**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. But it's going back to a cup of tea isn't it? Because when we were there with (name of person participant supported who had a dehumanizing healthcare experience) that I told you about, in 10 days we were never given a cuppa. They would come around with the tea trolley, want to give one to (name of person participant supported) who couldn't have one but they would never say to the member of staff.

**Professional/clinician**

A There’s obviously we’ve got the (senior colleague). In my team, in the community team that I work in we are a multi-disciplinary team so we’ve got [redacted number -relatively small team] nurses and our team leader is also a nurse. But we’ve got occupational therapists in the team. We’ve got a speech and language therapist. We’ve got a consultant psychiatrist and a clinical psychologist. An OT technician. They’ve got a team secretary, a medical secretary. So we are very much a multi-disciplinary team. So whenever a referral comes in it’s not…you know it mightn’t always be that it will go to a nurse, we will discuss it in our meetings – our [day of the week] meetings, our MDT’s – and decide the best way forward. And it might be if it’s somebody that isn’t known to us we’ll invite them in for an assessment clinic and we’ll decide based on the referral as a team who we feel are the best people to suddenly? back? And usually it will be psychiatry or psychology and then a nurse, or maybe one of the therapies if that feels more appropriate based on the information that comes in in the referral. So we all take sort of a comprehensive history and information about the patient who has come in to decide the best way forward, whether it is for the team, which person in the team, if we all joint work. So that’s sort of very much my team.

**Professional/clinician**

People then who….sort of there’s obviously different funding, some people will have social funding, some people will have health funding, some people will be 50/50, so there’s obviously a lot of care co-ordination around that. We do a lot. We do a lot you know.

**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.

**Professional/clinician**

Q And how do you work as a team to help people?

A So we meet, we’re in like conversation in the office picking the brains and that kind of thing, but we meet twice a week where we have… it's called a fishbowl meeting. But it's basically like a reflective meeting where if we're a bit stuck with a case or we want to reflect on something that we're finding a bit difficult, we take it to fishbowl. And we present the case. There's a bit of a formula that we should follow but sometimes we get a bit off topic where we go through the case, the context of the person, sorry. And then we kind of say what the barriers are, what are the outcomes, what do we need to kind of focus on, and just have a bit of a reflection on working with that person. And then other people kind of put in their perspective and their reflections. So we do that twice a week and it's so helpful. It can be really eye opening. It can help you think about different things that you never really considered just new perspectives and stuff that I might have overlooked, especially from being quite new, newly qualified as well. Previously I found that so helpful, just hearing about other cases and some of the complexities of the cases working with different courts and services and that kind of stuff, it was really insightful. So yeah we do that twice a week.

Q Mmm. And do you all have time to bring a case each or does it to be like you don't? Like how many cases can you get through in a fishbowl?

A A long fishbowl is probably about three cases, but we would typically bring something if we needed to, if something was actively going on. So I recently brought something to fishbowl because (information redacted), so I brought this individual to fishbowl to talk about ‘this is the situation, I had a bit of a reflection and this is my plan of action moving forwards’, can anyone else think of anything? I then brought my capacity assessment prep and spoke about ‘this is what I'm going to do to support this person maintaining capacity and trying to build capacity’, anything I'm missing? Let's try and reflect on this.

Q Yeah.

A That, and then the little query, took up the majority of fishbowl because it was quite a….

Q Big one, a complex one.

A Yeah, yeah.

Q So it's like a hive mind then.

**Carer**

Researcher – I’m assuming, failing to let you know when she makes appointments. Could you tell me a little bit about what effect that has on her overall care from your point of view?

Participant – Well, from our point of view, if we don’t know that she had contacted them, then we can’t support her around stuff… I know she has been in on a couple of occasions to do with her implant or wanting a coil or something, and then all of a sudden there is a letter about an appointment and it’s like… hold on a minute, where has that come from? So, we can’t always be there to support her. I know she is independent, and we are not knocking that, it would just be nice to have the heads up if, you know, she’s been in… she doesn’t even have to tell us what they’ve discussed, just a brief outline would be… like, oh ok, and then we could have discussions with her… like oh, cool. Very much like the fact that we changed doctor surgery, I mean, the only reason we found out about it is because she’d come back and said she wasn’t able to get her medication and when she went to go ask about it, she went back to the surgery, and they basically told her she’s not on the books anymore. It’s like… what do you mean you’re not on the books anymore? It was my colleague that turned around and said, “have you signed up for another doctors?” and she went “yeah…” so, you know what I mean? If it wasn’t for that, we might not even know she changed doctor surgery. So, for us, that’s a lot of information… you know, if she has to go into hospital, we are giving out the wrong information to the workers, you know, if it was an emergency or something and they needed to know a nurse or a doctor or whatever, and we are giving one, but actually she has moved. It’s just little things that need tweaking sometimes when people are within supported living… we’re not stopping them from doing anything, it’s just being a bit open, if you know what I mean.

