Q So to begin with do you mind just telling me kind of a little bit about kind of where you saw the project and what made you interested in taking part.

A I think I saw it through [charity], and I think it’s the first time I’ve actually seen a chance to sort of be represented somewhere. I’ve seen it through Project Artworks which was at the Turner Prize in [town] and I was thinking ‘that’s really good’, so when this came up I was like ‘oh, I’m going to give that a go’ kind of thing. So yeah. It’s really important because of my age group, so I’m 54 and grown up in the 70’s with a sibling with severe autism, learning difficulties and sensory processing disorder but not diagnosed until his 30s. So it was really, really difficult, there was no representation at all apart from like Peter and Jane books for children. So for me it was like I thought no, I’m just going to have a go at this because it’s really important.

Q Oh brilliant, well thank you very much. And I know it can be a challenge to find the time and stuff to take part in stuff like this, but yeah thank you for doing it. Do you want to tell me a little bit about kind of your experience and just kind of…yeah, what your situation is with your sibling and….yeah.

A So I’m not like a direct carer so I don’t do every day care. Oh gosh this is quite….so I call myself a distance carer. So I’m his deputy through the Court of Protection so I deal with his finances and then oversee and read his care plans. I also attend meetings and do end of year reports; and I authorise payments that need to be made, such as mobility vehicles; recently it’s a new summerhouse. But also I get calls in the middle of the night if he’s ill. Like recently I had to miss one of my really important appointments to sort of be on attendance for him because he wasn’t very well.

Q So very heavily involved then kind of, although you ???

A I’m very heavily involved. I mean I hear from….I have my email, because I have an email especially for him and sometimes I just think oh I just don’t want to open it today because I know I’m going to have to deal with something. That’s really difficult. And I see him about twice a year and then I’m in regular contact with his care staff probably every week really. If it goes a week and it’s like ‘oh OK, what’s happened’ kind of thing. So yeah. And he lives like in a specifically built complex for…I think they have six adults there and it’s mainly men. So he has his own bungalow with his own tenancy and his own motability vehicle. So yeah it’s specifically built by [charity].

Q OK. And how is the situation coming back then for you kind of overseeing everything and being so involved, how is that?

A How did it come about?

Q Yeah, what led to that?

A Well because I’m his sister. I mean….yeah. So when was it? It was 2016. 2016. Previous to that, 10 years previous to that he’d been in a hospital setting, you know lots of autistic people are in hospital settings, but it was in this kind of ex sort of mansion. The people that did, I don’t know if you’ve heard of the Winterbourne scandal.

Q Yeah of course, yeah.

A Yeah. So the people who owned my brother’s place were giving him the care kind of thing and then it became [place name] after that. So he was there in that setting for 10 years, because previous to that he was in [county], and previous to that he was in [country in the UK] which was loads of abuse going on there but we don’t know what happened to [brother]. So I became involved…. I mean I’ve always been involved and been going to meetings since I was 14, so I’ve been going for 30 years now, and [brother]’s only 17 months older than me. So we started going to meetings in [country in UK] and then I had quite a big break of about 10 years where I really didn’t go to the meetings and I had my family, my first child at 26/27. And then I kind of just got reports and just read them and saw him when I could, because I was living my own life, I needed to have my own life.

Time 4:45

And so then when I moved here, so probably about 21 years now it’s quite a while, I’ve been getting reports, going to meetings. But then when my dad died 12 years ago – well previous to that a little bit, he didn’t want to be involved and he found it really depressing going to these institutions. I mean they are horrendous places. And so then I stepped up in 2016 and became his appointee because they wouldn’t allocate a social worker, and there aren’t any social workers to do that really, they prefer the family do it. So yeah I’ve been his appointee since 2016, so coming up 8 years. Yeah. And I’d prefer that somebody else did it in a way but I just don’t find the system to work well enough for that. People in authority are not making the right choices for [brother] and they will not always spend his money wisely. So I’ve had to step in because there’s nobody else to do it really.

Q OK. And yeah how are you finding it then, you obviously said that there are some days where you kind of don’t want to open your emails.

