**Professional/clinician**

A OK. I think some of the best learning disability nurses that I've worked with have again just really got to know the individual. Just one nurse I'm thinking about who really got to know the person that we were working with, really learned some of the things that they liked, some of the things that he really enjoyed. And they connected and spoke about the things, so like candles and like lots of sensory smells, they were able to really you know strike up a conversation and build a good relationship based on some of the likes that the individual had. Yeah that’s the person that comes to mind.

**Carer - lives with patient-participant**

Q Yes, I’ve taken her a few times to her [town] clinic to see [name of psychologist], where she actively engages with [name of psychologist] and is almost excited to talk to her, you can see it in her facial features and her eyes, she’s really engaged in scenarios like that… [name of psychologist] will get her to do puzzles and stuff like that, just to establish where she was within the health and social care spectrum, what she understands and what she doesn’t understand… and she always enjoyed these things, so it was good fun taking her to these appointments because she genuinely wanted to get involved.

**Carer - lives with patient-participant**

…so I think she was amazing in what she did, and it was sort of a happy event for both, I think. She got something out of it and learned about an individual, so yeah…

**Professional/clinician**

Q Is there anything else you want to say about (name of patient-participant) ???

A Just that she’s lovely.

Q She is.

A Her and (name of patient-participant's husband) are lovely, they’re absolutely fantastic. I love going to visit them, we always have a really good chat, they’re really, really lovely people. They really, really are yeah, and they deserve the best, yeah they do. They deserve people to sort of advocate for them in the areas that they’re not so strong at doing that for themselves.

**Professional/clinician**

But certainly on community, you know I can go and I can sit and have half an hour with (name of patient-participant) and just chat about what she’s been doing at day centre, and what she’s been making, and what they’re having for dinner, or what’s happening on [patient-participant's favourite television programme] you know. And sometimes those conversations, you get a lot more out of somebody than if you’re bombarding them with questions. You know little things will slip in, or you’ll hear something and you’ll think “oh, I’m not quite sure about that”. You know it is really nice in this job that we are encouraged to get to know people, it’s fab, it’s great, yeah.

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

A They’re talking and they want to know how….they speak to (name of patient-participant’s husband) and they want to know how I’m getting on and….

Q Yeah, so they’re asking you questions. So they want to know more. They already know your name.

A Yeah.

Q They’re using your name, which I suppose is important as well, they’re remembering your name?

A They say “(name of patient-participant)”

Q How does it make you feel when they remember you?

A Very happy actually.

Q You’ve got this big smile as you’re talking about actually the staff.

**Carer - lives with patient-participant**

As we’ve gone on, we’ve got more and more experiences and we’ve used our past experiences to use what we’ve got now, which is a terrific bond with the people we look after.

**Family member**

This is why I used to specialize in communication and challenging behaviour because it doesn’t matter how violent you are to me I will reach you on a level.

**Family member**

A I mimicked his behaviour so he was mimicking mine, but then got it to a level where I took the reins – do you see what I mean? Where I made that violent act become a game and become not a violent act, it just became a soft play game, a playful game. And then it wasn’t until I stopped that reality and that, all those urges, came back. Because the problem wasn’t taken away, it was just blinded for a brief moment of time. But as an example this person could be reached and this person is reaching with hands out. Not in the physical sense of being worried and not wanting to be where he was at the time, but in the sense of help, you know.

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

A Just explained everything to us what they were going to do with (name of daughter/patient-participant) and made it fun. It wasn’t serious when they turned up. Because when people say “oh physios, OTs”, you think it’s all going to be a bit thing. They came, they did lots of singing, lots of activities, and (name of daughter/patient-participant) was loving it, you know engaging in songs. And then also I used to go swimming with the physio and the whole swimming session was done with music and nursery rhymes and… Yeah I did a lot. And I used to go to a group with other mums as well, that was good

**Carer - lives with patient-participant**

Meeting her where she’s at mentally and age wise, it just works, and humour is a big thing. She likes to be praised; she likes to think she has done something good to you as well. She’s a very kind, giving person.

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

Q So you said they were understanding and earlier you said the nurses were really kind, what was it that they said or what were their behaviours that conveyed to you this kindness and this understanding?

A Well the whole manner of the nurses, they were just….I can’t think of the words but they were just so lovely by way of, you know whatever she needed they would go above and beyond their jobs and they would make sure that we were as comfortable as possible. They always found time to talk to her and they always sort of dropped down to (name of daughter/patient-participant)’s level and spoke to her face to face, it was never that they were talking to her with their backs towards her. They were very understanding and compassionate.

