Q It’s recording. So cross my fingers and hope that it’s going. Can you see it’s recording too, it might have told you.

A It came up and I said ‘got it’ so yeah.

Q Great, thank you. And on my screen I can see it says it’s recording. So thank you very much for being here. So it’s just going to be….we have got some questions for you but somebody said to me at the end ‘did you ask me any questions’ because it turned into a bit of a chat. And that’s absolutely fine, it’s not like I’m interviewing you for a job or something, so it’s fine for it to be quite informal, and the questions are quite broad and answer them as you feel you want to. So I wanted to start really by saying what made you interested in taking part in the study, why did you want to talk to us?

A I think it’s important for people to understand what caring is about. I just don’t think people realise how hard it is and I think the more you can get that message out and the more we can have some kindness and compassion from others, then I think it would help everyone really.

Q Yeah. So would you mind telling me a little bit about your experience as a carer?

A Well I’ve been a carer really for….my daughter’s now 20, my youngest daughter. She was born with an extremely rare chromosome condition called Trisomy 9 Mosaicism, which we didn’t know until about 2 or 3 weeks after she was born. We thought she’d got a potential heart condition. She was born in [hospital] and that turned out to be OK so she was then transferred to the local hospital and then they said ‘something not right here’. So they did some tests and it came back with this genetic condition. And then it’s been a kind of rollercoaster ride from there really, just a massive learning process and…yeah just a different world that you enter, you know.

Q So is she still living at home with you?

A She is but she’s now weekly boarding at a college in [county] So I dropped her off this morning and I’ll pick her up on Friday afternoon, so she’s back at weekends and holidays.

Q And so you have just been through the transition process from children’s services to adult services?

A Well that was….so this is her second year now, so we had that, so yeah she joined [college] last September so we had that transition sort of that kind of year before.

Q So tell me a little bit about what that was like and what it was like when she was little compared to care of her now I guess.

A When she was little I think it’s easier in a way because she was small, I could carry her about. It was more things like pediatrician appointments, doctor appointments,[children’s hospital]. She had a craniofacial operation when she was 18 months so it was up and down to [city] all the time, that sort of thing. Then applying for DLA. You know her starting at nursery and school and that sort of thing. But then it’s harder when they get older because friends move on as their children get older. You know it’s OK, my older daughter is 22 so when they were both little and you’d go out with friends and socialise, and then suddenly their second child is moving on and they move away and you are left, you are left on your own. And suddenly then you’re child’s mum, friend and carer. So that gap starts to just grow. And you kind of feel forgotten about really in a way.

And then it becomes more intense because when [name]’s on holiday particularly, unless she does go to a disability club sometimes and she’s got a PA that we get so many hours in the holidays, but otherwise it’s just literally me and her. So she’s up 6 or 6.30 and you know then she’s signing car, walk, coffee, and we’ve got to fill the day, and it’s absolutely exhausting. So I’m absolutely knackered. And that’s what people don’t see. They don’t understand. And this is because I’m absolutely exhausted. And it’s just not right. And I know, I know how to look after myself but it doesn’t stop you feeling absolutely on your knees. And it’s just not right.

Time 5:30

Q And you shouldn’t have to look after yourself to that extent, do you know what I mean? I think you need to have more of a break.

A You know she’s 20, she shouldn’t have to spend so much time with her mum. You know she’s at college, she’s got a great social life, they are busy every day, they’re doing lots of stuff, she loves being in the house. And then suddenly she’s got to come back home. It’s kind of step forward, step back, step forward, step back you know. It’s ridiculous. My husband’s knackered, he doesn’t get a weekend. You know we used to get PA hours every week and we used to get 6 to 8 overnights a year, but now because she’s weekly boarding they just said ‘oh well because she’s weekly boarding you get your respite in the week now’. So we’re taking away….you only get PA hours in the holidays, no overnights. It’s like but my husband works. You know I’m lucky I don’t work, my husband works, we don’t get a weekend, we don’t get a holiday. And he’s just as knackered as I am to be honest.

Q Yeah. There’s always that….we have somebody with a learning disability and it’s always the three of us, not just the two of us.

