**Professional/clinician**

A But certainly the ones also that are willing to sort of look outside the box and look for other ways of doing things, not just seeing exactly what’s in front of you, look at the….well yeah I guess just look at is as a whole and look for other things, like if the radio was blaring, or if this could be upsetting, or if this could be an environment that could be distressing somebody. You know people who take more time to look at those things.

**Family member**

A It’s just taking back sometimes and thinking outside of the box.

Q What could that look like, thinking outside the box?

A Again, our hospital passports that we send in, we have these little phrases, we put these in our hospital passports. So we do like a mini breakdown. So “if I’m thirsty or if I’ve got a dry mouth or my mouth is stinging I would like a cup of tea”. If “I’ve had a cold for 20 years my nose is playing up” and we’ve got like a little ??? purifier which seems to help, or she just likes her nasal spray or a really hot honey and lemon tea, so it says “please offer me a honey and lemon tea or use my nasal spray”. So we’ve got these little short breakdowns, but sometimes these hospital passports get lost in translation. I think maybe these could be put on a board in her room, so a cleaner coming in, if she said “oh do you know what, I’ve got a really…” another one is a salty mouth. A salty mouth means she wants a cup of tea. But you wouldn’t know that.

Again with (name of sister-in-law/patient-participant), if she’s got pins and needles in her feet (name of sister-in-law/patient-participant) would tell you she’s got glass in her feet. If she’s on her monthly period she’ll tell you she’s got glass down there, because in theory if you cut yourself with glass you bleed. No, sand in her feet for (name of sister-in-law/patient-participant) if she’s got pins and needles, she’ll tell you she’s got sand in her shoes – not glass, sand, “I’ve got sand in my shoes” and she’ll tap her foot and just continue to tell you “I’ve got sand in my shoes”.

Q It makes a lot of sense, it’s like it’s a feeling of discomfort in that spot.

A Yeah. Well you’ve got pins and needles, so you imagine sand in your shoe it would feel that sensation.

Q Yeah, yeah, yeah it’s a good….all these examples you are giving me are like, that’s really good communication from the person that you are talking about. And I’m feeling a bit confused as to how someone wouldn’t know what they were on about. But I think that’s because people are in a rush aren’t they and they are not listening.

A Yeah. And some people “oh you’ve got a salty mouth, OK what do you want”. Their answer is “OK, I don’t understand, why is your mouth salty”. So they potentially would go to a doctor and say “she’s got a salty mouth” and the doctor would say “oh well I don’t know what a salty mouth means”.

Q Yeah. But think about it, if you have just eaten something salty and you have a salty mouth you would want a big glass of water. Like that’s just….

A Yeah. But if you break it down to a small point you can understand, right OK salt, what would you want if your mouth was salty, you would want a drink.

Q Yeah. It’s difficult to….

A But these are all put in hospital passports, and sometimes I’ve found these hospital passports just get lost in the documents, or somebody just wouldn’t look. And I’ve been in on 3, 4 occasions where I’ve said “right the documents here”. I’ve gone back in another time and that document has again been lost in handovers or just not passed on in handovers, and other people just not knowing that they’re there. But I think if they are passed on to everyone, including the cleaner who is going past.

**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 What as a social worker can you do to help people with learning disabilities to live more independent lives?

A I think that's one of the things that I love about this job is just thinking a bit creatively of how we can get somebody to live as independent as possible. So straightaway what comes to mind is the overnight trip to their hotel that they went to for their honeymoon. I think when that was first mentioned it was a bit of…other people were kind of like ‘oh I don’t know how we’d do that’. It was ‘how are we going to kind of think about this’, not shut it down completely but maybe a bit too risk adverse. So luckily I think we were really able to think a bit more creatively to support them to get going, maybe doing a bit of skill building as well to be as independent as possible and to do what they wanted to do. So like (name of patient-participant’s husband) has learned how to….well he’s learned how to use a mobile phone to make calls if they hit an emergency. A support worker who they're really familiar with and they know really well was there to support. The environment hotel was prepped ahead of time. Yeah just thinking a bit more creatively outside the box about how can we make things work just to help somebody be as independent as possible. So like with the carers who go in to provide personal care to (name of patient-participant), that was initially started as a ‘can we promote (name of patient-participant) to be as independent as possible with her shower routine. I'm not too sure that as a service or a care package that she will need long term because the reports are she's doing so well she might not. It was potentially a bit of skill building that was needed after being in hospital.

**Professional/clinician**

Q Something that I was struck by from hearing people talk about you, is that you seem to have a lot of ideas, a lot of creativity about ways of doing different things. How do you get, first the persistence to keep trying new things, and second how do you get all those ideas? Like how do you keep learning, how do you keep the brain so juicy and thinking of different things? Obviously you’ve got 40 years experience, that helps, but how did you get all that knowledge, how did you get that ability to think in different ways?

A I think it’s just the job. It’s just the role. It’s just learning from other nurses, learning from other practitioners. Watching, listening and taking an interest of wanting to better peoples’ lives. And sometimes it just happens. I had an issue yesterday with a client drinking in excess and he wanted to know the time. I said “right OK”. So we’d agree that he had a cup of tea every hour to try and stop him from the demands not being met and then him becoming frustrated because they weren’t met. I said “right OK, let’s do it every hour and see how that works”.

