, and we see it daily and hear it. I am not so polite these days, you want to make a ??? have some of this mate. And that’s the way I address it now, without confrontation, but if you want to make remarks that involved my daughter when she’s on the fucking floor having a seizure don’t think I’m going to turn the other cheek. Them days are way past me, way past me.

But this is why I was saying earlier that I personally think it would be a good thing to introduce it into the national curriculum as part of education. You can take it or leave it, as with religion and you’re taught as standard, why can’t this be made standard. If everybody understood this in your own little way, and being introduced to it at a young age gives them a better understanding as they get older. Maybe the ignorance won’t completely go, but if 40% of it went that would be a good thing. You know a bit more understanding in the world by way of disability, whether it be in there or physical, it shouldn’t matter. And be willing to help people, not just with disabilities, all people, everyone needs a hand. I know if I fall down one of the boys at work will pick me up “poor old fucker’s on the floor” like. Just simple things. But I personally think it would be a good thing educational wise. Because there are a lot of disabled people in this country and it’s time we addressed it and helped the younger ones understand, you know.

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

Q You’ve sort of given me some ideas about education. What do you think about for healthcare professionals? What advice would you give them to make their work more humanising?

A Well don’t need training, because my wife’s a carer and they’re training all the time.

**Professional/clinician**

A I think it’s just the job. It’s just the role. It’s just learning from other nurses, learning from other practitioners.

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

A With special needs, yeah. They probably knew that it’s good to be at that young age talking to other parents, yeah.

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

A It was the cause of the headaches. It was then. I think they were saying it was behavioural problems, we didn’t think it was, we thought it was a migraine or something going on with her head. Didn’t realise that the epilepsy could be connected. But they thought it was a behavioural problem I’m sure – I might be totally wrong with this. But in the end it turned out it was a migraine. I don’t know. (participant's wife/patient-participant's mother) will probably tell you a bit more than me because I’m sort of like I’m still working in those days so… But that was the thing. And we probably knew what….we knew, well (participant's wife/patient-participant's mother) knew.

**Professional/clinician**

A Yes. [Redacted] But she also became [role redacted], so she was still very, very approachable, very knowledgeable and used common sense, and compassionate with families as well, you know. We’ve had….I’ve been working with her simply with a family where a diagnosis is extremely difficult around epilepsy, we don’t know if it is, or if it’s trauma, or what it is. And basically she said to them “I don’t know the answers, I don’t know where to go with this. But let’s try this, this, this, this, if that don’t work come back to the drawing board and we’ll refresh and relook again”. And I think that is priceless you know, in that they’ve given the family hope. And helping me as well, because I’m still working with this family and thinking this is out of my remit, this is where ??? I can support with. But having her onside has been crucial, you know.

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

A Yeah, yeah. Because I know when the OT first phoned and said to come round, I said she’s a baby, it’s fine. But obviously you’ve got to get things in place. I couldn’t understand why they were coming so early, but yeah.

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

A So I good story was when we first seen (Name of consultant). And we went to see (Name of consultant) and she asked all about (Daughter/patient-participant) background and her history and things like that, and (Name of consultant) said “do you mind if I refer that”. And it sort of threw me at first because I’m thinking “refer her for what?” because obviously I didn’t think anything different.

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

Quite funny in a way because they told us some years ago, said this particular doctor - I think it was Dr (name of another doctor) – is now your epilepsy doctor, your doctor to go to with epilepsy problems. So when we went to see him we told him this, he said “yes it’s a bit of a joke”. I remember when he said it “it’s a bit of a joke, you know more about it than I do”. So he was pleasant enough but he didn’t understand. He didn’t really….

**Family member**

Q So what was that second nurse doing that the first nurse wasn’t?

A Just reassuring me that it wasn’t….the first nurse was making out it was my fault and the baby was being starved. And then when the second nurse come in and actually said, you know, and she could see him feeding in the bottle and there was a problem with his tongue-tie, she said actually he’s not being starved. I think she just took a little bit more time to assess the situation and just realised that actually it’s not a problem with the feeding. And he also had a (allergen redacted) allergy so they were pumping him with (allergen redacted) and then he came out in all… I think just jumping the gun a bit too quick and then….

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

A Well she’s not….her illnesses, they’re not – how can I put it – not speciality illnesses but they’re not….it’s not like flu or something like that. They’re all really related to her cerebral palsy you know, and the GP knows nothing about that. And I’m not blaming them at all but it’s not something that…and when you phone up for some specific reason there’s always, I don’t know there’s always something in the way. Do you know what I mean? There’s always “oh you’ll have to fill this form, you’ll have to see the doctor about it”, you know it’s like that a bit. And I know GPs have a lot to do, but there’s that.

**Family member**

Q Can you tell me a bit about what they were like with (Name of sister/patient-participant female)?