A No that’s right. Or, like on a Saturday, my husband takes [name] to horse riding – well she likes to sit on the horse, so he does that. He comes back then I take [name] to swimming because then that gives him 3 or 4 hours break because I take her swimming and we go for coffee and that sort of thing. And then it’s like what are we going to do on Sunday? You know. And it’s quite hard in winter when it’s cold and it’s wet you know, and you just end up going to the same….well we know every garden centre there is you know.

Q Yeah. It’s that ships that pass in the night thing with my husband sometimes. I feel like it’s one in, one out, one in, one out. And that’s really hard, it’s really hard.

A And it’s not….we love [name] dearly and it’s not her fault, but it’s the system, it’s the system’s fault. Just because she’s our daughter does not mean that we should have to care for her all the time, you know, but that’s the way it is. And we’re too good at what we do, you know, if I stood up tomorrow and said ‘can’t do this any more’ what would happen? You know I think it’s only if you keel over social services suddenly think ‘oh hang on, better get involved here’ you know. But you don’t, you keep going, you keep picking yourself up and you keep going because she’s our daughter and we want the best for her.

Q I’m going to ask a question and I know it’s a tricky one, but what about the future? Because there’s college for now, but how old will she be when she leaves college, how long can she stay there?

A So she’s got another 2 or possibly 3 years there. We know where we want her to go, there’s a place which is similar to where she is now, but that would be for ever, because it’s got a farm, it’s got gardening. [name] needs routine, she needs activities, she’s a busy girl so we know where we want her to go. Now whether there’s going to be a vacancy at the time that she leaves, we’ve no idea. So we need to look around as well to just see what else…there’s really nothing nearby that we see suitable, and again that’s wrong. So yeah it’s….

Q Do you have a social worker at the moment?

A Well we’ve got a social worker, she’s useless, she’s always been useless. You know we did all the work, we knew we wanted her….you know we even looked at different colleges, we knew we wanted her to go to [college]. So she basically just pops up when things need to be done, she’s not there to support, she’s not helpful at all.

Time 10:00

Q I bet she was there to take the night’s respite away.

A Yes. And I wouldn’t have minded….well first of all I think they should warn you about things like that, not just say ‘oh by the way….’ And they could say it in a different way, they could just say ‘look I’m really sorry but what happens now is that because she weekly boards we’re going to have to adjust the PA hours’. There are ways of saying things. And it doesn’t just impact us, [name] absolutely loves her PA, you know so they’ve taken away [name]’s friend if you like. And how can that be right.

Q I’m not absolutely sure that they can just say that you know because it should be based on [name]’s needs not on what they ‘in law’ – and I know that the law doesn’t happen – but in the social care changes are based on her needs, and her needs haven’t changed in the summer have they?

A It doesn’t make any difference. I’ve got a friend who is 74, her brother lives in supported living, and she still has to do a lot for him, doctor’s appointments, all sorts of things, and she spoke to social services and they said the same thing to her ‘oh well carers are in at the week so that’s your respite’. So she can never really go away at weekends, because he’s blind, he’d be left by himself in a flat for 2 days by himself. It’s the system. There’s just no care, there’s just no compassion.

Q And I think that, I mean we’d like to change the system, we really would like to change the system and we will do what we can to highlight this, but we know that people are experiencing this now. And you said earlier, you said ‘I know how to look after myself’ and I was really interested in what you do do, what does help you?

A So I run, I run 2 or 3 times a week. Saying that, it’s a bit hit and miss in the holidays because I have to get up really early.

Q I know, it’s that thing about you don’t have time to do the things that you know will help you.

A It’s not necessarily a time thing, it’s literally that you wake up and you’re exhausted you know. And it’s a feeling ‘I have to get up now because I have to get out because [partner]’s got to get on…’ you know [partner] works from home, my husband, so that’s fine but it’s still the fact….it’s the constant time, clock watching and things like that. So you know I run, I walk every day, I go to pilates every week. I shut myself away. I have to. At night I have to go upstairs, close the door and just have ‘me’ time. I withdraw, I can’t deal with people. Especially when [name]’s here in the day, when I’ve been with her all day, you know when it’s like from 6.30 til 8 o’clock at night.