**Professional/clinician**

**Medication story excerpt 1:**

We’ve got our [service that provides intensive support out in the community] team that we can link in with that will sort of focus around monitoring and formulated plans around behaviour. So yeah really when it’s more than just a social care need really. You know if somebody is sort of quite independent or is being managed well in the community and then there aren’t any health needs, then that generally would be sort of services led. But it’s when there’s a little bit more, a bit extra to help somebody to sort of keep their place in the community really. Yeah.

**Medication story excerpt 2:**

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.

**Medication story excerpt 3:**

We are now in the process of looking to see if we can get a private call commissioned now for the evening as well because I think that would be better for (name of patient-participant). If we could get it with the same company that would be really good just for communication purposes then between, you know between them if there had been any issues on the morning call or any issues on the evening call then obviously that would be communicated clearly, you know written in the book and documented.

That would give more a degree of flexibility then to sort of tweak the call times to make sure that they really are working for (name of patient-participant) and taken away then from a team of people who are doing it at the moment that it isn’t really part of their role to be doing.

**Medication story excerpt 4:**

Q Yeah. So obviously she was sort of saying for a long time that (time redacted - very early in the morning) was too early and it did take quite a while to get it to (time redacted - early in the morning, but more reasonable time). 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.

**Medication story excerpt 5:**

Q It does feel like the story is all about that whole health and social care and where that line is.

A Yeah.

Q Or the fact that they are together, they should be seen together shouldn’t they much more.

A Yeah. And that’s the thing. Like you can work really well together in terms of planning and brainstorming and trying to come up with ideas, but then when it comes to sort of the funding it’s a whole different….you know that’s not at the level that I would have a conversation with (name of social worker) in the office about what’s best for (name of patient-participant), that’s decided then by other people. And sometimes people who perhaps don’t know the person maybe. Yeah. You know their thing is to look after the budget and the funding and make sure that’s all in order, whereas I think down at our level it’s more about what does the person need and what’s going to….you know what meets their needs best, what works for them best. Yeah.

**Medication story excerpt 6:**

Q …in terms of thinking about her independence, and it’s so valuable to her. Is there any world where it wouldn’t have to be medicine prompters that come and do it.

A We have looked at the option of sort of like an electronic device.

Q Yeah.

A (redacted) I’ve sort of made some preliminary enquiries with the pharmacy and they’ve said “yeah we could try and accommodate and put the medication in the cartridges of the thing”, I forget what it’s called so this is going to sound terrible now on the recording because I don’t know what I’m talking about, but you know they’ve said that yeah they would try and accommodate that. But we’re thinking right, she’d need probably 2 or 3 and then it would be who would get them then and be responsible for putting them back in the device, and who would then….you know it might mean that the carers would need to go to the pharmacy more frequently and….yeah there would be a lot, a lot more I think that could go wrong with that.

And I think it’s looking then at the risks of sort of, you know if one sort of part of that chain fell down, then if somebody sort of didn’t take it to the pharmacy or the pharmacy didn’t fill it, or the battery went, or it wasn’t loaded in properly, or (name of patient-participant) didn’t happen to be there, it’s sort of managing the risks that could potentially come of that. Although I think it would be wonderful for her to be more independent and not have to have staff come in, I think at the moment that is sort of, you know you’re looking at how the other option would potentially work. I think the risks are less at the moment with the staff coming in because there can be that communication between them. Yeah.

Q There are too many variables, too many moving parts with that option.

A I think yeah, yeah. Yeah that we’ve not been able to sort of iron out. I mean we’ve talked about it lots, you know we’ve looked at the tutorial videos of the device, and yeah you know and as I said I’ve spoken to the pharmacy and we’ve sort of thought, right, if (name of patient-participant) could buy it herself, if we could do this, you know she would need to have two in the pharmacy and one out. The carers would have to pick up the prescription, you know it would have to be over…. You know we’ve tried to sort of work out over which time frames it would need to be taken to the pharmacy and picked up and put in. Yeah. And if they say right it’s 28 but she has medication every morning and every evening it would be 40. You know so we’ve tried, looking and trying to look to see if it can work. I don’t know. I’m not quite sure.

**Professional/clinician**

A Yeah. And (name of ward sister) was very much - and I tried to take that on board – “never ask anybody to do what you wouldn’t do yourself. Never expect anybody to do more than what you would do yourself. And be prepared to roll up your sleeves and get on with it”. You know we’re all here to do a job of work and let’s do it to the best of our abilities. And that’s what I try to say to the staff, we haven’t got the knowledge of it all. If we don’t know, ask if we don’t know. But always be prepared to take advice and learn. You know if you think you know it all then I don’t think you should be in this job, because we’ll never, ever know it all. And always just give all what you can as the best you can. But I’m also aware that you can’t do that without support. You know there’s no “I” in “team”, and you need a team and you need to be willing to be approachable but also to have the opportunity to talk and discuss and reflect on practice, and what is good and what does work, what doesn’t work.

