**Family member**

And these hospital passports I think would really help and the aspect of handing them down through daily shifts, monthly shifts. Because I think sometimes if someone has been there a few months that can be lost in translation, there’s a lot of agency staff in and out. And again we can’t help agency, I know exactly where we are. Sometimes someone phones in sick, sometimes you have to have the agency, it is part and parcel of the job unfortunately.

**Carer**

Anybody that came and did her health access plan, they were all great, they all played their part and got us to where we are now.

**Carer**

Q Hmm. I think….so the self-advocates and the researchers on the project that have learning disabilities, they’re really interested in the whole….I think it’s because they do a lot of campaigning about annual health checks and things like that. The other thing that they’re really interested in is people’s care plans and their health passports and things like that. Does (name of patient-participant) have one?

A A care plan?

Q Like a health passport for how they should be treated in hospital and how they should be communicated within the hospital.

A Oh traffic lights.

Q Yeah is that what you call it?

A Yeah.

Q Sorry, everyone calls it different things, so traffic lights OK.

A Yeah, yeah we call them traffic lights. So what they’re happy about, you know what not so much, and then what they really don’t like and want and things, yeah that’s what we call them, yeah. So yeah he does.

Q And do they get followed by the doctors and nurses that you work with, or do you tend to find that….

A Like I say they hardly ever go into hospital really to be honest with you. I can’t really say yes or no to it. It’s been a very long time since anybody’s been in hospital, but it seemed that everything went as to what was written and fluently. So yeah.

**Family member**

A They took her in. We did our usual hospital passports, mar charts. So things had all gone in, everything was great.

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

**NB. A = Family member; B = Patient-participant with learning disability**

Q And (Name of son/patient-participant) do you have a health passport do you know?

B We have a disability ???

A No we don’t have anything like that.

Q No there’s not anything on the file about how (Name of son/patient-participant) likes to talk or anything like that, or the healthcare.

A No. With the GP I remember I had to fill a form in as appointee regarding all his medication, all his treatment or I talk now openly.

Q OK. But anything about his communication preferences or to know whether (Name of son/patient-participant) is comfortable or not, anything like that ??? at the hospital?

A No. At the GP I noted other people, especially a friend of mine she just lives across the road, she goes for her child, they don’t give her anything because her child is older now. They say “your child is old enough to say what he wants for himself”. You as a mother you cannot take in that, you know.

Q Does her son have disabilities?

A Yeah. But me as a mother, call for (Name of son/patient-participant), you know they know that I am for him. (Name of son/patient-participant) doesn’t speak that much so I have to speak for him.

Q How do you find your mum speaking for you (Name of son/patient-participant)?

B I don’t mind, I don’t mind.

**Carer**

Q Yeah. You know that they have healthcare plans and passports and things like lots of patients…..

A Yeah.

Q Do you think they're useful? Do doctors use them?

A Well we have traffic lights here. They're endlessly updated, we keep them up to date. I think definitely we always take them especially to A& E because it's got up to date information and that kind of thing. So read what's really important, and so on. I think some doctors use them, yes. And I think some don't even look at them. And you can tell that by what they're saying. yeah. So that's again a very individual thing. I don't know I've even thought maybe they take on….. some people say “this is so useful, thank you for bringing this in”. Other people don't, you know.

Q You'd like them to though?

A Yeah I’d like them to. Yeah I think it would help them to make informed decisions about whatever their diagnosis might be or you know that kind of thing.

**Family member**

A We spoke to the liaison officer down there and it was the complete opposite. Everything that we’d handed over wasn’t translated to the staff. Every time the staff team changed or the shift handover had changed that wasn’t passed on.

**Family member**

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”.

**Family member**

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.

Q So with the hospital passports, are they fit for purpose? What’s your opinion on the hospital passports?

A I think they could be a little bit more detailed. I think it all depends on which company use them, I don’t think there’s a broad aspect of it. And maybe that’s the answer, the NHS creating their own hospital passports for the questions. And giving that space where are there key terms that this individual would use, are there key terms that we need to look out for. For example, (name of person participant supported B) will tell you she’s got a really upset stomach. If she’s got a really upset stomach what she’s telling you is, she’s hungry.

Q OK.

A But “I’ve just had a really funny turn and I’ve got a really upset stomach”. It’s either she’s hungry or she’s just had an epileptic seizure. So you just ask “are you hungry”, “no, no I’ve had a funny turn, my belly’s not well”. And you’re “right”. But her seizures are partials, so if you wouldn’t be sat with her you wouldn’t know that she would have one sometimes, it’s just sort of an absence, she would stare into a space, have this absent seizure lasting around 1 to 2 minutes. There’s no medication. And so again if you’re in there once every 3 hours, 2 hours, it’s going to be something that could be easily missed. But her answer would be to that “well I’ve got a bad stomach, I’ve had a funny turn”. You do offer food “no, no I don’t want food”. She may be a little confused with words and say it the other way round. So say for example “I’ve got a salty mouth” would be “I’ve mouth salty”, she wouldn’t quite be in the sentence until she’s eventually come around, which again her recovery time is only 2 minutes. So if you caught her in the midst of that you would see it, but otherwise you wouldn’t really realise unless she was telling you.

And just those key terms I think sometimes would go a long way for the individual to feel like she’s also being heard in hospital as well, rather than knowing. The support worker comes in which, and we’re like “right this is what this means, this is what this means” it’s sometimes met with the staff like “oh God, alright, OK”. That’s what I’ve found. Again, not always.

**Family member**

Q Have you got any thoughts on how you can get those hospital passports kind of… are there things that you can be doing while you’re there with her where you can be getting people to sort of know her a bit better or…. It just feels like the hospital passport has so much information on it and then people aren’t reading them.

A Yeah. So maybe if you….whereas every company has a different hospital passport, so we have our own different version and the company I worked in previously have their own different version.

Q OK.

A Potentially maybe the NHS could come up with….

Q Like a template.

A Yeah, a template or one that if we are going into that hospital this is the one I would like you to use. We can then feed that back into our files, and just the importance of how well they work, like key phrases that we use. Sometimes some of our individuals will speak sign language, so her sign for tea, a cup of tea, you know he’ll make the sign of a T and a cup. Cup of tea. His would be upon his chest, so all his signs would be on his chest. But if you didn’t know he’d just look like he was rubbing his chest, but he’s actually telling you he wants a cup of tea. So small key phrases, key things that they wouldn’t…because somebody might know sign language and think “well I still don’t know what he’s saying” because he’s adapted it to himself. So just keep things for the individuals and how important that is, and then feeding that into the daily handovers or their daily notes.

For example we’ve got – I’m going to make up a name – we’ve got Bob in bed 3. Bob does have learning disabilities, these are his key phrases. If he’s saying this to you that can be then handed over on a daily basis and the staff are aware if he is saying these words, if he is saying these phrases, what he would actually need. And again nobody is saying “oh we need to go straight and make him a cup of tea” but at least you know right, OK that’s one of my jobs to do, I’ve got to go round and make a cup of tea and Bob would like one and he likes 2 sugars.

**Family member**

A The hospital passport had got lost in translation. The mar charts when I looked at them weren’t correct, so there were certain medications that she weren’t taking that she’s always had. I spoke to the nurse staff who had said “no problem, we’ll get the learning disability liaison team to come down”.