**Carer - lives with patient-participant**

…[s]he is always very personal to [patient participant]. Over the years, she knows [patient participant]’s life. She remembers things, she remembers… we went for her bloods around [date], and she remembered the time before we told her we were taking [patient participant] on holiday, she was very excited, “So! Tell me [patient participant], how was your holiday?” It was really important; she remembered something [patient participant] had told her. She is a continuous person, unless she is on holiday or sick, we always see this particular nurse for [patient participant]’s bloods. [patient participant] doesn’t particularly like having needles stuck in her, but she likes to see this lady. She has sort of got a bond with her and it is worth having a needle stuck in your arm to be able to go and see this particular nurse. I won’t say it is something she looks particularly forward to, but it doesn’t hold any fear for her.

[CONTINUED]

A Yeah, we all have to have it done occasionally but [patient participant] struggles to relax her limbs, they’re always very tense, so she is very still in her approach and this lady can get [patient participant] to relax so she can easily get the blood. If she is not relaxed, it’s like trying to get blood out of a stone, it’s not going to happen. But, because she knows her and she is talking to her all the time she is doing it, she’ll say, “oh, you’ll just feel a little prick. Oh, and tell me, how did…” and she’ll just chat and have general conversation with [patient participant], before she knows it, it’s over and she’s finished, and she has just had a lovely chat.

**Carer**

And to talk with, rather than talk at

**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.

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

A When you go in there and tell them what you needed, and they’re like what, and then when you get in after they’ve done it its type type type

Q Yeah, do you not like it when they do the typing?

A They can’t actually listen, they type, my doctors don’t talk and type

Carer And they’re not looking at you while typing are they

A No

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

Carer (?) - Didn’t you say the radiographer who did the ??? injection into your hip, did she do it on (cuddly toy) first?

A Yeah

Carer Yeah

Q What?

Carer (patient participant) brought a (cuddly toy) with her to her appointment and the radiographer who was doing the dye injection into (patient participant's) hip did it on (cuddly toy) first

**Carer - lives with patient-participant**

A Ok, good experiences… [patient-participant] had to have a minor operation on her hand this year and she [was] obviously frightened, she had an operation previously, but she didn’t really remember it, she was anxious. We got to the hospital; she took her [cuddly toy] with her. They were just amazing with her. They made her feel calm, they laughed and joked with her, they talked about [name of cuddly toy], they allowed her to take [name of cuddly toy] into the pre-op room, and when she woke up [name of cuddly toy] had a theatre cap on, a cannular in his paw and a bandage on him exactly the same as [patient-participant] did, for her that is the single-most hospital conversation she talks about. It made a lasting impact on her, because she just says how lovely they were to do that and they had an understanding of her fear and her attachment to [name of cuddly toy], which is a toy [type of cuddly toy]. So, really, really positive. Top ten out of ten nursing and doctor skills there, it was amazing.

**Carer - lives with patient-participant**

A He was asking her for the name of all the Beatles, the pop group. She didn’t know. The Beatles to her are an insect, she wasn’t into the pop music. He was asking her when the battle of Hastings was. You and I might know, it’s 1066, but [patient-participant]’s never going to know that. Her learning ability at school never really got beyond year four or five, you know, like a six- or seven-year-old. She would never know the answer to questions like that. They were all like that, questions she didn’t know the answer to at all, which made her feel silly and made me feel sorry for her. She kept saying, “I’m sorry, I’m sorry, I’m sorry,” but she didn’t actually have anything to be feel sorry about. He wasn’t being age-related appropriate in the questions for her. So, yeah it was pretty poor.

**Professional/clinician**

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.

**Family member**

I then stepped back and the liaison officer stepped in and started having those conversations with (name) the same as I would have, asking her questions “oh what’s your favourite programme (name)”. (name of person participant supported at work A) was a little reluctant with new people so I would say “oh come on (name), what do we watch in the afternoons?” “Oh well I like (names of programmes)”. “Oh” she said “well maybe we can get you a TV”.

And then because she’d created that bond with (name of person participant supported at work A), getting something for (name of person participant supported at work A) that was her favourite “oh could you, could you really get me a TV.

**Family member**

She sat and took the time to find that and have those conversations. She just listened and wrote that into the plan and passed it on to all the support staff. Even the cleaner who would come round in the day, she would talk to (name of person participant supported at work A) about her favourite programmes because she knew what those programmes were. So because (name of person participant supported at work A) didn’t have any family or didn’t have anyone to visit, it was only the support staff.

**Family member**

And because we are limited of what we can do according to her care plan and her hours sometimes the only people that she would see are the people at the hospital, she wouldn’t have the visitors. And then sometimes she would feel even low watching visiting times especially, watching other people have those visitors and other people coming to visit. So when the staff around the hospital would speak to (name) and say “oh what are you watching today (name)”, “oh well I’ve watched (programme) and this happened and this happened”. “Oh yeah and we’ve got (programme) at 3”, “yeah, yeah got (programme) at 3”. It’s that social engagement then that somebody does know and does know what time her programme is on, and she feels like she is important and valued and that. And all it is is talking about a TV programme. But the value she then received from that is ten fold.