And I guess not be dictated to. You know because quite often managers say “well we are doing it this way”. And I’m like “well why? We tried it before and it doesn’t work”. “Well tough, you’ve still got to do it”. And I’m like but that’s not how things should be, they should be a bit more fluid, they should be a bit more two-way. Yes I know we’ve all got restraints and we’ve all targets unfortunately that we have to meet, but we’re not numbers either you know, we’re not a number that needs a tick box. And quite often that’s what I feel some of the work can resemble, you know it’s filling a form in and ticking a box so that there’s a statistic to say that that’s been done. But you know we’re not are we, you know we’re not, you know it, it’s more about being validated and more about being listened to and people having the opportunity to express their emotions and offload.

And I just try to do that, like I said with the youngsters as well. You know listen to them and the difficulties that they may have and support in whatever way I can. And equally they’re supportive to me, you know especially with “what have I don’t now, please come and help”. And they do you know, so yeah. And humour, you know I use a lot of humour in there. I pulled my drawer apart yesterday, they were hysterical, it’s just like “argh…” I’ve got a little 3-drawer like filing cabinet, but I got something rammed in it so I had to pull the drawer out, couldn’t get the drawer back in then. Well they were all hysterical because I’m always doing stupid things like that. So that’s where I need support, it’s like “ooooh”.

**Professional/clinician**

A I don’t know if I could give particular examples, because again I think that’s something that we sort of do. So always thinking outside the box, it sort of isn’t for us, if that makes sense. Again it is this sort of like, oh you know, you know around like yeah desensitisation work and things like that, rather than just going in and you know whacking a cap on somebody and think “right how can we do this, how can we introduce this, what’s the best time for this person when are they more likely to be receptive to it” you know “what if we just show them this, what if we show pictures, what if we do a social story, what if we let them touch it or if we let them feel it, what if we try it on….” you know it’s just something that we do as part of our….yeah part of our every day really you know.

And that’s what’s really good like in the team, being part of the MDT is, you know we’ll have a case discussion element. And what’s really nice in (name of hospital) as well is that we’ll have peer supervision days with other community nurses from other teams. Because obviously we’ve got the (name of team), there’s (name of team) there’s the (name of team) team, the (name of team) the (name of team) and we’ll have sort of every 5 or 6 weeks we’ll have a CPD day, Continuing Professional Development, and then a peer supervision day. And we’ll bring different nurses from different teams and we might bring cases, and we’ll all have a discussion. And everyone is all like “well what about this, have you tried that” or “we had this is our team and we tried this and it’s really good”. And that’s really encouraged in learning disabilities in (name of hospital). And yeah, so yeah.

**Professional/clinician**

Q Have you been involved at all about sort of getting the tablet prompters?

A Not at all, no.

Q That's a healthcare thing, separate.

A That is, yeah. That'll be a community nurse, (name of LD community nurse) who usually organizes that. I think the slight, slight crossover with social care commission is the care agency who we commission collect prescriptions and put them into the locked box, and that's it.

**Professional/clinician**

The colleague came back and we all kind of built a plan together and just came up with a plan.

**Carer**

Participant – I think a positive story for her was when we got [name of psychologist], the psychologist, involved. We got to understand how she works… does that make sense? Do you know what I mean? So, we found out there was a lot of trauma, so we were able to support around that, we found out there was a lot of abandonment issues, so we were able to support… and understand, able to understand things when they happen… ok, that’s happening probably because of A B C or D, which we would have never of done if we hadn’t of had the psychologist supporting us with that. So, a massive two-year bit of work went on behind the scenes of all that and I can’t knock anything that [name of psychologist] and her team had done because every time we went to [name of psychologist] and said, “we’re having issues with this,” and [name of psychologist] would pull someone out of the woodwork and the team would then go through the process of whatever they… yeah, like OT referrals we had… she had a massive team at some point, as well as us in here, which guided us to be where we are today.

**Carer**

She always put [patient-participant] first. Even when we thought we didn’t agree with the things she said, she would explain the reasons why we need to be thinking slightly different. I suppose that’s the psychology stuff in life, isn’t it? I do find psychology quite fascinating, so maybe that’s why.

**Carer**

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

Participant – 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**

Researcher – Thinking about your current experiences and your historical experiences of the NHS, what are your worries and hopes for healthcare services for people with LD’s.

