Q Does it tell you that we’re recording?

A Yeah sure.

Q Alright, OK. So thank you very much [Name]for doing this. I have a script to go through and you’ll be delighted to know that you are the first person that we have used the script with, so if we need to change the script that’s fine too, we’re not asking big questions ??? with you saying that.

A Yeah sure.

Q But I wanted to know first of all why did you want to take part in the study?

A Well I’m interested in loads of areas. Mainly it’s disability related to learning disability and autism but within that there is mental health as well. I do get involved in the Health and Social Care Trust in [Northern City], been involved in that Trust for many years. Before COVID I was actually taking in what’s called ‘place visits’, which is visiting wards in an environmental process and other aspects, and I attend some of their meetings. But I get involved in quite a lot of areas. It keeps me going.

Q Yeah that’s really good. And so do you want to tell me, I know you mentioned it when we were on a call before but do you want to tell me a little bit about your experiences as a carer?

A Sure. I joined a single parent family in 1984. My wife had 3 children, the son who was the oldest was getting married a week or two after I joined the family. And I knew the son before but it wasn’t anything to do with me meeting his mum, it’s just the [Northern City] village connections which seem to crop up all the time.

Q Yes.

A So initially I was introduced to the youngest daughter who was of course still at school, round about 11 or 12 or possibly 13, 14, I can’t remember. And there was always some mystery in the house, there was always a room I was never introduced to go into. And a few weeks later I saw who was the other daughter walking down the hallway. She was walking down. She’d got mobility problems which was obvious and I didn’t know anything else about her at that stage. But my wife then talked about her. I’d had no connections with any form of disability, let alone learning disability and autism. So once I knew – we didn’t know about the autism at that stage but the learning disability was there, there was also a lot of physical disability, there was a sensory disability, and it was a steep curve for me to learn. So I don’t know how I managed it now, possibly because I was a manager and I gave myself time off to go to meetings with my wife – or my wife to be – because I didn’t want to say anything that would make anything worse. But it became obvious by listening to the so-called professionals that you couldn’t make it worse than it was. They were adept at making it worse themselves. But I still didn’t take that much part in discussions because my wife knew much more than myself, until the occasion when for some reason she couldn’t make it and I turned up and they thought they could walk all over me – and I soon put them right. I went round every person and told them what I thought.

Time 5:00

But I was working 5 days, it was only evenings and weekends that I could get involved. And we were doing that care ourselves. Prior to me coming the younger daughter was helping her mum as much as she could, even though she was at an extremely young age and in those days I knew nothing about Young Carers either. So we progressed, we were managing without any major input from authorities to some degree, but then my wife’s health started to deteriorate. She’d already got back problems which was caused during her career as a nurse and somehow arthritis had been caused, eventually she got it in both knees, hips, shoulders and the spine, with the spine being the most severe. But then her health went on to deteriorate with Diabetes 2 and other problems possibly relating from the Diabetes, so we were continually going backwards and forwards to hospitals while trying to care for my daughter – well both daughters but the one with disabilities. She was still going to school for about a year or so and we were using respite services as and when. But we became disillusioned with respite.

Q Can you tell me a bit more about the respite services, what were you offered?

A We tried virtually every social service respite in [Norrthern City] and for one reason or another we pulled her from those services. My daughter wasn’t that talkative in those days so we didn’t have much….she never discussed her respite with us whatsoever. But there was always something that didn’t seem right. She was transported there and back through the council transport services and they were telling us various things. They used to go into the building not challenged because there was nobody around. They went into her room and the daughter was there completely on her own and they just took her and nobody even knew they’d been in and gone out. That didn’t ride well with us and we pulled her from that service for that particular reason.

She tried another one. We took her to the dentist, brought her in about half 9-ish, no staff around, no supervision, and when we enquired where the staff were they were all in a meeting. Anyone could have entered that service. So we pulled her from that.

The best respite we ever got was in the old [Northern City] Hospital in what was technically a Rehab ward where my wife had actually worked previously. And I can’t remember why we went up there. But my wife, while whatever was being done to my daughter was being done she was talking to the sister and she said ‘oh…’ they must have got round to the subject of respite and said ‘well why don’t you allow us to do respite’. We left her there for that evening for a meal, came back and collected her, and then we used that service on a regular basis until they decided to shut the hospital.

