**Professional/clinician**

He was extremely unwell in COVID, ended up on a life support, didn’t know if he was going to make it. There was a lot of safeguarding went on because of poor management of his care. He was in a way discriminated against because he was learning disability. So that was a big piece of work which we didn’t get resolution to, but he came out OK the other end. Now I’ve always worked in that he wouldn’t go anywhere, wouldn’t go out, wouldn’t do anything, but slowly I gained his trust by visiting and saying “come for a ride with me”. “No, no I don’t want to go anywhere, no, no”. I said “come on, tell you what we’ll just go for a ride, we’ll pull up to a….” oh God, a thing on the side of the road and have a cup of tea, you know so we don’t have to go in, we don’t have to do anything. We’ll just go and have a cup of tea. He came. We went walking in his local community, called in a couple of shops, that worked. Taken me 10 years mind, it’s taken me a long time. Then it would be “right, do you want to come with me to the café” – no problem.

[CONTINUED]

And I just felt that that was immense for him. You know I could have quite easily not bothered. But to me I knew how much he got out of the time that I spent with him. He was engaged, he’d ask me about my car, he’d ask me what the screen was, the sat-nav “isn’t that marvellous” you know. And we’ve gone to one of the local facilities they had, computer screens there with….oh God, quizzes about nature and things like that, and he’d love to do them. And he’d talk about them afterwards. Whereas it took a while for him to get my trust before I could get his trust in other people. And you know his quality of life has obviously improved immensely you know. But yeah that is one that…. And also it meant that I didn’t need to remain involved. He had been seriously mentally unwell as well and been admitted prior, so you know obviously the need was there. But his ability to trust and engage wasn’t you know, and it was just through perseverance really.

**Professional/clinician**

A So there was one just last week actually, a colleague supported a lady who has a mild learning disability, lives independently in her home. My colleague helped her with a hair problem. So basically the lady… it was, and I'm still a bit unsure about the situation but the lady had recently been referred to the team but she was known historically. So a colleague went to see her and there was basically just a lot of matting of her hair, really like she was just not managing her hair at all. So colleagues brought her to the hairdressers. The hairdressers actually turned them away and said they couldn't help at all. And their suggestion was to cut it all off, which I think was just completely heartbreaking. The colleague came back and we all kind of built a plan together and just came up with a plan. And amazingly my colleague went out, brought all of the stuff that was needed, spent time with the individual and actually physically supported them to take care of their hair and to de-matt their hair basically. So the huge win, she didn't need to have all of her hair cut off or shaved off. She's got lovely long hair that is now knot free. that my colleague was really lovely enough to support her to do. I think that's a really nice outcome for that young lady.

Q Yeah. It shows like it's not all about….social work is more than just social care, right? It's about….I don’t know, hair for women is so important, right, so a story like that I think is really, really, really important. And I'm a bit disappointed in the hairdresser though.

A I know. I know. That was really gutting for the hairdresser to turn them away and suggest the only way to manage it was to cut it off. I wonder if it was about how long it would take, or the cost element to it, or if it was somebody with a learning disability and they just didn't want to. I just don't know, I wasn't there when the hairdresser said it. But for this lady, you know she's a young lady, she actually works in supported employment and she was really self-conscious to go to work as I say because of the state of her hair. So yeah, such a lovely outcome for her. But this is some of the stuff that I think people don't really hear about social workers, you know.

**Carer**

…[o]n 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.

**Carer**

Nothing is…. I can’t say it’s not fully investigated or looked at and that because I’m not a doctor, but the way that it’s done is not like the lady I was just speaking about you know, with that soft touch and explaining the communication. Just goes that level beyond, yeah.

**Professional/clinician**

Q And I also, correct me if I’m wrong, but I also got a sense from what you described there that there’s something innate in….like something innate in someone’s personality that maybe helps them be this calming and nice person to patients.

A Yeah. Yeah. And I think so. And I think that is absolutely it. I think to go into sort of learning disability nursing, or I guess any kind of fields whether it be social work, you’ve got to want to do it. You know it’s got to be something I think that’s in you. I know that sounds a bit thing, but it is, it’s got to be something that you want to do isn’t it? It’s not just a job, you know it is more a vocation. And I know that sounds really sort of, really naff like. But it is. You’ve got to be passionate and you’ve got to be a certain kind of person, otherwise you’re not the right fit for the majority of the people that we work with, the type of work that we do.

**Carer - lives with patient-participant**

A Yep. So, I will continue caring for (patient-participant) until I no longer can. I’m due to retire (time redacted; fewer than 5 years) and I shan’t. As long as I am still able to care for him… I mean, he’s regularly asked and monitored by adult social care and shared lives if he’s still happy and if there is anything we can to improve his life, and he is very settled and very content.