Participant – There has to be more recognition for the health and social care sector. You know, I think it was about this time last year that there was something like [over a thousand] or odd vacancies within [county] in the health and social care setting. Not enough was being done to actively fill those vacancies, and I think it comes down to the settings… the training settings, and obviously, you know, the financial side of it does play a part in this. There is not the same recognition as if you were an NHS nurse for a health and social care carer, there’s a big gulf between the two still. I think going forward, there has to be a closer relationship between mainstream national health service and the health and social care sector. There isn’t at the moment… the two have to be more aligned.

**Carer**

Researcher – It sounds like you’re saying that [name of psychologist]’s involvement with [patient-participant] has almost given [patient-participant] a voice beyond her immediate healthcare, doesn’t it?

Participant – Yeah, it’s like now… so, we do a meeting now and I’ll say to her, “give me what you want to talk about within that meeting,” so we continued that on. She’s involved in… to be fair, we do team meetings and we actually, normally, the person is involved with their review with my team and then team meetings are normally close-knit team meetings, but because [patient-participant] has always had a say since [name of psychologist], we involve her in those meetings as well. Sometimes you do have to have meetings without her, but it’s better to have them with her because she then knows that we understand what she wants, do you know what I mean? So, yeah, the last meetings we had there was her mum and dad involved in all of them. Which means that she is definitely leading her team because we’ve got nothing to hide… not that we do, does that make sense? It’s all out in the open, you know, if we say, “that’s not the best route to go down, have you thought about doing this?” to her in front of everybody rather than behind the scenes, if you know what I mean. So, she really is leading everything.

**Carer - lives with patient-participant**

Researcher – What advice would you have as a carer to a doctor, or healthcare professional within the NHS, what could they do to make the work more humanising?

Participant – I think understanding the… if you’ve got learning disabilities, I think you’ve got to understand where those come from, and I think it would be good to have insight from a professional to discuss these things… so that the carer has a better understanding and then in return, the health professional understands the carer, what they’re trying to do. So, it’s like a mixture, it’s feeding off each other.

Researcher – Thank you. Have you always felt involved enough… do you think the NHS has involved you enough as a carer in their decisions or information gathering processes?

Participant – Yes and no. I think there is a lot of… they tend to sort of have… when there is process being put together, when there is a care plan being put together by a professional, I think that sometimes it is just a taper of questions not tailored to the individual, a standard form, a standard way of doing it. I think that has to be more person-centred, more tailored to the individual, you know, care plans, assessments, they have to be more tailored to the individual rather than just a generalisation.

**Carer**

A Just ignore me. 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.

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

Q How do people look after you?

A They come together.

**Carer**

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**

First of all the security man, he's not part of a medical team but he was helpful, he was accepting he was kind, and I keep saying that.

**Carer**

A Definitely. And also she got what she needed to have, which was an X-ray. 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.

**Carer**

A Somebody who listens, who just listens, who considers what's being said to make a difference for that particular person and not just be based on tick boxes and their job or my job but to have the person - which I always thought is supposed to be the focus of attention. But we can only all do that if we all work together. And I think the NHS, some staff looked down on social care.

Q Right.

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: But yet when we're in (name of person participant supports who had a dehumanizing healthcare experience) situation or…little do they know how much they need us to be there.

Q Yeah.

A Because a lot of our guys at these two homes, you couldn't leave there anyway because the staff on the wards wouldn't cope with the additional parts in addition to the clinical treatment.

**Carer**

There's some great nurses. There's some great doctors, great security guys and receptionists and there just probably aren't enough with the right attitude. Same as us here.

**Carer**

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**

Participant – When you’re a genuine carer, you’re more in tuned with the person you are caring for and are able to advocate maybe their anxieties, needs… not 100% because I’m not a professional as such… but you’re able to push them to the right people

**Carer - lives with patient participant**

Researcher – Sure. One thing that that I’ve been wondering in general around the learning disability team in (county), because we have been able to observe some really positive practices there, are you noticing a difference between the care (patient-participant) receives from the learning disability team and from more general practice, GP maybe or a hospital

Participant – I think GPs are a bit more proactive in guiding us towards learning disability help if I ask for help, whereas before I would have just been told to google it, whereas now there seems to be a much closer relationship between the GPs and learning disabilities team really. (patient-participant) has got grief issues around his mum, and I’d said to the GP at one of the visits how worried I am about (patient-participant’s) inability to deal with his grief, and they referred us to a learning disabilities grief counsellor, which was brilliant. That was good because his (family member) is on end-of-life support and that is severally going to impact (patient-participant)’s mental health. So, I know I can go back to them and get some help with him coming to terms with the loss of his (family member).