A It’s very stressful to be honest, it’s very….. I’ve had to kind of like really sort of change my mindset about how consumed I get with the injustice of it all, because so much is wrong, just so much is wrong. You know like you could be working in Amazon one day and then working with my brother who has complex needs. And I was thinking it’s like sending the cleaner in to do brain surgery, you just wouldn’t do it. So I’m just met with like a lot of incompetency with care workers who don’t know anything about autism, or about my brother, or complex needs, or sensory processing disorder, and they’re just taught on the job. And I’m like where do you do that? Like even the cashier at Tesco doesn’t learn on the job, they have training and stuff. And they do give them training but it’s too complex for I think your average Joe Bloggs to take on the work. So yeah it’s very, very draining emotionally and mentally.

Physically as well, like when I go to the meetings when I do….thankfully they’re on Zoom but when I was going in person I felt I had to go to a park to walk it off, the mental load, because I just thought I’m just not coping with these meetings. Because it’s with psychiatrists, you know people who are dealing with millions of pounds and you’re deciding about peoples’ care and I’m going I’m just like your sister, you know, and I’m kind of like making it up as I go along and learning as I go along. So yeah it is. But then there’s nobody else really to do it, this part. So I think well I’ll have to do it and then try to adjust how I react to situations, which is….

Q And how is that working?

A Well recently, I mean as an example I was meant to go for like complex sleep studies overnight, and my brother’s place phoned and I had to cancel that because he’d had some drooping on one side of his body and I thought oh my God well I can’t go and do this. But then afterwards I thought, well usually I do go in a bit of a spiral of like ‘oh my God he’s going to die’ or whatever, you know what would mum say, you know ‘oh my God’. And then I was like ‘right, I’m just going to have to like draw a line under this, I’m going to have to park it over here, put it in a little container, leave it there, I can do nothing’. Because the paramedics were saying do you want us to take him to hospital, and I was going well it’s not my call, it’s not my job to decide what you need to do. And I used to get quite consumed by that, and then I think actually no, it’s your job, you’re looking after him, you’re getting paid. I mean it costs hundreds of thousands to keep him there every year, it’s not my job. So it’s sort of like, you know changing my mindset. But it is quite difficult because it’s always running in the background you know like a programme, you know how he is today and you know have got the energy to ask or phone. And I think well he’s fine, he’s being looked after. So yeah.

Q And you said your dad didn’t want to do it any more because he was struggling with it.

A Yes.

Q Was that then a conversation you had with your dad, is it something you always knew was going to kind of come to you as you were growing up, if you were involved in it.

A I knew it would. I knew kind of thing it would come to me eventually, but dad didn’t say anything, he just said ‘I’m not going any more’. You know he didn’t discuss anything at all. No he just said I’m not going, which was really upsetting because I was like well you need to go, he’s going to be really upset you’re not seeing him obviously. And then he died. So [brother], you know they just said he’d died kind of thing, and it was like….I don’t know how [brother] reacted, because he’s not non-verbal but he’s very….he doesn’t talk, I’ve never had a conversation with him. So yeah. So it was passed on to me. Because one of the commissioners, that was it, she approached me about who would be his appointee after he left the hospital, and they like family members to do it obviously because of accountability and so on. So yeah, no discussion, it was just like ‘it’s there, you’ve got to do it’ kind of thing, which is really frustrating.

Time 10:14

Q Yeah. And am I right in thinking then kind of you’d prefer someone else to be doing it but because you can’t trust them, you know other people they don’t make the right choices for him, you’re kind of….so it’s kind of….

A Yeah. I have approached the Office of the Public Guardian who I have to give accounts to every year and also [charity] about doing a joint deputyship but they haven’t got back to me, they’re very, very slack at returning emails and stuff, and then I have got to go through the emails and go ‘oh God I haven’t acted on that, I haven’t had a response on that, oh I need to do that’ kind of thing. So that’s in my Inbox still. Because it would be nice to think ‘OK you do that, you spend the money’ but then I get a breakdown of what’s happening, rather than someone just having sole responsibility of it.

Q Mmm, I guess it’s kind of more work to kind of trawl through your emails and kind of chase it.