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

A Well the physio (name of physio) she was just very chatty, great with (name of daughter/patient-participant), just very relaxed. Lots of singing she did with the physio. And then the OT was the same as well, very pleasant, great with (name of daughter/patient-participant), talked to (name of daughter/patient-participant) directly, low down with her. Rather than asking us questions they asked her questions, what she wanted to do.

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

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

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

A And it’s nice for him to come out to see (name of daughter/patient-participant)’s home setting and how she reacts to him coming out to her home, where she’s always gone out to his home really into that room, his workplace.

**Professional/clinician**

And I love spending time with (Name of patient-participant) anyway, she’s such a lovely young woman and she’s so funny. And when you get to know her she’s got her own communication style and she says things for different things. And I can work that out I can…but other things, and I love to help her.

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

A Yeah, yeah. Obviously (name of daughter/patient-participant) has seen a lot of people, and if they say “oh yeah I like (popular cartoon character)” or “my daughter watches that”, you’re talking about something she likes and you can see “oh, they’re alright, they can stay”.

**Family member**

Q And when you say “get down to her level” are you talking like metaphorically or are you talking about getting down to eye level because she’s using a chair?

A Eye level, yeah when she’s using a chair. I think (Name of sister/patient-participant female) finds it quite intimidating if somebody is like stood over her and talking to her. She’s definitely more relaxed if somebody comes in and they get down and they talk to her. She doesn’t like loud voices either so talking to her softly. And some people do that and some people don’t, and (Name of sister/patient-participant female) picks up on that straightaway. So I think she’s finding that hard. And she knows who she likes and she knows what appointments she likes to go to, and I feel like it’s the people that actually do communicate with her like that. Yeah she doesn’t forget either, so…

**Family member**

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

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

**Family member**

A Yes, and ask her questions again, like “what is your favourite song, what did you watch last night on TV”, like take a general interest in her interests and then use that to communicate with (Name of sister/patient-participant female). And she understands that then and then she builds a relationship with them. And she likes (name of healthcare practitioner), if you get off on the wrong foot with (Name of sister/patient-participant female) there’s no…

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

A Well probably a bad choice of words. But if (name of daughter/patient-participant) likes you that’s half the battle. If you get on with her, you can see (name of daughter/patient-participant) face, you know if (name of daughter/patient-participant) doesn’t like you, there’s something…I don’t know, I don’t know what it could be, it could be anything, done something in the past or something, then we know. But you can tell as soon as….do you want any names?

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

A Yeah. Well when she first started she was a little bit nervous if you like, but it didn’t take long for her to sort of adapt. And she does like doing things. And if she likes you she’ll get on, and she does like them. So yeah she’s gone on really well.

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

But all I wish that, all we can wish for with (name of daughter/patient-participant) is that everybody who looks after (name of daughter/patient-participant) knows (name of daughter/patient-participant) you know not keep swapping and changing different people. And I know sometimes you’ve got to see different experts and all that, but I think now we’re pretty much sort of fixed into people we see. I mean even people like you, you know she knows you now. But she didn’t before did she? But then maybe now over these next couple of visits, you walk in and she’ll be like “oh (name of researcher)”.

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

Q Yeah. So what advice would you give for, you know there’s a student nurse or a student psychiatrist and they’re about to meet (name of daughter/patient-participant). What advice would you give them?

A I would say be yourself and don’t be officious.

Q Officious?

A Mmm. Don’t be a student. Don’t come in and start asking questions. Say hello. You know be friendly. Don’t come in and go “right I want to do this, I want to do that”. Have a cup of tea first and, you know just be normal.

Q Yeah.

A I mean I used to be a [sport] coach, and the difference in teaching and coaching is probably that. In coaching you get to know the person and all that. Teaching is just really like a clipboard, they just teach, there is no interaction if you know what I mean? I was a pretty good coach actually so…

**Family member**

Q So you’ve mentioned a couple of times before talking to her in a better way. Like have you got any examples of people that have spoken to her and they seem to really get her, connect with her, what do they do?

A Yeah I think when people speak to (Name of sister/patient-participant female) straightaway I think people can kind of gauge like the mental age of (Name of sister/patient-participant female) as well. So I think they need to try and speak to her maybe more like as a younger person, not as an adult as she is. Because she’s classed as an adult now it doesn’t mean that she is an adult, she doesn’t understand adult languages. So I think when she’s gone to places some people, you know get down to her level, they talk to her about things, like she’s normally carrying a (popular cartoon character) doll so they’re like “do you like (popular cartoon character)”. And I think that kind of…I think people need to adapt to that certain person. And it’s quite clear that you can see the way she needs to be spoken to. And I think that’s not the case, I think they speak to her like an adult, and (Name of sister/patient-participant female) doesn’t get it. So I feel that….and some people are really good at it and some people are just not. So I don’t know. If some people have different training, or some people it’s just the way they are.