It’s quite funny actually because she’ll be upstairs and then she’ll come down and she’ll point at my bag because she wants me to go upstairs, it’s her way of settling down here as well. And I’m kind of ‘do you know, that’s fine’ I’m so tired I’m fine. So I go upstairs and I watch TV and I close the door. But I have to shut myself away from people. So you know I know what I need to do. But sometimes even though you know what you need to do it doesn’t help. You know it’s very difficult to recharge your batteries when you never get any time off.

Q And so the social worker’s useless, that’s the theme, that’s even if they can find….absent, no-one’s got one or useless. Is there anybody else who has been of use to you?

A [name]’s PA, an absolute God-send, I don’t know what we would have done without her. She was with us through lock….you know when she could take [name] out when lockdown started to open up. Again, in lockdown because there wasn’t enough staff at [name]’s college they had to look at the children who would be safe and loved at home and those who wouldn’t. So [name] spent 6 months at home. And that was really hard work, you know especially when [name]….a big thing for [name] is going for a walk and getting coffee, there’s no coffee shops, you know everything closed down. She had no idea what was going on. You know she’s severely mentally delayed, she’s non-verbal but she understands a lot as well, but she’s very adaptable thankfully so you know that was OK. So we took out a flask instead and that sort of thing and luckily she was OK with that. But it’s very hard when you suddenly think where are we going to go today because there’s nowhere to go.

Time 15:30

So yeah her PA is amazing, we don’t have family nearby. I don’t know, people that you thought were friends aren’t friends, they literally….they walk away. I understand that everybody is busy, everybody has got their own lives, but there’s only one good friend of mine and I will be there for her and she will always be there for me. And I think that’s a sign of the times, that we’ve lost that community spirit, that we don’t look out for each other but is so important. So yeah it’s literally….yeah I think her PA is the main person really.

Q Other parents of disabled children, have you ever been part of support groups or online stuff?

A Yes well I actually worked, my last job was working for a charity called [name], so they support families who have got children with additional needs disabilities throughout [county]. So I was part of that and I was lucky to be part of that because I was at all the training for parent/carers, I used to go to parent/carer coffee mornings, so I did a lot of work with parents and professionals. So I know exactly what’s out there and I’m happy to signpost, even though I don’t work now I’m happy to signpost parents and support them as I can. So I’ve been in a good position where I’ve known what I’ve needed to do for [name], whether it’s, you know what forms need filling in, or I’ve learnt stuff that I didn’t realise and that sort of thing. So that was a good thing to be part of.

Q And we’ve had…. people feel mixed a bit about parent groups, some people have really loved them and other people have not really liked them.

A I still sometimes go to parent/carer coffee mornings but the problem I find is, most of the mums there have children at mainstream and they are younger children, so I’ve never found really that many parents who are in my situation. So I don’t necessarily always go because….I mean when [name] was born there was no internet as such, there was no Facebook groups, everything wasn’t as it is now, so very much on our own and had to just deal with stuff.

Q Yeah. I mean I remember….do you know IPSI the independent panel?

A Yeah.

Q And I was phoning them, I used to phone them up and sit there for 2 hours while the phone line was open and not get through, and you’d have to sit there for 2 hours the next day. Now of course it’s all online and it’s been a fantastic change because I can go on Twitter and ask a question and it comes straight back. Amazing. That’s been an amazing change.

A Yeah. I suppose in a way we’ve kind of learnt to get on with stuff. Yeah I’m a member of lots of groups on Facebook so get lots of information that way. But you know the things you have to deal with, like the DWP, I have to call in every month boarder dates for [name]. So I have to ring in and tell them when she’s been at home. So there’s no email address, I have to get on the phone and I sit here and when it’s 9 o’clock I hit the button on my phone and you have to go through the 20 questions until you get through to someone, and then you know. So that is ridiculous, absolute madness. So things like that and just having to deal with it, it’s just ridiculous.