A It is when there’s so much at the minute like with his motability vehicle, you know they’re using an electric one and it’s shared. There’s just a couple of big things that just keep like ticking over because it’s not finalized, you know it’s emails backwards and forwards, backwards and forwards about it. Because they need my say-so because I have to buy the thing, and then they want me to find it, and I’m going ‘no you find what he needs’, I’m not doing that work because that’s like trawling the internet for, you know a needle in a haystack kind of thing. So I’ve had to be quite sort of tough and go ‘no, sorry, you do that, that’s your job’ and they don’t want to do it.

Q Kind of being assertive.

A Yeah delegating, which is tricky.

Q Yeah. Do you mind just being a bit more explicit then about the impact it has on you, either now or kind of growing up as well perhaps if you were going to meetings from the age of 14 and kind of what that was like for you.

A Gosh it’s quite long isn’t it, you’ll have to remind me halfway through I know I’ll probably detour.

Q That’s fine.

A Growing up. I’ll try and sort of stick to those years for a minute and then go on to the other bits. Yeah so he started going into respite care when I was 13, so he was probably….I was 12/13, he was 14/15. Because he was really….well you would say he was violent but really he was just distressed at home because ??? of the environment. So then I would go to the, it was called [place name]. So it was just basically some houses on an estate where we could leave him – who knows what happened to him, my God, I dread to think, it was the early 80s so who knows. See that’s another thing, you just don’t know what’s happened because he can’t communicate. So that was really difficult. I’d visit and I remember like just having to wait in like really strange like empty rooms with people shouting in the background, you know distressed, upset or whatever and me just like…. And then I remember playing with some of the toys, like little Fisher Price toys while I was there. So I remember that occasion.

And then as I got a bit older, because my mum didn’t drive and my parents were divorced by the time I was 13 – that was difficult – and so the social worker, thank God we did have a social worker for about 6 years, she was very consistent with us which was great. And she would drive us to [country in the UK] where my brother was then taken from [town] because there’s no place near….you know like now, still, there’s no places near relatives home. That’s 40/50 years later still the same situation so it shows you this lack of willingness on the government’s behalf of actually tackling this issue. So yeah she would drive us from [town] to [country in UK] in the depth of snow and all sorts twice a year, every six months we’d go for a review, or every 3 months. And then she left and I went to uni.

And then kind of from there I didn’t really….I just got the reports for quite some time, probably 9 years, where I was at uni, moved to [city] and then started a family. It was only when I moved back to [town] that I kind of became a bit more involved, because I sort of expected my dad to do it really because I thought it was their responsibility, not mine you know. And then just saw him when I could. So yeah. So what else? I know it was quite a complex question that one. What else did you want to know?

Time 15:06

Q So yeah it was just kind of, I guess, the impact on you really in terms of….yeah, mental health and….yeah.

A I think….I’m just exploring that, I’m in therapy at the minute because I’ve got complex PTSD and some of that is from childhood I think, being brought up with a sibling with severe learning difficulties and autism and everything. So I would say, like you know you read about glass children, so I didn’t get what I needed as a child, like my needs went unmet kind of thing. Which I’m just literally exploring the last year or so, like in a child work? and so on and realising it’s had a massive impact all through my life, and then obviously making me have bad choices as an adult. Although my nan was my attachment figure because my dad left, and also he drank so he wasn’t really there. And he was a tarmac-er so we’re really working class, he was a tarmac-er and he was out at 6, back at 5, pub at 6, never saw him really. And so he couldn’t cope with [brother]’s behaviour. And then mum couldn’t cope. And then there was so domestic violence and a suicide attempt as well. So there was quite a lot of heavy mental health issues that were never talked about kind of thing, and mum never got any help.

So then of course me being 17 months younger it was almost like ‘well you’re OK’ kind of thing because you’re normal, you’re getting on alright. But I wasn’t, it impacted me greatly because [brother] needed all the attention so I didn’t get the attention I needed, which was really, really difficult.

Q And were you aware of that at the time or is it something kind of with adulthood and hindsight that you are able to look back on.