She then went to another hospital setting in the grounds of [Northern City Hospital] the Care Trust, it wasn’t ideal but technically it looked to appear the best that was available. We had problems and put in complaints and we were there at that service until it shut about 19….16/17 something like that. And we then moved to another service, brand new service. Teething problems which you would expect, then they got rid of the manager, and then she was going there for about 3 years or so and they had 5 or 6 managers in those. And the service just deteriorated so we just pulled her, by which time we’d already got some form of paid care and we never….we thought we needed more care, we just applied for it.

Time 10:46

Q So you had a period of time where you were using these respite services and then there was a point, did you get a Direct Payment, is that what was paid?

A Yeah.

Q When did that happen?

A About 2008.

Q Yeah.

A Yeah my wife wasn’t financially minded but to some degree I was so it was nothing unusual for me to manage fairly largish sums of money. In fact our care package was really, when it went to 24/7 was a really expensive package. But we had had problems with paid carers. At one point when I had actually gone down, I wasn’t actually working in finance, I was at the [Name] Hospital and I’d gone down to 3 days and for some reason we got rid of both the carers and there was just her and myself looking after her 7 days a week.

Q So did you go down to 3 days because you wanted to care, or you felt you had to?

A They had it 60 in those days and I took….I had got my….when I left one occupation I reduced my pension age from 65 to 60, so technically that pension is actually paying me what I was earning. So possibly I did reduce it to help. And being in the NHS there’s so many days you can have as carer days, so I was working 3 days and I took 2 days off on carers which meant I only was going to go in 1 day, which was the Friday. I turned in on the Friday, somebody said to me ‘are you OK’, at which point I just broke down. And technically I then gave up work. That was when I was 62. But I’d got a history of mental health since the 1970s for one reason or another and I’ve been suffering mental health to some degree ever since. So the subject of the research was certainly of interest to me.

Q So do you feel being a carer, do you feel like the relationship between your mental health and being a carer that they are connected to one another? Or you always had mental health issues so they’re not connected?

A It’s stressful being a carer. I mean life in itself is stressful but being a carer creates much more stress, and it depends on how you can actually manage those degrees of stress which then relates to what comes through on a mental health basis. So it would have had some sort of connection, not that I would have blamed being a carer.

Q No. I feel that, you know the administration around a Direct Payment and the thing about the support workers, I feel sometimes like I’ve got two jobs. I feel the stress of that.

Time 15:08

A Well when you mention administration, the administration on my part wasn’t a problem. I converted all the forms, because I’d got a degree of….well I hadn’t got a degree in the university meaning but in some sort of knowledge I could create spreadsheets and Word documents etc and how to put formulas in, so it did slightly make it easier with time sheets. I created a time sheet and put formulas in so I didn’t have to do any calculations, and various other forms I created. And managing the money, there was no problem. But the promised support that was in the initial information was never there. Even if we were lucky to get a social worker they didn’t understand our Direct Payments either.

Q No.

A In fact even the Finance at [Northern City]Council didn’t understand Direct Payments – and certainly not disability related expenses. At one financial review I had to explain disability related expenses to the person coming.

Q Yeah you do feel you have to become an expert in all sorts of things don’t you?

A Oh yeah. And I only knew about DRE’s because of my involvement in disabilities, which stemmed from a complaint. Yeah we complained about the last respite service and the Deputy Director of Adult Social Care did the complaint to the best as he could, but of course his hands were tied. And I found out he did some meetings at [Name] on a monthly basis so I went to his meetings, and at times there was only me and him there, and it’s surprising what you get to know when there’s just two people. And there’s a degree of trust in that area. And then I found out from him that somebody else in the meeting was in another group so I then went and joined that other group, and from that group found out more places to go. So it just snowballed. And then I started actually looking on the internet for interesting areas to get involved in, which is how I managed to start getting involved in research.

Q It’s been a massive change hasn’t it, you know when my son was little there was none of that, you know. Now it’s such an amazing place to meet other people and to get information and stuff it’s been game changing for us really.

A I mean COVID was bad but at least it brought in virtual.

Q Yes. And I think for lots of people with learning disabilities actually it’s brought them into a space that they were excluded from before.

A Yeah but currently I’m still a member of the Learning Disability Partnership Board and when we met face to face there were a lot of people with learning disabilities attend. And as soon as we went virtual, virtually none. Either they couldn’t afford the equipment or whatever, or that they just didn’t like going….