**Carer - lives with patient-participant**

Participant – And the good story is when the GP did his annual health check and found that he (identifying diagnosis redacted; the issue was surrounding the patient-participant's genitalia) and she was very good, she came out and explained to me and to (patient-participant) that he (identifying diagnosis redacted; the issue was surrounding the patient-participant's genitalia). Because we don’t know what went on when he was with his mum. He couldn’t remember anything. She went on to explain that she would have some tests done. I said, you know, could we expedite those? While it’s not an urgent healthcare problem, (patient-participant) is anxious, he suffers with dreadful anxiety, and he was absolutely distraught for days. So, we got the appointment very, very quickly and nothing abnormal was discovered. This nurse had then called a meeting and insisted that every single learning disability male had their (genitalia) checked in the annual health check. I also reported that to shared lives and they reported that in their newsletter and made a point that we as carers must ensure that our service users are checked properly, which (patient-participant) really hadn’t been for several years. So, that was quite a good outcome really, not just for (patient-participant) but for male patients with a learning disability

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

She’s been our rock she has (name of LD community nurse). I couldn’t praise her enough. Because it’s her help that’s helped us get through all of this. I think without her either me or (name of wife/patient-participant's mum) we’d be knackered to be honest with you because the people we’ve been to and turning to are just…just couldn’t do it, be there for us or….well not so much us but for (Name of daughter/patient-participant). But (name of LD community nurse), she goes above and beyond to help you. Like they say “give us a ring”. You can’t get hold of nobody. You get hold of (name of LD community nurse), it may take her a day or half a day but she will get hold of these people to have a chat and put them in the picture. And we also pointed it out when we went to that big meeting about (name of LD community nurse). What a lady. What a lady.

**Carer**

A Well treating well, I mean you should always treat somebody how you want to be treated yourself, you know that’s the fundamental part of it. And the hopes is that they get treated as the legislation that’s in place of the person-centred care. But don’t just looking at it as a documentation that’s telling you that they’ve got to be at centre, you’ve got to take that emotion and you’ve got to be involved, not just treat it as tick boxes sort of in your head, like “right that’s been done, that’s been done, that’s been done”. You’ve got to actually have, like I say, emotion or express yourself. So it’s quite like you’re passionate then about it rather than just being playing ??? like stereotypical and you’re just ticking the box going down, down, down. And so that would be like your straight line. And then if you have passionate stuff then that’s when it branches out then. So my analogy is I suppose if you’re just ticking the boxes you’re like the trunk of a tree, but then with the branches then that’s where you’re giving the passion so we can fulfil them, you know. That’s what I think anyway.

And the other side of the coin then is, I don’t even want to think about that really but I suppose it does happen, is the negative side of care where again that comes down I suppose just to tick boxing, so you’re just doing personal care routine but you’re not fully checking to make sure that, you know skin integrity or something is declining and stuff like that you know. So it might not even be something you’re doing intentionally but because you’re not ticking that bit more passion or empathy that you’re not fulfilling the whole role, which then could be the decline of care for somebody then. Especially with somebody who has learning disabilities they might not be able to tell you themselves you know, where a regular person could.

**Professional/clinician**

I’ve been fortunate enough to be able to work part-time and bring up my family, which has suited my needs. I love the job. It’s varied. Every day you know you don’t know what sort of problems you might be coming into and difficulties families are encountering. I think I do recognise a lot of the families’ difficulties and what they have to go through on a daily basis in keeping their caring role continuing. And I try to support them in whatever way I can. I know I can be a little bit more available than I should be in that I will answer the phone when I’m not in work if I know the family is genuine, which most of them are. You know they only ring if they are desperate or they’re stuck or don’t know where to go, and if I can help them I will do that.

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. But then I also think they are dealing with a lot on a daily basis, you know they have got significant pressures on them to remain coping in their homes, and what little services there are out there to meet some of our peoples’ needs.

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

And on one occasion they wanted blood from (Name of daughter/patient-participant) – well quite often – and the phlebotomist weren’t able to get it because she….they found it very difficult to get blood from her. In the end I think she’d had so much taken that it didn’t work. So he took it more than once. He said “you’ll have to wait until the end of the surgery until I’m free and then I’ll do it”. So he did, each time, and he was lovely with (Name of daughter/patient-participant) and he managed to get the blood each time.