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

We’ve also….she suggested a number of times where (name of daughter/patient-participant)’s health is going maybe have (name of daughter/patient-participant)’s bloods done. I’ll email whoever needs to be emailed, like (name of nurse) or (name of dietician).

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

Q So from your perspective the learning disability service works quite….

A Really well because everything comes under that learning disability. You’ve got the professors, you’ve got the speech therapist, you’ve got the OTs, you’ve got them all and they all come under the….which is a fantastic idea. Because a standard OT, say for instance somebody has got capacity and all of a sudden they have an accident and they become disabled and you have just an OT out to assess their abilities and what’s needed, they can understand them. But learning difs is another area, it’s so complex, it’s so hard for the individuals to explain what they need, when they need it, and them being professionals in learning difs in certain areas like OT, dieticians different things like that, they understand, they are level and they fully understand.

**Carer**

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 incontinence 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?

Q Well and from…yeah I mean it sounds really infuriating and I was really surprised that it’s not a social care decision, I’m surprised that that is a healthcare decision.

A Yeah, it's healthcare.

Q I'm surprised by that.

A Yeah, they work for the NHS and they’re, yeah community bladder and bowel service.

Q Yeah, it doesn't sound to me like…. it becomes a healthcare problem if she's not in the right absorbency, right?

A Well it will do, yeah. But yeah all people who wear incontinence pads have to be assessed by the bladder and bowel service.

Q Wow, I didn't know that.

A Yeah. So if they have any change in their need… and I get it, but I get that, I can go with all that.

Q So why is it necessary? Is it because you need to monitor….like why is it healthcare not social care?

A I have no idea, it's just how the system works.

Q OK. There's not a reason then, it's just how the chips lay.

A Yeah, yeah, who funds it and everything. Yeah it's definitely NHS. But it drives me nuts.

Q Yeah, it sounds really frustrating. It just seems like that should be your decision or like a carers. That sounds to me like it should be your problem.

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.

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

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

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

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

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

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

A Yeah.

Q Oh that’s so good.

Carer (?) - We book them.

Q Oh okay.

Carer (?) - To any procedure or appointment.

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

Carer (?) - Yes.

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

Anything that needs to be done I do it for (name of daughter/patient-participant) because (name of daughter/patient-participant) is not capable of doing these things herself. So my husband is also involved, I involve him, I tell him of all of her appointments, the outcomes. If it’s an appointment that I feel he should be there he will come with us to that appointment. He will pass over information as well from his point of view.

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

And (name of LD community nurse) came with us. She had hold of (Name of daughter/patient-participant) to make sure that me and (name of wife/patient-participant's mum) could address a panel on an even type keel but knowing that (Name of daughter/patient-participant) is in good hands by the side of us like, you know

**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).

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

Q And the community nurse spent the time at the top with her and she mentioned…

A [redacted]

Q Yeah. So was that something you talked about before and sort of agreed that would happen?

A Like what?

Q As in you sort of mentioned that she did that to allow you guys to be there in the present.

A Yeah, no it wasn’t planned, it wasn’t planned it just happened.

Q Was that how you wanted her in that meeting?

A Did we want (name of LD community nurse) at the meeting?

Q As in is that the best thing she could have done for you in that meeting do you think?

A Definitely, definitely. Because it freed up…because we’d been to meetings in the past and the way (Name of daughter/patient-participant) is we can’t be on the same level because one of us had got to deal with (Name of daughter/patient-participant) and one of us had got to do the talking. And sometimes my mind goes blank and sometimes (name of wife/patient-participant's mum) does, so we will bounce off each other to keep singing off the same page. But that was just something that (name of LD community nurse) done on her own. Because we were going to sit (Name of daughter/patient-participant) between us and talk, and (name of LD community nurse) said “come on, come on, I love (Name of daughter/patient-participant), we’ll do some drawing on a sheet and you and (name of wife/patient-participant's mum) can have a good conversation with the group like”, you know.

But that wasn’t planned, no. No she just done that. But that’s (name of LD community nurse) for you. She’s a really, really good person. But that helped massively because it let me and (name of wife/patient-participant's mum) talk to the professors and everybody.

**Professional/clinician**

A (Name of doctor) is so down to earth, she is so approachable, she is so willing to listen. Doesn’t always agree with you, you know. And I would say all the doctors that I’ve worked with are very similar, but (name of doctor) stands out a little bit. [Redacted] breath of fresh air.... You know it was like her door’s always open. She’s only there one day a week but in that one day you were like straight in, “what I can do about this, this and this, what do you suggest?” And just had your back as well. You know we’ve been in difficult situations where we’ve had to use physical interventions then shall I say, and my and (name of doctor) have been in the middle of it. And she’s also very good at praising us in that time. You know I had a lovely letter from her following that, which you don’t always get from other people you know – or not to me sorry, she sent to the managers of how well we had dealt with that situation and how tricky it was. So you know she’s always available to support and boost you when you’re in those situations as well. So yeah.