Q Yeah. I know that [self advocacy organization in Northern City] did a lot of work on getting people online.

A Yeah I know [organisation’s lead]– it’s spelt differently – although I don’t think she’s that well at the moment.

Q Yeah, yeah.

A But I’ve got to know Young Carers and the Carer’s Centre, I’m involved in the Carer’s Centre. But yeah mental health is with everyone, whether people realise it or not.

Time 20:00

Q Yeah, yeah. So if you were to think about, because we are thinking that we are going to make these little films and we want them to be stories that would be useful to other carers and to practitioners, do you have one story or one theme, you know one sort of set of ideas that you might think that you wanted to tell. If you could tell a story what would the story be?

A Oh, right. Around mental health?

Q Yeah, and care.

A There’s so many. Which ones to pick. There’s the story of setting on our care provider that we were using right up until last October, which worked as well as it could do and at times even better.

Q That would be great to hear about that, a good story is really nice to hear.

A Yeah. I mean there’s been some instances when it wasn’t so good but at least that care provider was prepared to listen, which unfortunately….well I was going to say ‘not many do’, but a certain number don’t.

Q Yeah.

A And then they were providing carers who they thought would fit into our situation, and if they didn’t then they said ‘fine, we’ll find somebody else’, which again is highly unusual. Because I’m into safeguarding as well and before COVID I was running my own LD carer’s support network, which to some degree I’m still doing but the carers aren’t actually as active with me as they used to be. Although I’m in contact with them on a weekly basis and they can contact me any time they wish. And I used to hear horrendous stories that they were just mentioning in chat but never wanted me to take it any further, and they always were very guarded that they didn’t give me enough information that I could take it on as a concern. And the first provider we had was awful.

Q So I’m going to ask a question that’s a big question, but what do you think needs to change for family carers and people with learning disabilities to be well supported. What would that look like?

A A system is the easiest answer. Because unfortunately the system as it is at the moment, everybody has to fit the system, whereas the system should fit the person. And that is an almighty change. And it can only come from the top, and I can’t see a government doing it. So everybody will be left to either flounder or suffer. Plus the fact that there’s insufficient money in any aspects of care.

Q But you did have different versions of care, different quality care didn’t you though that period even though the system was broken.

A Oh yeah, yeah. But I used to challenge systems, I’ve done it all my working life. If somebody said I couldn’t get it then I’d say ‘well I’m going to somebody who says I can’.

Q I think that’s really important that you’re saying you can challenge. The system is broken and we need to change that but in between times you still can, and you have, challenged systems. So I think hearing how you’ve done that is probably quite important.

Time 25:00

A The simple one was, we’d already got an electronic Parker bath for my daughter and it was getting too small and we wanted a larger version, and the council were saying there wasn’t such a version any bigger. We used the internet and found out that America had brought one over to Britain. And so they then told us it was too big for the bathroom, and we proved it wasn’t. They wanted us to take a wall out and we said no. It was a tight fit but it worked. I mean they wanted to put in a wet room, and with my wife’s arthritis in her knees I said to them, I said ‘well how is she going to wash her feet?’ I said if she gets on the floor she’ll need some help back up again. So I threw wet room out every time they mentioned it. And I think I must have gone through at least four, possibly five areas of management before somebody said you can have what you want. Time consuming, stressful, and a lot of carers would have given up at the first hurdle.

Q Why do you think you didn’t give up?

A Me. Well myself. Both myself and my wife are fighters. Possibly in different ways which was helpful, we didn’t always agree but we worked together. She had her way of dealing with things and I had my way and in most instances they interlocked, which again could be unusual. How she managed as a single parent I have no idea.

Q No, it’s really difficult isn’t it if you feel that you are on your own with this stuff.

A Because she had no help whatsoever from her previous partners. In fact I’m really surprised she looked for a third!

Q But she obviously found a good one. Third time lucky you see.

A If it had been me I would have packed up at the first one.

Q Well I’m glad she didn’t, I’m really glad she didn’t.

A No I mean the family really suffered, both the people that she had, violently – not to the children but certainly to her. And that was always deep in her mind. My wife wasn’t one for admitting mental problems, she was of the opinion that people should pull themselves together. But when she was going though it of course she didn’t, and she wasn’t one for asking for help either.