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

A And (name of LD nurse) was there, the nurse. (name of LD nurse)’s been very good as well because it wasn’t last year, the year before, (name of daughter/patient-participant) just stopped eating and lost loads of weight and we just didn’t…. So (name of LD nurse) used to come and weigh (name of daughter/patient-participant) and it became… (name of daughter/patient-participant) quite enjoyed it because she’d come and weigh (name of daughter/patient-participant) and then we would weigh some (popular cartoon character) toys.

[continued]

A So that’s what (name of daughter/patient-participant) associates (name of LD nurse) with, she’s coming to weigh the toys.

[continued]

Q Yeah. How is she with (name of daughter/patient-participant) in terms of like getting her….

A Oh, she comes, say “hi (name of daughter/patient-participant) I’ve come to weigh your (popular cartoon character) dolls, who are you weighing today”. So that’s…. (name of daughter/patient-participant) does mention (name of LD nurse) quite a lot actually so she obviously likes (name of LD nurse). So we’d always weigh (name of daughter/patient-participant) first and then it would be either (popular cartoon character) or these big ones over here. So it was quite nice that when (name of LD nurse) was coming she knew it was not all about (name of daughter/patient-participant), (name of daughter/patient-participant) was going to have a bit of fun weighing stuff, yeah. So yeah she was very good.

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

A I was making her laugh and she was making me laugh about the [participant's pet] walking

**Carer**

A I think, I have a service user up the top who has dementia, he can get quite upset around new people and I think some healthcare professionals have almost been a little bit weary of doing or saying certain things around him but he was having one particular day where he had gone back to being younger and he was doing his boxing and he was just dancing around pretending to box and getting quite agitated with the situation and this doctor put her bag down and started boxing with him, and in his room he has a punch bag and she said come on then I’ll give you a go and I think that stuck in my mind, as I thought you are just being human, it was nice just for you to take the time to get into his space where he’s at, at that particular time and wait for him to be ready to speak to you rather than saying I’ll come back another day. That did stick in my mind as I thought, that’s care, that’s someone that actually wants to see what the issues is with him when he is ready, they waited for him to be ready.

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

Q OK. Have you seen how the physios help to win her over, does he do anything special to make…

A I think they have like toys that (Name of sister/patient-participant) likes. And they talk about [popular cartoon character that patient-participant adores]. Or like her splints have like a [popular cartoon character] sign on it and I think she gets excited to see that. Or they’ll put music on that she likes. And yeah I just think she feels comfortable. And she goes swimming with them, I think she likes swimming, so I think it makes her feel more at ease doing things she enjoys, or music she likes, things like that, yeah.

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

A I’d say like [popular cartoon character]. Yeah I think she likes people who are out there. I’m a bit shy so like sometimes if I like go to (Name of sister/patient-participant) and I don’t want to sing and dance I get a bit nervous. But she really likes my boyfriend (name of boyfriend) and he’s training to be [healthcare professional], so he just speaks to different people all the time. So he’ll like say “oh (Name of sister/patient-participant)” about [popular cartoon character], and he’ll sing. She likes that, yeah. So that. Or a present.

Q A present. She likes a present?

A Yeah, or like a toy she can hold on to while she’s there or something like that, yeah.

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

Q What is Doctor [name] saying?

A He’s saying thank you. He had a coffee with us

Q Do you want to draw it here?

A That’s a coffee

Q Lovely. Do you want to draw yourself in there too? Otherwise, it looks like Doctor [name] is drinking coffee on his own

A I had squash that day, orange one

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

A We talk about a lot of stuff with him. We talk about the play I did.

Q Great!

A [Name of carer] and [Name of carer]

Q What are they doing?

A They are talking about the programs(?) like ‘Get Me Out of Here’

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

A I think she’s on the very edge somewhere, I don’t know where but…. yeah she is sort of (geographical detail redacted) anyway, so I’m kind of relating to her with her ??? her smile. Even though when you talk to her and you talk to me it doesn’t sound like any difference, not that I think of anyway.

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

Q Was there something that (Name of consultant) was conveying that made you feel able to be really honest when you met with her?

A Maybe it’s just the (nationality) thing again.

Q That sort of you having that in common?

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

Q …so this is about when you had your implant fitted and the nurse talked you through it, what else makes a good nurse?

A She gave me a numbing jab and said it won’t hurt, just relax and listen to music on my Walkman because I took my Walkman.

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

I mean generally most of the people that we’ve met and gone through have been really nice, especially at her early age. The physios there were lovely. But I think (name of daughter/patient-participant) has that effect on people, you know when people look at (name of daughter/patient-participant) and she sort of says something funny, they automatically bond. So she’s an easy child to sort of get close to, do you know what I mean?