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

A No, no, but just someone there you can turn to. Like what me and (name of wife/patient-participant's mum) have been going through with (Name of daughter/patient-participant), just to talk to someone who’s got our background, say “listen guys, give this a little try, do that”. And you don’t get that. The only person we’ve had to do this with is (name of LD community nurse) because you just can’t get hold of these people. Even (name of LD community nurse) struggles to get hold of these people, they’re busy people, I understand. But a simple phone call, you know.

**Professional/clinician**

And it all comes back to – like I’ve never seen this in social services issues or changes, local authority issues, but what we’ve found – and I know me and my colleagues and we’ve campaigned as well, is that all we’re having then is lots more referrals because peoples’ behaviour has deteriorated, peoples’ mental health has deteriorated because they haven’t got that support network that they had previously. So then they’re ending up on more medication, they’re ending up having assessment needs changed. And it’s all about occupation. To me occupation is key to peoples’ well-being, but those occupations have basically been pulled from underneath their feet without consultation, without discussion. And like I said, I’ve had 2 or 3 people have to move into supported living because the families can no longer cope without a 5-day day service, or a 4-day day service, whatever they were having.

**Professional/clinician**

Had discussions with social services, colleagues, campaigning on peoples’ behalf where behaviour had deteriorated and said “our assessment clearly states this is because of lack of occupation, lack of engagement, not having meaningful activities to attend”, so all that’s been documented towards social services and the social worker.

And I know they’ve felt frustrated as well. You know I’ve had those conversations with them, it’s like “we haven’t got nowhere to go with this, we haven’t got anything else we can offer”. And it has made relationships a bit more strained you know, because you can see what’s needed and what should cry out, but they’re not willing, they’re not willing to offer, you know. So families as well, I’ve had countless discussions with families and offered to support in whatever way, again I can.

**Professional/clinician**

Quite often in clinic when we go to clinic (Name of patient-participant) in the past can be quite disruptive, so I take her out for a walk so mum can talk openly with the consultant. You know I’ll engage with (Name of patient-participant) so that that dialogue that is required around her needs, I try and keep things a little bit better for the appointment to be more productive, as opposed to trying to work around them.

I can catch up with the letter and I can catch up with what’s been said afterwards, but it’s more about (Name of patient-participant) having her needs met in that moment and mum and dad having the freedom to express themselves, to be able to say what the issues are and what the difficulties are. Because otherwise it’s not going to be productive is it, it’s not going to get…and the appointment will just – I can’t say fail – but they won’t get out of it what both parties need. So that’s the type of thing that I try to do, to try and be the middle man you know, to help within that.

**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.

**Professional/clinician**

And mainly working with others, you know it’s not just my ideas, it’s everybody’s ideas. And asking as well “do you think it will work – if it won’t, why, what could be done different?” I think it’s just being open to suggestions. I know right I haven’t got all the answers, I don’t know the answer to everything. 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**

Every day. You know there’s always something that you can see in some of the others that I work with, there’s always something that I think I can find from somebody to think “oh that was good, that was a real good piece of work”, you know “that interaction was really good, that made that person feel good about themselves”.

**Professional/clinician**

But the social worker, took a social worker there and said he would so benefit from a support worker, doesn’t need a nurse to do this role it can be anybody. I said….twice I took a social worker there, and when the question was put to him “do you want a support worker” he would say “no, no, no, too ???, too ???”

[CONTINUED]

Anyway COVID happened so I was able to, almost through the back door, say “he’ll have a support worker now because we didn’t have to do the interviews and all that lot, they agreed. They agreed that he could have a support worker. I did the introductions. I went with them for a few weeks to be able to build that relationship with them, and we went to cafes and we went for walks and we went and did things like that. And eventually then I could pull out. He is now going out every fortnight with that person. He won’t have any more, he doesn’t want any more, but he does go out, he does have a relationship, he does go into cafes, he does go to nice places. He’s been to the pictures. He’s been on a train to the beach. He’s been to (name of castle) castle. None of those things I would have been able to offer him because I haven’t got the capacity. So even though COVID was bad, that was good for him. And it now means I’ve discharged him, you know because I’ve been replaced by somebody that can do it like.

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

A Yeah. So it was just good to have a meeting and tie it all together, talk about (name of daughter/patient-participant) weight and the weighing and the seizures, which we think that’s what they are. Yeah and then there was the other meeting with (Name of consultant), I think you were there when she suggested the injections for migraines, because she said it’s quite rare to have seizures and migraines. But they definitely are helping. (Name of consultant) said to read up on it, and I said “yeah we will”. And I just think well we’ll give it a go.