Time 20:00

They also stopped her PIP payments last December, and I rang up and said ‘why has it stopped’ and they said….when she joined [college] they said to me well we need to send a form to the college to confirm who is funding the placement. So they sent the wrong form, so I rang them up. Then they sent….yeah that’s right they didn’t send the form. Then they sent the wrong form so I rang them again. Then they sent the right form but when I rang up they said ‘well we haven’t received the form’. And I said ‘but it’s been sent twice’. And I said ‘can I scan it and email it to you’ – ‘no we don’t have an email address’. I said ‘but how can you stop, without notice, someone’s payments?’ ‘Well we haven’t received the form’. OK. But you know it’s either been lost in the post or it’s in the scanning room somewhere. Right. So I actually emailed my local MP and just said ‘sort this out, it’s just ridiculous’ and eventually it was sorted out after Christmas. But it’s just like how can you do that, it just doesn’t make sense.

So you know on top of the caring role, hands-on caring role, you’ve got all the administration, all the paperwork, and it’s other things that people don’t have to do. Like you know we’ve set up our Wills and a Trust Fund for [name] so she inherits, it goes into the Trust Fund. And I only found that out by going to a parent/carer coffee morning and there was a lady there from [legal firm] who was talking about savings and….and I was like oh my God I had no idea that if you’ve got over £6,000, [name]’s got over £6,000, they reduce benefits. Over £16,000 she loses them completely. And she’d got a Child Trust Fund that we’d been putting money into – so we stopped that, we changed her Premium Bonds, transferred those to us. We got Renaissance Legal to do her Will and Trust. And then we’ve had the whole saga of having to go through the Court Protection to become Deputies to access her Child Trust Fund, which is just absolutely ridiculous.

Q Yeah ??? campaign.

A I’ve been on TV twice talking about that. Because there are only 15 families I think that have gone through the process. It’s just madness. So now…that was horrendous filling in all those forms, I now have to complete a yearly report. It’s utter madness.

Q ???before I was in this I would have thought a social worker would tell you those things.

A No.

Q I think that’s what other people probably think, that someone tells you.

A No.

Q They didn’t tell me anything. Or what they did tell me wasn’t true necessarily, it was always other parents who told me.

A Yeah that’s how you learn things, from other parents, because your social worker won’t do that. And that’s because probably they haven’t got time and they haven’t got enough staff.

Q Yeah and they don’t want to tell you anything that’s going to give you any more resources because they are trying to hold on to them – well that’s how it feels to me, like they are trying to hold on to them.

A Yeah.

Q And I think people don’t know that. You know I think people probably still think ‘well if something happens the state will swing in’ but they just don’t.

A No, no they don’t, you’re left to get on with it and that’s it.

Q Yeah. And do you think, because we are focusing on mental health in particular, is there anything that you particularly wanted to say about the impact on your mental health or support for people’s mental health?

A I think it’s just that people do not understand. I walk out the door, I’m dressed, I’ve got my make-up on you know, I’m ‘hello, how are you’ and people have got no idea what you are dealing with inside. That’s the thing. Even friends who should know just choose to ignore it you know and don’t offer help or support. I don’t know whether they do that because they think you’ll be constantly asking for that – it’s not that. But it would be nice. You know I go for a walk with my neighbour quite a lot but she would never ever think in the school holidays to say ‘shall I come to Wakehurst with you’? [name] walks very slowly so it would be a very slow walk for my neighbour. But it really put her out just to go…. You know [name]’s non-verbal, I talk to her lots but I don’t get that interaction you know. So we are doing lots of stuff but it’s not the same. I do stuff for her, it’s not what I want to do.

Time 25:35

But I’m having to do these things because I’m having to keep [name] busy. I don’t want to have to go every day and think ‘OK what are we going to do this morning; what are we going to do this afternoon; OK let’s go to [local town]again this morning because that’s what [name] likes’. You know and that’s fine but I don’t….some days you think ‘I don’t want to do this any more’. I’m 63 on Wednesday you know, I was able to retire at 60, and I’m just like ‘this is not what I should be doing’. I should be able to go on holiday with my husband, I should be able to do what I want. But I’m trapped in this situation because it is the way it is. I don’t know I’m just rambling a bit. But it’s just frustrating that we are not recognised. We do a job. It’s a really difficult job. And we’re just not recognised for what we do. I mean again it’s just not right.