And he said it is better, but now he’s urinating a lot more and having accidents a lot more. I said “OK, well why don’t we just cut the cup size down”. So we’re not taking away what he’s got, we’re just….we’re still giving him the same but obviously the volume will be reduced, and if you feel then maybe reduce it by quarter of an hour, so instead of every hour it’s every hour and a quarter. And you just learn from those situations and adapt to what can work. It’s not one cap fits all but it’s like “OK if that doesn’t work it’s not the end of the line, why don’t we think of an alternative”.

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.

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

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. But when you’re sat down in a relaxed atmosphere (Name of daughter/patient-participant) sleeping or she’s playing, but you’re in a relaxed atmosphere and you talk like, you know. And that’s when she’ll say “well try this” or “try it this way”. Because you get so clouded yourself with the care of (Name of daughter/patient-participant) you don’t always have the broader look.

**Professional/clinician**

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

A Yeah she has.

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

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

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

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

**Carer**

A OK. The lady in there as well, because there are basically four in here, her name is (name of resident 2) so she has this cough ??? And when I took….me and a senior worker took her to a care appointment thing….so she has a thing of…if you are saying “this is wrong with you” she will also say it’s wrong with her. So the doctor was like “oh how is your throat?, how is it”. And she said, she was trying to like demonstrate because she don’t verbally speak very well as well but she uses sign language which you can understand. Like if you keep guessing the answers she will say yes or no, if you are right she will say yes, and if you are wrong she will say no. So when the doctor was saying “and how is your throat” she said “fine”. Like fine, the way she do the signing. And the doctor was saying “oh I have one like that, and my dad too”, and she said “yeah”, she was like “dad”. “Dad had one” like the way she does a signing thing. So if she’s doing that signing you are able to like connect the words and she will say yes and flow along with you. And the man was making it fun for her to explain, express herself, and the man was asking her how does she feel when she’s trying to clear her throat, can she demonstrate? Which she did and she was like (coughs) just like the way she does it. So she was really happy and the doctor asked “any other thing”, she said, her leg. When he challenged her for the truth. And she went to that leg. So the doctor went and touched her leg “oh, oh” like making this sound. And initially she was not having her leg painful because someone hit the leg on the way and she was describing it to her. So aside going there for the throat the doctor was ??? attention for her leg.

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

A Once a month she holds a Zoom call for everybody that’s involved with (name of daughter/patient-participant) i.e. the staff; the manager from (name of respite home); the carers that are with (name of daughter/patient-participant) from a (day) to a (day); herself obviously; and myself. And every month we’ll just talk about if there’s been any changes with medication, any changes in behaviour. If there’s any issues with certain things it will all be brought up. And obviously the main one is (name of daughter/patient-participant)’s eating, she will come up with different suggestions to try and prompt, and different places for staff to take her where she can sit, having something to eat and be distracted by people watching to encourage her that way. There’s loads of different ideas that she’s come up with. And it’s usually once a month or she’ll make a house visit and we’ll talk about it then, or if there’s an issue there’s always texts. We keep in contact regular most weeks or every fortnight, there’s always that information being passed over. And also we have a handover twice a day with carers when I’m handing (name of daughter/patient-participant) over to the carers, I’ll tell them whether she’s had any seizures, whether any rescue meds have been used, and obviously it’s all being recorded. But we’re all singing off the same hymn sheet and that is the way forward, communication is the key.

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

A Yeah. She’s been fantastic, she has. She hasn’t had obviously any part in the medication side, but it’s just simple guidance. Suggestions now of where (Name of daughter/patient-participant) is refusing to take meds, it was (name of LD community nurse) who actually suggested and made it was OK with the professors, that we can open up the capsules and put them in her protein yogurts. Because she stopped swallowing tablets completely and we were really struggling to get her to take them. It’s made life a lot easier. I mean just simple suggestions like that and a little bit of encouragement.

**Professional/clinician**

A Yeah. So I think you know that's where the whole technology part came from because being able to have a magnifier on my phone is, you know so… it's just opened up so many more opportunities and given me more opportunities. Yeah.

Q Do you think that it helps you think more creatively about your work in any way?

A Yeah I think it probably does. Maybe also a bit more understanding or empathy you know about the barriers that the world puts on people and disadvantages that we experience. I suppose I feel like I've a bit more of an eye opener I suppose.

Q What do you mean by that?

A To some of the barriers that some people who have disadvantages can face. So for example, being in a lecture hall and not being able to access the information that a peer of mine who potentially doesn't have any disadvantages that I know about or that they've mentioned. I think I have a bit more…. I don't know if ‘understanding’ the right word. I think I've lost my train of thought. I suppose what I'm just trying to say is that I can understand some of the disadvantages that people face who have a disability, having a lived experience. Does that make sense?

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

A You know at one point I’ve had to hold her hands, cupping her hands and (name of wife/patient-participant's mum) had to put her meds in her like, you know. And these were tablet form then before somebody had the brainwave, the brainwave came of (name of LD community nurse).

Q The capsule ???

A Yeah, which made life instantly easier for us you know.

**Professional/clinician**

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.

**Family member**

Q …do you have any sort of advice for how healthcare professionals can make their work more humanising?

A Again I know it’s really difficult but I think it boils down to time. The time you are willing to spend with that person and actually listen. I think listening is the key. Listening and taking that away and thinking, as I said, outside the box. Where she would say “I’ve got sand in my feet”, think of that, look at that, and think right well what would that mean to me if I had sand in my shoes, how would that feel? And try and break down those conversations rather than just thinking “oh well I don’t know what she’s saying”, have that broader aspect around it as thinking outside the box when you are speaking to somebody with learning disabilities what that could possibly mean.