**Professional/clinician**

You know I’ve just been talking to another mother that I haven’t got a role that I’ve got to discharge, his epilepsy is now well-controlled, and I’ve said “look, I’m on the end of the phone if you need to run anything by me”. But unfortunately I can’t stay involved because there isn’t a role for me, our time is pressured as well and I can pick somebody else up instead. But I know that their needs are no less now than when I started with them, it’s just things have settled in one area. But their son’s needs are still high – and how little they have and how little support that they have. And they are [profession redacted - requires a degree and has cultural and social capital] that have retired but they can’t enjoy their retirement because they have to, you know continue to care for their son or put him in care – that’s the cracks of what they’ve got, you know. And I just think it’s hard and if I can help in any way then, you know I’ve said “just ring me, I’ve got no problem, just ring me, if I can help or pass you on to the right person I’m more than willing to do that”.

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

You know she’s the only one out of them all that’s seen (Name of daughter/patient-participant) at her worst. And she’s gone above and beyond to try and help by way of support, just support. She’s been helping when me and (name of wife/patient-participant's mum) breaking our heart, and for (Name of daughter/patient-participant), because it’s all about (Name of daughter/patient-participant) with (name of LD community nurse). And you can see the worry in her face. And then she says “I am really concerned about (Name of daughter/patient-participant)”. She wouldn’t go in and make her feel “oh fucking hell what’s going on” like you know what I mean? It’s all positive. But you can see the concern in her face.

**Professional/clinician**

So I just think of my role in that instance is “what can I do to help, what can I support, can I not be the epilepsy service, can I speak to the GP on their behalf?” I’ve gone and picked up medications because the pharmacy has been difficult with mum – was difficult with me as well, and if I can take some of that brunt because they are dealing with (Name of patient-participant) needs on a daily basis, if I can lessen some of the difficulties, that’s what I aim to do. I can’t be there all the time but if I can I will do my very best and just help. And just listen as well, just quite often just go and visit, listen and try to understand what they are going through. Quite often in clinic when we go to clinic (Name of patient-participant) in the past can be quite disruptive, so I take her out for a walk so mum can talk openly with the consultant. You know I’ll engage with (Name of patient-participant) so that that dialogue that is required around her needs, I try and keep things a little bit better for the appointment to be more productive, as opposed to trying to work around them.

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

But we did always manage to get through and (Name of consultant) gave us her other… her non-NHS email, her personal email address so that if we had a problem and we were worried about something we could send her an email and she would communicate with us and book a….she would see us at the end of one of her clinics or something. And we would go happily and sit there for an hour and a half before we saw anybody but we would…. So we always knew she was there if we needed her. And (Name of daughter/patient-participant) had total trust in (Name of consultant). If (Name of consultant) asked her any questions she would always answer them, and whatever (Name of consultant) said she should do, she believed it was right.

**Professional/clinician**

Q There is one thing that worries me a little bit about sort of hearing you speak – well there’s lots of things that worry me but they already did worry me. And this worried me too to be fair and you said it right at the beginning, that like the reason why you do such a great job is because you go above and beyond. And sometimes when I hear patients and families in these interviews, that’s what they described as well, somebody who is willing to go above and beyond. I’m not sure how sustainable that is for most people though who work for the NHS.

A I think it could be but I think a lot of them don’t want to, you know. I could still do it within my role but the sustainability is the pressure on the amount of paperwork, the amount of assessment, the amount of documents that now have to be completed which takes up 60% of my time.

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

Because the same thing happened with (Name of wife/patient-participant’s mother). She knew (Name of wife/patient-participant’s mother) wasn’t very well and “have you heard that”, “have you done this”, “have you done that”. And so we did and it ended up she’d got an irregular…(Name of wife/patient-participant’s mother) had (condition) is it called? (description of symptoms). And unfortunately the treatment for that was to thin the blood so that she wouldn’t then because of that, because of the heart not working properly you might have a clot and have a stroke. But when she had the hemorrhage of course the fact that she was on blood thinners meant they had that much less chance of doing anything about it. They said unfortunately the fact that she’s on (medication) means the blood’s a lot thinner and it’s just a lot worse than it would have been.

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

And she did far more than that because she helped in other ways with (Name of daughter/patient-participant) other health, you know in a GP sort of way she’d say….I can’t remember what but she’d sometimes suggest she did something or “try eating so-and-so”, she would do things like that, I can’t remember what. But I remember sometimes, well (Name of consultant) thinks it would be a good idea if you had so-and-so, so we’ll do that. Yeah.

**Carer**

Participant – I would say in experiences with working experiences I won’t let things drop until we get to where we need to get, so I feel it’s been fairly good in being able to get hold of people we need to get hold of and I am quite happy to ask lots of questions and seeing what’s the next step, what can we do now, I am always prying, so I think that’s the thing if you getting in contact with someone, I think sometimes they will give you the basics but if you are willing to probe a little bit and ask what else then they are a little bit more open to say well there’s this, there’s this, there’s this. Do you see what I mean?