Q There’s been campaigns in the past around people with learning disabilities leading ordinary lives.

A Yes.

Q That’s all you’re saying isn’t it, I’d like to live an ordinary life. I’d like to be able to go and have a coffee when I want a coffee to the place that I want to have a coffee at.

A Yes.

A Yeah, yeah I know. The last couple of years, you know usually [name] my elder daughter has been around so it’s been quite good, and then [name] her boyfriend lives here in the week because he works local, and [name] adores him. So when [partner] went away it was fine because you’ve got them there as well and it takes a bit off you. But the last….

Q We do exactly the same you know.

A We haven’t…I mean it’s funny, a friend of mine whose son is autistic and diabetic and she said, ‘you know we go on holiday’, but she said ‘it’s the same shit but it’s just somewhere else’. And it’s true because you go on holiday doing exactly the same things you do at home it’s just in a different place.

Q Yeah, it does help me to have a different view to look at, I think that does help me a bit, but I know exactly what you mean, yeah.

A Yeah.

Q So we’re kind of trying to work out who people get support from. So not the social worker, friends not so much, other parents – yes you receive quite a lot from that.

A We don’t, well our parents don’t live close by so….

Q I’m sorry I meant other parents of disabled children.

A Oh yes, sorry.

Q Some people get support from families of other people, they just don’t, you know it depends. Things like the GP. So would the GP know or notice or care that you were a carer do you think?

Time 30:00

A No. No. In fact when we went into lockdown and I wanted to get [name] vaccinated they didn’t even have me down as a carer and they didn’t have [name] on the disability register. And I said ‘how can that be?’ A few years ago I went to the doctor, I just felt an emotional wreck, I just felt completely out of sorts. And I said to her ‘I don’t know if it’s because I’m a carer, or whether I’m going through the menopause, or whether it’s both’. And she said ‘are you having hot flushes’ and I said no not really. And she said ‘well I wouldn’t recommend HRT then, I think anti-depressants would be good for you’. And it’s kind of ‘OK’. I mean that should not necessarily be the first choice. She didn’t talk to me about my caring role, she didn’t suggest….and I have actually been to my own doctors and presented, when I worked at [charity] about carers and all this and that information. But there was nothing from her about ‘well are you a member of a group’ or ‘have you got support’ there was none of that whatsoever. So again….

Q What about talking therapies, did she offer anything?

A No, nothing.

Q So it was anti-depressants or nothing.

A Just anti-depressants, and that was it, yeah. So no understanding there at all. And I don’t know, I think that’s what you want sometimes, just for someone to have a bit of understanding. It is that kindness, that compassion that doesn’t seem to exist a lot of the time.

Q Yeah. And some people have had referrals to, it’s called IAPTs Access to Psychological Therapies, they’ve been offered CBT and things. But then they’ve found that unhelpful because it’s like a sort of papering over, you know.

A Yes.

Q Because people have said things like writing lists isn’t going to help me, you can’t reframe it, you know the things that are happening it’s not possible just to reframe them. So yeah I think people have been offered medication, they’ve been offered therapy that they feel doesn’t work for them. The odd Yoga class, you know, just spot them going…. people are like ‘urgh’. So yeah people feel that they are not offered what they need. Or that they don’t have the time, like you were saying, that they don’t have the time that they know will work.

A Yes. I suppose I know, I mean my husband knows, I say to him ‘I’ve hit that brick wall’ and he knows I’m at that point where I feel very emotional, very upset because I’m just tired and you know he knows that when I snap his head off it’s because I’ve got no-one else…. You know I said to him, if you didn’t work from home you probably wouldn’t get a lot of this barrage, but you just happen to be here. So you know he can say one word and that’s it, you know it’s like ‘ra-ra-ra-ra….’ So I do know people I can message or whatever and talk to if I need to, but I think at the end of the day I just need that quietness sometimes, which I’ve got now, go for a walk, go for a run, and I just have to do that. I just have to find that way to just recharge my batteries. But a lot of people don’t get that chance. If they are looking after a child that is medically ill and they literally do not have any time whatsoever, then suggesting they go for Yoga, even online, is not going to work – is it?

Q No.