Q Why do you think she found it difficult to ask for help?

Time 28:46

A Hard to say really. Her childhood wasn’t as good as it should be. She came from a Jamaican background and her mother was really into religion, Jehovah’s Witness, which none of the children wanted, but of course they had no choice. And her mother was of the opinion that children should do what they’re told, in certain violent ways. Yeah, some of the violence that was metered out to some of them were horrendous. And the middle child wasn’t all that strong and had many mental issues, possibly brought up and made worse by the mother’s behaviour to her. So my wife had to be….she was the eldest of the three so she had to be strong for them, especially when the father came over first in the 50’s – not on Windrush but soon after – he got himself established in [Northern City] and brought the wife, and then the three children then followed on their own. My wife was round about 12 at the time. And in those days it wasn’t just one flight over. But it looks like they were helped by the authorities. But my wife was scared of flying even before she got on, and she never flew again.

Q I can imagine.

A So all their life they were under tremendous pressures not knowing whether they were going to be admonished for this or that. But I think she enjoyed the life in Jamaica, had no choice but to come over here. A big stress for somebody especially how Britain was in the 50s and 60s, slightly better now but still a long way to go. And then having to, on top of that have the stress of three children bringing up on her own, one that had so many disabilities, and a system in both Health and Social Care that wasn’t really advantageous. I’m not sure which was worse, the health or the social care. Because the health model to this day is not that great, and social care model is slightly better. To me, something in between would be much more beneficial. And that’s where the problem is, integration of the systems.

Q Yeah. So if you think about all the experience that you have, and I’m sure that you do this, when you meet people who are family carers and they’ve not got as much experience as you, or perhaps they are younger and the people they care for are younger, and if you are advising them what are the sorts of things that you would be telling them?

A You’ve got to be very careful. You really need to listen to them so that they can explain what they wish to explain and don’t try to force them to tell you what possibly they may not wish to tell. Just let them speak, and on hearing what they say you’ve then got to decide what is best to advise them. And what you hear from one person may most likely not be the same thing you would tell another, which is where the system is at fault because it’s a one fits all system.

Q Sorry I’m just going to…. I’ve got someone banging at my door, just one second, sorry. Sorry he banged and went, so that’s OK.

Time 34:52

Q I think what you said is so important and I think that already when we have been talking to family carers as part of the project you are so right that people are all different and that you need to listen to them and not come with your idea of what should or shouldn’t happen, or why they think what they think. And the other thing I think that’s come through really strongly is that family carers know that about each other and they’re really good at listening to each other. And even when they disagree, they don’t disagree they are really just trying to understand each other’s perspectives. And I think services don’t do that, they come with a view and want to impose that view, and family carers are not doing that.

A No. I mean the first problem with the authorities is listening, they’re not very good at listening. They think they’re very good at telling people but they’re hopeless at that as well. And they seem to view that one carer is similar to another carer, and what a carer does one day is exactly the same for the next. I mean it’s not. It can change throughout the day. And if the system’s not there to listen, well it’s not going to work.

Q And I think, you know we talked about the difficulties of changing the system and you know that feels like a very long way away, but there are individuals working in those systems so I think about when the social worker went – sorry rarely comes to see us – I wonder about how they speak to us and whether they could find out what we think rather than starting from what they think.

A You see that’s another thing, the social worker has to work within the system and in many instances they’re not allowed to do what they’ve been trained to do. So because a social worker says this and that doesn’t mean that they particularly believe this and that, they’ve been told to say this and that.

Q But some are better than others though.

A Oh yeah I mean you’ll find that in any profession, there are ones that will challenge to a degree. But of course if they challenge it’s their job they’re challenging and if they make too many waves then they won’t have one.

Q And I think especially when you get new ones, you know ones that are new to post, I think they don’t know how to sort of work the system – do you know what I mean – I think some of them learn how to work the system a bit and….

A Yeah well they’re going on the theory, and unfortunately a lot of the times they think they know everything.

Q Yeah.

A And the skill is putting theory into practice.

Q Yeah, there seems to be a bit of a gap there.