**Professional/clinician**

…Everybody has something to bring. It’s like our admin, our admin support and the wheels that keep us all going. They’re absolutely amazing, you know how they keep us going. They have games for us to do. We had kind of the durkees? little tiny ducks all Christmas so you had to find these. And they’re always finding something to buoy us along and keep us going. And they do the fun side while we’re doing the mundane. But I guess as a team we wouldn’t function without that – well we would but it wouldn’t be as enjoyable and it wouldn’t be….you know. And I’m always singing their praises because the admin are the backbone then of sorting us out and keeping us on track and making sure we’re….giving us a five minute warning before the next MDT and things like that. I do think there’s a role for everybody and everybody is required to complete that role to keep us all supported. Yeah.

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

A Yeah, beetroot, avocado. Yeah she is eating really well. So yeah. So obviously we saw her. And then she phoned me not long ago to see how (name of daughter/patient-participant) was getting on and I said “absolutely fine”. And they did send out a speech and language lady to see (name of daughter/patient-participant) eating a yogurt, a biscuit, and I think it was a banana. And (name of daughter/patient-participant) ate the lot while she was here, and hadn’t eaten properly for weeks. Because I thought there was something wrong with her….I thought she was losing her swallowing. But no. It was just something she went through, and then lost weight, and then started eating.

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

Q Do you think that….how was autism explained to you after the diagnosis ???

A Yeah so after I was diagnosed I went….I think I went back to the [Autism Service] and they explained the results. They even gave me this big book with autism for adults, for kids, all this stuff that you can do, all the strategies that you could use and put in place. And then they’ve actually linked me up with a social group as well. So we go out and do certain activities, or we go for food, it’s just getting to know all these other people that’s got the same diagnosis but you all have different stuff, yeah you have either some second ??? with them or different stuff. Like this guy (name of male), he was diagnosed as well when he was younger, he studied in different courses when he was ??? Yeah and….it’s just been good to get in touch with people that are just like you. And there’s no pressure to actually turn up to all of them, you can turn up when you want to, turn up for the ones you like. And the ladies and the guys that run them, they’re all very nice. They’re all the same people all the time so you get to know them, you get used to them, there’s no frightening experiences, it’s just a very lovely, really lovely group.

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

Q I think it frees up some of the consultant’s time. But yeah I think some people think that [they] should spend that money on doctors instead, but he does a very good job. I think he’s a good example of it working.

A Well he does all the background anyway doesn’t he? So he finds out the stuff that’s going on every day and he can sort of summarize it to her, and if he says “oh I think we should increase or decrease or change” then obviously go feedback that back to (Name of consultant) and within minutes they can make a decision. But like maybe for (Daughter/patient-participant) to have seen that appointment with (Name of consultant) might have taken another 3 months.

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

So I think booking an appointment for quarter of an hour/20 minutes or whatever it is, that is wrong for people like her and I think that’s caused her a bit of grief in the past, and still does I think. (redacted)...And I think that all stems from the fact that if she’s got a patient she will spend as long as she needs to with that patient – and I think that didn’t always suit other people. I don’t know.

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

A Not really. (name of associate) actually surprised me that day because nobody had ever said anything about it. They’d never said something like ‘we’ll put you on this medication, you’ll not be able to have this’ or ‘you’ll be able to have this’. You think nothing like that has ever come up, even with (Name of consultant) to be honest. I think maybe (name of associate) is like….like that one step down from (Name of consultant) who actually will connect and ask these personal things. And then (Name of consultant), she’s like the one up who will do these certain things but forget to ask these certain questions. But they’re both working together anyway so they’re all in the same....the same medical file and the same documents, and they’re both looking over it and then decide what’s best to help me reach that goal and vision.

So I think it’s a very good idea that people like they have with (Name of consultant) and (name of associate) that they work together to actually come up with a way to get all these goals and figures out in how to achieve them by using a certain medication to do it. But also explain to someone like me that being on a medication like (name of medication), being on that would have problems if I wanted to have kids, so maybe we would do that as a last, very last resort, option. Which was a good idea because now that they’ve given me this (name of medication) meds that I don’t think I’ll need any (name of medication) because this one’s been helping me a lot as well. So we’ll just see where it goes now.

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

Q Do you have an ideal story of healthcare, so a sense of how you would like appointments involving (Daughter/patient-participant) to run. What would be your perfect ideal situation?

A I think (Name of consultant) has nailed it.

Q So one of the other questions is about like the best doctor, nurse or social worker you’ve met.

A It’s got to be (Name of consultant).