A The physios were amazing. They come in, again speak to (Name of sister/patient-participant) “have you got your (popular cartoon character) doll today, what have you been doing today, oh I’ve just been playing your favourite song”. They speak to her to get her warmed up first and then (Name of sister/patient-participant) just instantly clicks with them and she’s happy to do what they want to do then. And I think early on they realised that what they needed to do and they continue it every time.

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

And at the time, in the beginning, it was difficult but she seemed to know the right things to do, and she was very sort of in communication with us.

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

A Because (Name of consultant) asked me about her family background and I was telling her things. And she said “what’s (Daughter/patient-participant) like on a day-to-day”. And I said she does the most random of stuff. I said like I asked her to watch eggs boiling.

Q She’ll literally watch eggs boiling.

A She’s stood there watching eggs boiling and she’s turning the eggs, like that in the pan with the boiling hot water. She’s literally doing that. And then there was a few other things that was mentioned, and then that’s when (Name of consultant) said “oh do you mind if I make a referral”. Because the stuff that I’d said obviously must have brought things to light with her.

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

Q And what about the GP surgery, if you could change it to the best GP surgery for your family what would they be doing differently?

A I think she needs to read her notes. I think she needs to read up or like maybe not be so rude.

Q The reading your notes would really go far wouldn’t it?

A Yeah. Or like…or she would have seen that (Name of sister/patient-participant) has had district nurses come out and take bloods before. Or maybe just even ask the reason why, like what’s the reason you are requesting this? Yeah that’s what I’d say.

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

But I feel like people who work in places with learning disabilities, they need to go on a course that actually understands how their brain works. To have like a thing about autism and just behavioural issues in general, and what you can do to help that. I feel like those carers need to be more….like to be a carer I feel like there needs to be like a – there might actually be, I don’t know – but there needs to be like a certain job role for them and that like my mum could go to and be like “oh I know they’re qualified, I know they can do everything”, like “oh I’ll have two for that day”. Because I just feel like my mum’s got two carers but I feel like she struggles to find like people who would 1000% know what to do, do you know what I mean? So yeah.

**Family member**

And then obviously you are younger and they’re much older and they’re more professional, they obviously know more than you and all the rest of it, and you would think they are, being qualified people, they know their ??? and you don’t, you are nobody.

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

Q Yeah. So is there anything else, like if we wanted to be more (name of community nurse) what would I have to do? If I wanted to be a nurse that was as good as her what would you tell me I need to do?

A What you need to do is shadow her.

Q Shadow her.

A Shadow her and let her tell you, you watch what she does and just go for it. I mean she would be the top one to learn it off.

**Family member**

But like I said at the end of the day I’ve never been one to shy away from saying….you know more so now as I get older because these men called professionals, they may know more than you and they may get paid more than you, but they’ve lived with them for 20 minutes in an appointment not for the other 23 hours and 30 minutes….

**Family member**

A Yeah. As I say he took over from my pediatrician. Because I was thinking “oh if he’s been training by you then we’re going to have a good one here”. Haha! Yeah.

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

So no he was always very helpful and I think very useful to (Name of consultant). And people liked him – at least we did. I think he was quite knowledgeable, even if he wasn’t qualified, I think he knew what he was talking about but he didn’t push himself. And certainly that last (day) he’d come back with a smile on his face “yes they’re going to do that”, and we knew he’d had a battle. He was good though. I liked him. And I think he was very competent, more competent than his rank probably, I think he’d got a lot of experience. And I think (Name of consultant) found him useful – or finds him useful, I don’t know, hopefully he’s still there.

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

A Yeah. I mean if you came in and, I don’t know, “oh hello (name of daughter/patient-participant) do you like [popular cartoon]” and all of that, straightaway. But if you came in like “oh (name of daughter/patient-participant) have you done….” you know being officious, you wouldn’t get that sort of rapport that you would if you were human, you know if you were sort of like an everyday person. You get your facts and stuff but you get around it in a different way, do you know what I mean? If you came in, I don’t know if you had a bloody old ??? in your hand or something like that “oh”, (name of daughter/patient-participant) she would straightaway.

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

…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**

And if she didn’t feel very good “do you think we ought to try and tell (Name of consultant) about that?” you know.

So we always shared the belief with her that there was a person whose knowledge and skill will help her.

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

A Yeah. And so next time we saw (Name of consultant) I’d still got this cough. She said “have you been….” and I wasn’t going, it was (Name of daughter/patient-participant) we were seeing. And she said “you’ve still got that cough, have you been to the doctor?” I said “no”. “Promise me you’ll go. Promise”. I said “alright I promise I’ll go”. So having promised I’d got to go. So I did. And I made the appointment – in those days you could make an appointment to see somebody you knew – and I saw (name of GP). And he listened to my chest and he said “I can’t find anything wrong”. And I said “oh well fine, it was just (Name of consultant) that said you go and see….” “Oh alright, well if (Name of consultant)” and he knew who (Name of consultant) was “if (Name of consultant) says that, we’d better get an x-ray”.