A I mean one of the agencies we had used to recruit a lot of the carers through being medical students and they’d been told various things. And they came saying to me ‘you do this and that’. And I just turned round to them and said ‘look, you’ve been told this and that, and that is just theory’. I says ‘you are here to learn’. I said ‘don’t forget that learning never stops and if you are going to have the attitude that you know everything because you’ve been told it’, I said ‘that is theory. Here you’ve got practice’ and I said ‘theory doesn’t always fit practice’. And if they liked it, fine, if they didn’t I said I don’t want them.

Q Yeah.

A I don’t know why I am how I am. I just think a lot. My wife used to say I complain too much but she didn’t object when my complaining got what she wanted.

Time 40:10

Q It sounds like you were a great team, that you complimented each other.

A Yeah.

Q I think maybe there’s something about having a team, even if it’s one other person, you need a team in all of this if you’re going to make ???

A And family structures these days don’t always go for teams because for one reason or another a lot of….in fact the stresses of family life break up the….

Q Yeah. So it’s finding your team isn’t it. And I think some people have got online teams now. It might be it won’t necessarily be your family that is in your team but finding a team or building a team.

A Yeah. I mean you’ve only got to look at some situations. I mean Stephen Lawrence, the mother and father was a great team but eventually it split them up.

Q Yeah. I mean it does put, all of this care, fighting, does put pressure on relationships.

A Yeah. I mean it leads to many breakdowns because the person can’t take it.

Q Yeah. And I think that we, in my own situation, we don’t have much time for each other because we’re doing all of this other stuff, we’re still….and we are a team and we’re a good team but you know the project is [name] all things focused on him. And that’s tough sometimes.

A Yeah I mean this is the problem I have with the authorities. Everybody is an expert in their own field and at times expertise leads to power, or power leads to expertise. And once somebody has got power they don’t want to release it.

Q No I think that’s true, yeah.

A But working within areas of humans, then that power has to be released because technically in many instances there aren’t any right or wrong ways to do things.

Q I think actually you’re power less in some of these systems and I think that that’s stressful as well, feeling that you’re not in control of anything and decisions are made by a panel and you don’t even know who is on the panel and….

A And the panel could even be one person.

Q Yeah I know! I know!

A Whereas the Care Act was saying you shouldn’t have panels.

Q Yeah.

A There’s a lot in….to me the Care Act didn’t go far enough because it said ‘guidance’ instead of ‘must’. And people don’t want to use the Care Act, or possibly don’t even know the Care Act and are very surprised when they’re told they going against the Care Act. And what really annoyed me was at the start of COVID when the government said the authorities could temporarily not abide by the Care Act, when really it should have been more important than they did.

Time 44:18

Q Well do you know, I’m going to tell you a story now. That when that happened [northern county] where I live was one of the 8 or 9 local authorities that enacted the Care Act easements and we started a process of judicial review. We wrote a pre-action letter. And they hadn’t consulted, they hadn’t informed anybody that they’d done it and they withdrew the easements. So they said it was nothing to do with the letter but they withdrew the easements. But I was thinking, crikey, even in COVID times when we were really worried about [name] getting ill and what would happen if he went to hospital, we were having to do this other layer of fighting, you know. It was crazy times really because you’re living all this stress of COVID and then we had this additional layer of ‘well I cannot let them do this, I can’t let them do Care Act easements’. And there was no reason. [Northern county] wasn’t particularly badly affected by COVID at the point where they did it, it wasn’t on its knees or anything. And they just did it and they hid it and they didn’t consult. And you know it was just enraging, I think that’s the other thing that….

A Typical of power.

Q Yeah. It’s just that I cannot bear the social injustice, the casual you know every day. And even in COVID they are at it, secretly at it.

A Well [Northern City]said they never did, but whether I believe them is another matter.

Q Well no that’s a really good point, because lots of them didn’t do it on paper but they did do it in practice that’s for sure. And I think that lots of support hasn’t come back, you know, things that went during COVID have not come back.

A Well of course I do have sympathies to a degree with Local Authorities because since 2010 there’s been austerity cuts, which should never have been imposed. And even though they say austerity cuts are no longer taking place, they still are. And an authority which never put enough money into social care, for them to have to reduce social care. The budget used to come to the Partnership Board once it had all been agreed, and they did a presentation and said it was being reduced by a certain percentage while they said social care requirements were increasing by 5%. And it made no sense to reduce.

Q No. And did you see the news yesterday where they were interviewing Cameron about austerity and the impact on the NHS and the impact on COVID, and I thought oh crikey. Yeah.