A And the fact that they’ve even suggested that….

Q Shows them that they don’t have a clue what’s going on.

A No.

Q I know. So I’m just thinking about….I’ve got a question here about what do you think needs to change for carers to be well supported and I think you’ve kind of talked about that in terms of it’s the system isn’t it? So there needs to be more support, more timely support, more support where people really get it and they really understand what the situation is that you are in. And it sounds like we need to do something about social workers, we need to do something about GPs, is there anybody else that would be on your hit list?

Time 35:00

A Schools. I am tired at [name] being stared at by children. You know you’d think she had 3 heads. You know she walks differently, she walks with her head down, we link arms, and I totally get….I get a little bit frustrated when disability is shown as someone who is in a wheelchair, or has lost a limb, or like on Strictly, Rose was deaf, you know things like that. But these people still look normal so it’s acceptable. And kids will literally walk past [name] open-mouthed. And I was like….you know and I just smile at them but I don’t understand why schools….I just think disability needs to be spoken about in schools. But the fact that kids, a lot of kids in mainstream school are excluded because they are naughty when they’re not naughty they’re just trying to cope with the situation. So I think disability in mainstream is just not good anyway but I think if you don’t educate children about children like [name] and for them to understand what autism or ADHD is then they’re not going to grow into adults that understand about it. I think it’s just literally about being kind to each other. We are all human beings. Just be kind.

I’ve had literally two instances. I was in Nero’s with [name] – her favourite coffee shop – and there was a mum and two boys sat next to us. And one of the boys was saying ‘why is she wearing those?’ She used to wear Snaffos, so you know like the plastic foot things? And I think his mum literally said ‘well why don’t you ask’. And I was like thank God for that, I’m always happy to answer questions, you know. So I said ‘she wears those because otherwise her knees come in a bit and it’s to support her hips – have you got any other questions?’ And afterwards I said to his mum ‘thank you so much’ you know. It’s just a nice thing to do when people ask and you can explain and they’re interested and they want to know, rather than just staring at her, you know. So I think there’s a lot of work to be done in mainstream, just education. Just generally. People….I mean what Chris Packham did when he did those videos of the….

Q Yeah he did a programme didn’t he?

A I thought that was fantastic because it’s actually that person saying ‘this is how it is for me’. And it’s just like why don’t they show that in schools. For the child whose got autism in the class or ADHD, why don’t they get that child to stand up and say ‘this is how I am, this is how I feel’ so the other children can understand. But it’s just like ‘no, let’s exclude that child because they disrupt the lesson and whatever’. So how can we become inclusive when we are just trying to push people out? So the term ‘disability’ is just not understood really at all.

Q And I think you know don’t you that we’ve got these interviews and we are going to make some little films and digital stories with people. Did you say you didn’t want to do that bit?

A No, no I didn’t say that. You know sometimes you think that’s something else I’ve got to do you know, but I’m happy to do it. But sometimes, at the time, you just think ‘I can’t think about it, it’s too much’.

Q Do you know that we can pay for [name]’s PA, we can pay for some time when you are doing it?

A It doesn’t matter because now she’s at college so I have that time.

Q We’ve got some workshops on a Saturday afternoon. I mean I’m not pressurising you to take part because we can work around that, but if you did want to do something on a Saturday afternoon – because I think if [name] hasn’t seen her PA for a while, if she hasn’t had the money, we could pay for, we can cover the time that you would be at the workshop. Do you see what I mean?

Time 40:00

A The thing is I take her to swimming on a Saturday afternoon.

Q Oh OK.

A That’s the thing, and I have to get in the pool with her because she still can’t swim.

Q Yes sure. So if we are going to do this though, so because we have got this money and we’re having trouble spending it, so people are wanting to spend it. So we can give you vouchers for your time in terms of participating but we do have this money. So if you think about the time that you are going to spend with us, if you like in the week, I think we can pay that carer….tell us what the carer placement costs would be for the time that you spend with us and then we can pay that, and then you could use that another time. Do you see what I mean?

A To be honest I’m not worried about the costs, although that might sound a bit flippant to say, but I’m not concerned about that. I can do things in the week but it’s just difficult on a Saturday afternoon because I take her swimming.