Q So just talk me through what makes (Name of consultant) stand out to you as…

A Because she listens and she cares. And she doesn’t jump in to ask me straightaway, she listens to (Daughter/patient-participant) and then she will sort of look….I think it’s the (place) thing, she’ll look as if to say “is she telling the truth” like, do you know what I mean? It’s the way that (Name of consultant) looks at you. Because she knows I’ve got something to say and then she’ll sort of give me the nod to say it so to speak. Or that’s the way I read it.

**[continued]**

A It’s sort of giving you….it’s sort of you’re going to look at somebody and not say nothing but you know that they’re waiting for you to talk. Do you know what I mean? Or they’re waiting for you to say something. It’s like, I don’t know, it’s like they know you’ve got something to say. And it’s like you’re sat there poised, ready to say something. And then you don’t say nothing and then she sort of looks at you like that, and then it’s….right, and then you’re in straightaway.

Q So you’re getting non-verbal invitations to corroborate what’s….

A Yes….been said or to dismiss what (Daughter/patient-participant) has said. Or, you know, “do you read”, “yeah”, yeah you do read but like there was the time when we was in that meeting and she said “oh do you read books”, “yeah”. No (Daughter/patient-participant) you’re reading your phone, that’s not the same as reading a book, because obviously the night light and things like that.

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

Q No it’s good. I mean a lot of my observations have been with (Name of consultant) so it’s been good to get a couple of him as well just to get that other perspective and that other kind of way of working.

A I think they work well as a team as well don’t they? Because I know when we’ve seen (Name of associate clinician), (Name of consultant) was still there but we didn’t see (Name of consultant) but I know he was back and forth.

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

A Yes they’re just auxiliaries. But they were very nice. The nurses were mixed, and I had mixed difficulty in understanding what some of them were saying. I think their language skills weren’t very good. You know I understand that they’ve had to recruit people from abroad and so on, but I think they need to be able to speak a bit more clearly than some of them do. I didn’t know what some of them were saying. There was one of the doctors who came round and I didn’t know what he’d said. And I had to say to…. one of the consultants (or level doctors?) and I’d have to say to one of the other doctors who was there with him – you know they follow like a train – can you come back afterwards and tell me what he said because I don’t know. She said “you’re not the only person”. So she’d come back at the end of his round and tell me what he’d said. And that’s not very good, at consultant level, the doctor going round needs to be able to communicate with people. He’d tell me and I’d not know what he was saying. Just not know. And I wasn’t the only person who had that problem.

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

Researcher - …and did [name of carer] help you with this experience?

Participant – Yeah.

Researcher – What did she do to support you?

Participant – She held my arm up like that so that I could have my implant in.

**Carer**

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

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

**Carer**

Participant – And you might not get it that day, it might be the next day, so that can be a bit tricky when you need to speak to someone. Overall I think it’s pretty good within the care sector and get to people that you need to get to, but outside of residential homes and care homes I would say it was more tricky.

Researcher – How is it and why is it easier for care homes to have to make that contact because is it you have preferential treatment sounds so wrong.

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.

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

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

**Carer**

Researcher – …thank you for being so open, I can tell that wasn’t easy for you to recall. The idea of you being [patient-participant]’s shield and [name of psychologist] being your shield is very interesting, kind of like the ripple effect of care, maybe, in some ways

Participant – Yeah. Like I said, I’ve just had to defend her so much

**Carer**

Participant – …there is a lack of understanding with LD for sure, especially in how people use a lot of analogies and sayings for things. You know, “frog in my throat.” People with LD don’t understand that or if they do… we need to check, “do you understand that saying I just used?”

Researcher – Mhm

Participant – Because even though the [medical doctor; specialism redacted to aid anonymisation] that [patient-participant] was seeing for a while… she’s not having surgery now but she was seeing him for quite a long time, and he was classic… using lots of different sayings, “out of the frying pan, into the fire,” and I said to [patient-participant], “do you understand what he means by that?” in a gentle way, respectful to him, a respectful way, and she didn’t. So, I helped him to understand that people with LD are often very literal.

**Professional/clinician**

A 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.

Q It sounds like she helps you to not feel alone with these really big complex cases, right?

A Yes. But I can say there’s been benefits in all of them, and the nurses. And the youngsters coming through, I’m so impressed with them. The colleagues I work with at the moment, there’s three young staff members, they in the future, and you know I see my role as very much supporting them, giving them my knowledge, giving them what I know, whatever I can share. Because they need to have as much as they can now to be able to keep it going. Because I do worry that they may not sustain it, do you know, because of other pressures, because of management issues and difficulties we’ve encountered you know and what. If I can support them then I will in whatever way I can. But I’ve also been extremely impressed with what they are achieving. You know they are just really good. And like I say, there’s three of them and they’ve all got different skills in different ways and are able to give those skills, or give the families, the best they can. And I just hope that I’m showing them as well how that can be maintained and what is good for….that I know is good then and what is available to do.