A Yeah. I mean perhaps there isn’t enough money to go around but unfortunately governments always find it when they want to.

Q Yes it’s interesting who they are happy to spend money on and who not, yeah absolutely.

A So I have sympathies with Local Authorities but it didn’t stop me complaining.

Q No. Because there is the Care Act and I think while it’s there we can use it can’t we?

A Yeah.

Q You know if they want delivering again then I can say that.

A But then trying to get a judicial review is not easy either.

Q No. We were really, really lucky when we did that because funded that through…there’s a law firm called [name] and they have a social justice fund. And so we funded the judicial review through their social justice fund, and then if it had gone on we would have got Legal Aid for [name] you know because he doesn’t have any money. So that was the plan. Yeah but we need, the government calls them ‘activist lawyers’, we need activist lawyers in our lives.

A Yeah I wanted to do a judicial review but didn’t find anybody willing to take it on. I tried [name] in [Northern City] but they didn’t want to know, because they were only taking the ones on that they felt sure they would win.

Q Yes. Well I was very grateful to [solicitor’s name] you know that they threw themselves behind it. They worked really hard.

A Good. But then when it gets to court the judge might not even abide by the Care Act either.

Q No, no. And I’ve been involved in several judiciary reviews but I’ve never actually gone the full way with one - and I hope I don’t have to. But yeah they’re….you have to use what you have to use don’t you?

Time 50:00

A Yeah.I mean with our daughter, in many respects we got virtually everything that we wanted but it was a fight. If it had been left to my wife I think we would have given up. She’d had enough. And she didn’t really know the system.

Q No, no.

A There was an instance where she was trying to tell the social worker, a young social worker, new, what I was doing with the Direct Payment. And I knew full well what that social worker would come back and say. Everything my wife said was true but of course the social worker came back ‘well we can take it away from you’. Which is not what my wife wanted and I wanted. Because I’d told the council in no uncertain terms that I don’t trust them. And I told them that very rarely would people trust them. And people are scared, it’s a big organisation, and the council can’t understand why people don’t go to them. For one thing, nobody wants to set foot in a council building

Q No. And I think one of the things that people have told us is that they worry about talking about their mental health because they worry that they’ll now be a safeguarding concern, so they can’t talk about it really.

A Yeah, I mean that’s the problem with young carers, they don’t want to admit they’re young carers because the scare is that they’ll be carted off. It’s certainly been known umpteen times by various authorities.

Q Yeah. And there’s been some interesting writing about the idea that people don’t identify. You know lots of people, I think there was something in Carers Week actually about 75% of people who could identify as a carer, don’t. You know there’s an explanation of why somebody wouldn’t because they’re frightened of what that will mean.

A Well some don’t actually understand what a carer is, because they say ‘well I’m not caring, it’s my relative, it’s my duty to do it’.

Q Exactly. And I think that people just see it as ordinary, do you know what I mean, they don’t see it as additional to what other people might be doing because you don’t know what other family relationships are like do you, so what you do is just ordinary to you.

A So in a lot of areas we try not to use the word ‘carer’.

Q Yeah. And in the project, the people we’ve been talking to don’t like ‘carer’, they don’t like the word ‘carer’, they just see themselves….you know someone said ‘it’s mum, brother, sister, grand….’ you know. Yeah I think that is a problem.

A I mean the [Northern City] Teaching Hospitals are wanting to bring in a project called A Carers Passport where carers will be identified - and hopefully on admission - and then they will have some form of recognition on the wards that they can gain access and be allowed to do this and that, and will be consulted throughout the stay, which because of confidentiality is not the case. I’ve put umpteen complaints in through PALS? about how my wife was treated in hospital. She was allergic to any form of codeine medication, and they gave it to her. I went in and found her just laid out on the bed. I mean the day before she was complaining not feeling great, and I went in, and there she was. Her meal was by her side. So I just got hold of the meal and just tried to feed her. And when she decided she’d had enough I went and asked at the nurses station. And luckily they were listening, they contacted the Lead Nurse who was also prepared to listen. In my presence she went through the medical record and I could see there there was a codeine med. But my real concern is, they could see her laid out on the bed so why wouldn’t somebody do something? But of course it was at the height of COVID. Luckily they’d relaxed visits so I could go in. God knows what would have happened if I wasn’t allowed to.