Q OK, sure, that’s absolutely fine.

A And you know we can pay, and we’ve done it before, we have paid Sally whatever, because what’s the choice? So it’s not the money.

Q But you would be….you don’t have to do it but you would be doing us a favour. Because we’ve told the funder, and we’re trying really hard to work with funders and say ‘we have to give people vouchers for their time, we have to cover these, this is an access cost’ you know, so we have the money and we’ll just give it back to the funder. So have a think about it.

A OK.

Q But it would be quite nice to think that, for me it would be quite nice to think that from you taking part in this you had a few more hours where you could sit quiet, you could go out for a coffee with your husband. I’d be thrilled. You know have a think, have a think, because we have got some time available. So we’re going to do these, and people are like ‘I can’t make a film’. So you don’t have to be able to make a film because we have got people who can do that, and you don’t even have to have an idea about what a film might be because we can talk that through with you. But I was part of a previous project, I was a participant in a previous project where we did this and I didn’t have a clue about what I wanted to make a film about and I didn’t have a clue how to make a film. But I did make a film.

A Well done.

Q Yes, I was well chuffed with myself. So it’s just something to think about, about what would you like to make a film about. And I was thinking about from what you said, I was wondering about you know you could make a film for children. You know maybe you want to talk about something else but when you were talking about schools I was thinking ‘ooh maybe…’ Have a think about what it is that it would be that you want to make a film about and we’ll be back in touch. And we’ve got somebody called [name] who is a young person, which is what we need in these situations, and Martha is a student with us at [northern city] and she was part of an internship project. And we wrote an academic paper and she made a film to go with it, which was quite tricky because it’s quite tricky to turn that thing into the other thing. So she’s got lots of skills with doing that and there’s a whole team of people in Canada as well, but probably it would be [name] that would be working with you on it. So we can be back in touch about that.

So what I’ll do is, I will send this off to be transcribed and then I’ll anonymise it. But if you want to take any of it out, if there’s anything left that you think is identifying, or just if you think ‘I just don’t like that’. Or, alternatively if you think ‘I never want to read it ever again’ because sometimes reading it is not very nice, do you know what I mean, you think ‘ooh’. There’s something about seeing it on the page that sometimes isn’t very nice. That would be OK too. And then we’ll be back in touch about how to do the digital story telling without Saturday afternoons.

A OK.

Q But before I stop is there anything that you wanted to ask me about me or about the project, or anything else that you wanted to say?

A So what do you want to happen from the information you get from carers?

Time 44:40

Q Well I think there’s multiple things that we want to happen, like you have spoken about the things that we want to happen. I mean I would like the system to change so that we have more support, that we didn’t live in a system where there’s an assumption that people are swinging the lead all the time. I’d like social workers to tell people what they are entitled to and support them to get it. I think that we would like people in the general public to be more aware of what our lives are like. This funding, there was a call-out and it was about carers of older people and adults and their mental health, and in the funding call itself it didn’t mention carers of adults with learning disabilities.

A Right.

Q You know, I mean that was from the National Institute for Health Research. How could they put a call-out and they just ignored us. So it is about raising awareness and including us in that stuff around carers, but also I think that what people are saying is, ‘we are not the same as other people because we’ve been doing it for longer, our experiences are different and so some of the interventions that you are offering for that group of carers won’t be the same as they are for us.’ And that’s the message I think that we need to try and get out there.

A I think it’s interesting as well because I don’t think carers necessarily understand other carers. For example I know someone who went to a coffee morning through a carer support and all the people there were older people looking after a wife or husband. And the girl that went got chatting to this chap and he could not understand how she could be a carer because she was caring for a child. He kept saying ‘but it’s your child’ and she said ‘yeah but I’m a carer because I have to do other stuff’. And he could not get it at all. So I think, you know there’s even that. So within the caring sector itself it’s…

And I remember when I was working for [charity] one of the girls I worked with….my mum had breast cancer – actually I’m from [northern city] my mum’s in [northern city] – and so she was going to have a mastectomy. And I said ‘oh I’ve got to go up and look after my mum’ and she said ‘are you taking [name] with you?’. I’m like ??? how would you not know that I can’t do that, you know. And I was absolutely flabbergasted that she….you know I’ve talked about [name] and I was absolutely gobsmacked. So it’s just even within the caring industry itself we don’t quite understand what’s going on.