So he sent me down to (town) for a chest x-ray and the following week I think, I’ve still got the letter upstairs, it’s quite an interesting letter. “Nothing wrong with your chest but what the x-ray did show was you’ve got a sizeable tumor on (organ)”.

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

A I think the only way people would learn from it is by being with her when she’s doing it. You couldn’t explain to somebody, you’ve just got to be there and see how she….how she….how she treats people, how she speaks to them to give them confidence that they can be honest with her. I think it would be difficult for people who haven’t got a compassionate nature to follow that. I think it can be only by watching her that… you couldn’t teach it in a classroom, you couldn’t say “this is what you do, this is what you don’t do”, you’ve just got to see how she actually operates and gives people confidence that they’re being listened to and understood. That she’s not there imposing her thoughts on you, she gets your input first by asking you questions.

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

I doubt if some of her fellow consultants have got that gift so don’t do it. But if you have got that gift don’t resist it. Because I could see how it helped (Name of daughter/patient-participant). When she was holding her hand I could see she was gaining knowledge from that, and she said “I can tell she’s unhappy or worried about something”, she could feel that in whatever.

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

Because they don’t know (name of daughter/patient-participant) as much as we do. Because that was the frustrating part of that that meeting. We knew what was wrong and what was causing it, but I don’t think…. they sort of disagreed with us. But (name of consultant - epilepsy) agreed with us. And then we got to the stage where we got this injection and it seems to be working.

Q Do you want to tell me the story then of you having that bit of a conflict perhaps.

A Well it was no conflict with me, we just didn’t agree. We thought we knew what was wrong, obviously we’re not medically trained or anything, but you know your daughter don’t you?

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

Q I know you had tried to lose weight before so what is the difference between before and when you worked with [name of dietician]?

A I was struggling with my thyroid and I couldn’t get my weight off and it was making me unhappy, now my thyroid has gone down I am happy.

Q OK and how has [name of dietician] helped you?

A She helped me get carbs, protein, vegetables, lots of fruit, 5 fruit and vegetables a day, carbs, I am trying to aim for 7, I am trying my best, meat I have my meat today burger and had lots of salad and water, then I have fruit, banana for breakfast and water. This is my second one, I have been on 2, number 3 then the 4th one.

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

Q There is something I would like to understand more, how she talked you through it

A Like that, relax and put your arms like that

Q So she told you to put your arms out

A Then she’s already done and put the bandage and plaster on it

Q So she did it very quickly

A Yeah, I didn’t want to watch as it would make me faint

**Carer**

…not being felt like you're a number and that person having knowledge of what’s going on and knowing you well enough and to explain it in a way that you need to have it explained.

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

A …like I did a course in…what’s it called….high school for a qualification to be a carer, and that was the easiest thing of my life. I feel like it’s too easy to become a carer, do you know what I mean? Because I feel like it’s a big responsibility. So I feel like to be a carer for people with disabilities I feel like you need something more, because I don’t think it is just…it’s not care, it’s not just personal care and things like that, it’s a lot of mental strain to them and you. So I think there should be more understanding about that.

Q So you did that qualification and you were like “this would not equip me to look after my own sister”.

A No, no. And I feel like that it helped me because I like know about (Name of sister/patient-participant), I could relate like. If I didn’t know (Name of sister/patient-participant) I wouldn’t know what a hoist is. So I sort of knew a bit more than everyone else. But everyone else you’re just sort of write a coursework and then “oh you’re done”. It’s like “well how does that make you equipped”?

**Professional/clinician**

I’ve got a vast knowledge of experience now but that’s come with time and, like I said it might work for one person but it might not work for somebody else, so let’s just trial and error a little bit as well.

**Professional/clinician**

A I think it would be a lot more availability of options for people to make those choices of what it is they would like to do. It would be like therapy sessions, along with physical activities, along with learning, self-help, independence, skill development in whatever they feel they would benefit or would want to pursue. I’ve done things like DBT and CBT to be able to improve my practice, you know to learn about the thing that drives people, that keeps them in a ??? traumatized state, so that again we can hone in on them. And what I was struck with the DBT sessions, a lot of them was around occupation, was around keeping people enlightened, energized, functioning well.

**Carer**

Q As constructive feedback, what do you think the NHS should be focusing on in order to improve the healthcare with people with learning disabilities?

A Well, if you want to understand somebody you can’t generalise them, can you?

Q For sure.

A If you do, you’re going to get it wrong. So, that should be the case across the board. Everybody needs to be treated as the individuals they are. But, with LD, obviously extra training… you know, the Oliver McGowan training has gone into the whole of the NHS, we are doing it here. Lots of people I know that don’t work in care are doing it too, which is great. So, the communications are better.