But on another occasion my wife said ‘oh they want me to have oxygen’. ‘Oh’. She said ‘they’ll have a word with you’. And a week later nobody had had a word. And I went to the Nurses Station, this doctor came, ‘oh we weren’t going to talk to you about it, it’s confidential’. And when I got home the carers had actually turned away the delivery of oxygen, quite rightly, because I’d only just found out that they were going to start delivering it. I phoned the company and played merry hell with them and said ‘don’t you deliver it until I authorise you that it’s fine to do so’. And I found out they’d not even done a home assessment, which they were supposed to be authorised. So I just jumped up and down.

Q As ??? Yeah.

A I mean the system worked fine after that.

Q Yeah.

A So I am now on oxygen but not 24/7 like the wife. So I knew the system as well as they did. And they did follow it. But it’s what you know and what you don’t know. And if you don’t know there’s nobody prepared to tell you – or they say they’re not allowed to tell you.

Q Yeah. So I’m thinking about the next bit of the project and I’m thinking about all the things that you know in your head and finding a way of trying to get them out of your head and share them with other people I suppose. And so it won’t be until October but we are going to have some digital storytelling workshops, which sounds a bit scary but they’re actually not scary. So they would be online again, and it’s working with people. So we have people who are film makers and artists and can do all the technical stuff. And then it’s about working with you really to create an idea for a short film, the films are normally sort of like 3 or 4 minutes long, but they can be really, really powerful. So it’s sometimes when you add images and sounds or music to the words that you say, or just doing it in a little bit more of a creative way, you learn something new. I don’t know how to explain it. And I think there’s so much in what you’ve said about the way that you’ve worked as a team, the way that you’ve fought, the way that you’ve got knowledge, the way that you’ve shared knowledge, your understanding of the system, that there would be a way of thinking about storying that, you know and making it into a little film.

A And I’m still learning.

Q Yeah, yeah. But I think you’ve got so much to share, you know people can learn so much from you because you’ve got so much experience over such a long period of time, you know.

A The only problem with the filming is my camera.

Q Yeah you don’t need that, you don’t need to worry about the camera because what they can do is help you to find images and so on and make what you’ve created. So you don’t need any….you just need to be able to talk, you don’t need any technical….

A Well I have no problems with that!

Time 1:00:00

Q Yeah, you don’t need technical skills. All you need to do is to talk to somebody about what to do and they can help you do it or they will do it.

A Yeah I have no qualms about filming at all. I’ve took part in quite a lot of filming.

Q Yeah. So what I’ll do is, I’m going to send the recording off to a transcriber so we’ll have a copy of what you’ve said, and I’ll send that back to you just so that you can see what you said. And then we’ll be in touch.

A I’ll be able to remember what I said then!

Q Yeah, it’s good isn’t it! And then I’ll be in touch about the dates for the workshops, which won’t be until October.

A That’s fine.

Q We’ve got to interview people before then. And I’ll just stay in touch in the meantime.

A You started by saying about there was a script, it didn’t seem as though….

Q Oh I’ve been preparing my script, yeah I’ve been through it.

A It didn’t seem as though we were following a script.

Q Ah, well good! Yes I’ve been through all the questions. The only thing was, do you have any questions for us was the last question.

A My only question when I do research is how it’s going to be used, what it’s going to be used?

Q Yeah, so if I explain about the whole project. So we’ve done a review of the literature, which has been really interesting in itself. So we’ve done a review of what’s already out there about carers of adults with learning disabilities, and the answer is ‘not much’. Because when research is done about carer mental health it usually focuses on carers of older people, so that’s interesting in itself to find that. The other thing that’s really interesting that isn’t in any of the literature is the word ‘love’. So ‘love’ doesn’t seem to be discussed in that, and family carers obviously think that’s quite important.

A Mmm, although I never mentioned it.

Q Well do you know it was there though wasn’t it, it was there in everything that you said. And the next bit that we had planned was that we….you know there are lots of surveys about carer mental health?

A Yeah.