Q Yeah. And it’s been really interesting as well that when we were planning the project we talked to different carers and different organisations and stuff and we are working with SIBS which is the siblings organisation. And they said you cannot have, when you bring people together, you can’t get siblings and parents together to do this digital storytelling workshop because the siblings won’t want to say what they want to say in front of parents. And I thought that’s so, so important.

But yeah I think that thing that everybody is different, you know everybody understands things differently. So we’ve had a lot of conversations about what it means to have mental health difficulties. So we’ve got a group of carers, they’re actually sibling carers, parent carers and people with learning disabilities that we go back to and say ‘this is what is happening, this is what we kind of do, what do you think?’ And when we talk about mental health people have very different understandings of what that means. And some people feel that they had mental health issues and this has made it more difficult; some people feel that they don’t have them and why would we think that you do just because you’re a carer. And other people will say ‘well I’ve got them now because of what’s happened to me, because of all this stuff’ you know. And I think they don’t think that they’ve got a disorder or anything, they just think if you do things to people, in the end, you know.

Time 50:00

But I think that’s important too, that when you are working with people you make an assumption about how they understand what’s happened to them, because people have different ways of understanding it. And I think that might be really important for people to know.

A Yes, I mean I wouldn’t necessarily say to someone I’ve got mental health issues because I’m a carer, but I know how tired I get and how low you can feel because you literally are so tired. And it’s relentless, that’s the thing, it’s the relentlessness that you know without respite, or for a little respite, and you know it’s just the acceptance I think of ‘this is the way it is, this is how I feel and at the end of the day I just have to get on with it.’

Q And I think it’s the time isn’t it, if you think that it’s 20 years, 20 years of caring. And that’s really different from somebody caring for their older partner isn’t it?

A Yes.

Q We’ve been doing this for years and years and years and years and I think the cumulative effect of that makes it a bit different as well.

A Yes. And it’s not like someone….you know you’ve had to adapt because as they are growing you are learning, they are changing, and you know there is different forms to fill in and… you know when [name] hit puberty you’ve got to deal with all that. And it’s not just me as well, you know if I’m not around [partner] has to deal with [name]’s period, he has to change her pad. I mean how many….

Q How many dads do that?

A Yeah how many dads do that? And how many dads actually think that that’s what happens, you know. And it’s not great, but we have no choice. I mean he has no choice, if for some reason I’m not here he has to deal with it. You know we still have to wipe her bottom because she can’t reach, she can’t deal with that, you know. Yesterday she had a real pooh-narmy, you know, and that was horrendous. But it’s just like ‘OK we’ll just have to deal with that, clear it all up and….’ But how many others have a 20 year old that you have to deal with that? That is the thing. They are not seeing….they see [name] when she goes out and they say ‘hello [name], how are you, are you off for coffee’ and it’s all….you know – no idea the things that you actually have to…you know. But it’s all part of it, you know.

Q Yeah, yeah I know. It does feel, lots of people have said it feels like hidden work that no-one really sees. And even when you’re out in public they don’t really see everything that is behind all of that I suppose.

A I don’t think people want to, because you enter a world that you don’t think you were going to enter and didn’t necessarily want to enter. So I think people will shy away from it because it’s not their world and they don’t think it’s going to be their world. But things change, you know children become ill, partners become ill. So your life can change overnight so people shouldn’t be so arrogant to think that it’s not their problem.

Q No. And just because it’s not happening to them, there are lots of things that are not happening to us that we should still care about.

A Yes.

Q Yeah I agree, I agree. Is there anything else that you wanted to say or anything else that you wanted to ask? Have I answered your question, sorry?

A I don’t think so.

Q OK. So we will be in touch. Thank you very much for talking to me it’s been a real pleasure to meet you and thank you for taking the time.

A No, thank you.

Q OK and we’ll be in touch with you. Thanks so much.

A Alright, thanks a lot.

Q Take care. Bye.