Q And the plan was that we’d work with carers and we’d develop a survey and they could choose the topics and the questions, and we thought that might produce a different kind of survey. And what they told us was, we don’t want a survey, we hate tick boxes, tick boxes are not going to allow us to tell you how it is. And so we are now going to produce an online exhibition, so people will be able to send us stories or pictures or sounds, songs whatever and we’ll put those up online, and they feel that will represent their experiences a bit better. And then we’ve got these interviews and digital storytelling workshops. So we’ll have interview data, and we’ll have films that we can show people, and then we’re going to pull all of that learning together and we’re going to make some resources for family carers. So there will be things that hopefully will be helpful to family carers but also to people that help family carers, or are supposed to support family carers. So people like we’ve talk about like social workers, maybe GPs. We don’t know who does help to be honest, there are not that many people that seem to be helping.

A Everybody thinks they are helping but sometimes it can be a hindrance.

Q Yeah. So what we’ll try and do is share it with commissioners, social workers, GPs, mental health service providers, anybody that people are telling us that we should be talking to, that’s what we will try and do. And we’ll have produced these materials that we can share with them.

A Two major areas you’ve not mentioned, one is how is it going to be put out to carers, even carers who don’t know they’re carers? And the other big one is the government.

Q Yeah. So how it’s going to be put out to carers is, we’ve got lots of connections with some carers organisations and with organisations that support people with learning disabilities. So we’ll be pushing it out to them through those organisations. The bigger problem is of course the people who don’t see themselves as carers, though reaching them is always going to be really difficult so I guess any ideas about how we do that for people who don’t see themselves as carers we’d be really grateful for. And then in terms of the government, as you know because you know about the system, it’s really difficult for us to shift what’s happening in government. And we’ve struggled with this with research for years basically because what we want them to do they’re not interested in doing, you know this government is not really interested, they won’t even talk about social care will they? But what we are going to do is like a very targeting approach. So when we have our research findings we are going to write to the Minister responsible and say ‘we found this, what are your plans for doing something about it’. And we can also try and do that through things like the All Parliamentary Group for People with Learning Disabilities. But in the past I haven’t found those very successful ways of getting government to shift. I think we need to….I don’t know we need to build the pressure on them to convince them that this is more a problem that they need to engage with.

Time 1:06:20

A And the other thing is, how is it going to get into the diverse community?

Q So we are working with, on the research project team we are very conscious of the fact that this kind of research is often very white, middle class white, and so we have a research team which includes a person from the South-East Asian community, and also someone from the Roma community, because they are….

A Oh right.

Q Yeah, you can imagine the exclusion that they experience. So we are working very hard to try and involve people with diverse backgrounds and experiences. But if you know anybody that you think might be interested in taking part in the research and if you ask them if they would mind passing details on I would be really interested, particularly people from communities that are normally marginalized in research.

A Yeah. Have you got any connection at [name]?

Q Is that in [Northern City]?

A Yeah it’s the Caribbean Centre.

Q Yeah. So I think that we tried to contact them and didn’t get a reply. But it’s because we don’t know them.

A Yeah. My connections there aren’t that good. There was somebody who used to come to meetings, I can’t remember his name now. But Health and Social Care do hold meetings in the building through Flourish, and Flourish technically is in [name].

Q OK. I will double check whether we contacted them and I’ll try and contact them again. Thank you very much for that.

A And when I was taking part in Leading [Northern City], the group I was connected with were using the Somali Centre on [Name] Road.

Q OK, thank you. I’ll definitely follow those up.

A But in the groups I’m in it’s always our wish to get more involvement in the diverse community. Just before COVID I was made Chair of the Adult Safeguarding Customer Forum and it was one of my wishes to go out into the community, because unless you go out you’ve got no chance of connecting because they won’t come to you.

Q No, no, and we do have many things like translation, so we have thought about this. But it is hard to remove the barriers to people participating, and especially if they’ve had bad experiences in the past.

A Yeah, and then COVID came and it all fell apart and I’ve now resigned from Chair because of my circumstances. But I still go to the meetings.

Q Thank you, that’s really useful.

A So unfortunately I haven’t got any connections myself.

Q No but I will try, I will try. Yeah that’s really helpful. So thank you very much for talking to me and I will be in touch with the transcript and I will be in touch about the workshops. And if there’s anything that occurs to you in the meantime feel free to email me or get back in touch.

A And vice versa.

Q Thank you.

A Yeah. So I’m always here on email some time during the day, and you’ve got my phone number if you can’t get access.

Q Yeah thank you. Thank you so much and I’ll be in touch. Lovely to see you, thank you.

A And you have a good day.

Q You too, thank you.

A Thanks. Bye.