A No I wasn’t aware at the time I don’t think, I just felt quite jealous. You know all of the things as a young child you feel kind of thing and you think ‘well why do I feel like I am’ like I’m in a family, you know you just don’t realise what it is, you’re a child and they were attachment figures and so on. And so no. But it has, it’s been a massive impact. And I think it’s also impact me, you know being conditioned as a woman in the 70s into the 80s and so on and then taking care of other people and the responsibility of looking after other people. And it’s only in the last kind of few years I’ve started to go ‘no actually this is what I need’ kind of thing, pulling myself back into…because I’m an artist so I’m pulling back into my sort of art profession. So yeah it’s a big….yeah. We’re just not looked after kind of thing because a sibling needs all that time and attention because of their behaviour, because they can’t live in a normal house as such, because he’d just clear every work surface because it was visually upsetting. So I had a lock on my door, on the outside of my door eventually, to stop him going in and ransacking it kind of thing. Yeah.

Q And did you get any support as a child, kind of externally, or any kind of acknowledge of the position you were in?

A No not at all really. It was almost in the 70s. So I was born in 69 so I grew up in the 70s, 80s teenage years, which were great years really, especially for music and stuff you know, it was good for me I think. But no there was nothing. And yeah it was almost….I never admitted to having a brother with learning difficulties. Because I knew one other family who adopted like three Downs Syndrome kids, so I got in with their sister, we were like in the same year and stuff and we used to go and play music together in her room and whatever. But it didn’t make me a latch key kid because I didn’t have a key, but it made me that kind of like ‘well there’s nothing at home so I’ll go out and look for that kind of attachment’. Very detrimental you know and children shouldn’t be doing that kind of thing.

Q Yeah. So really it had a kind of profound impact then on, like you said, kind of who you are in your adulthood or early adulthood.

A Yeah, because it’s like I feel like I have to look after myself. And it’s like actually you don’t have to do that kind of thing. When I found [charity] I was like ‘oh my God, that’s great’. I found them a few years ago, I was like this is really good that people actually get…like with my brother’s situation the other night, I just went on and said ‘look this is happening’ and they understood, you know I didn’t have to explain things. So with my brother is was like I’m just ashamed of him really and I felt bad that I felt ashamed of him because he wasn’t like normal as such, you know. And yeah. Because there was nothing, there was no representation anywhere, in the news, it didn’t seem on TV, at school you had to be normal.

Time 20:34

Q Yeah. And I guess if you’ve got parents as well who are struggling with the situation then that’s not necessarily modeling to you that kind of openness and….

A Oh God no. I’m only learning through my kids really about, you know attachment parenting. I’ve been practicing that since….my oldest is 27 so I’ve been doing that since they were born and stuff. So yeah it’s learning. Yeah it’s a lot of…. And now different generational learning with the third child, he’s 11. So you know I mean it’s just completely different. Which is good, it is a good thing but it is very, very challenging not having any groundwork in it kind of thing, you know.

Q Yeah. Do you mind me just asking about, kind of you said obviously you’re in therapy now and some of the post traumatic stress is related to your childhood then and that situation. Was there something specific which prompted you to get therapy now, or have you in the past kind of tried and things, or kind of….do you mind just….obviously don’t speak about anything which you are not comfortable with but I’m just curious as to how that’s come about and how it’s….

A I wanted to have therapy because of childhood trauma and stuff that happened at school. And we got to COVID and I was just like ‘I don’t want to die like this’. I literally was like ‘shit, I really don’t want to die feeling like this’. And also, getting to my 50s, I’d just turned 50 so I was like ‘I’ve just got to do it’. So I started therapy in lockdown, the first lockdown in the like….I think it was May. Yeah.

Q So that’s a tense lockdown experience then.

A It was, it was the best thing. I should have done it 20 or 30 years ago but I didn’t have the money and stuff, resources, bringing up kids you know. But I was also in therapy beforehand, because we had a fourth child who sadly passed away in 2016, the same year my brother moved out of hospital we lost [name]. He had a genetic condition called Edward Syndrome.

Q OK yeah.

A So he was with us for five and a half days, and the majority of my artwork kind of centres around my grieving process kind of thing and how it’s changed over the years. Yeah so I went into sort of specialist bereavement therapy for baby loss, and I was in there for 3 years. And then that finished, came to a sort of natural end as it had to in I think February 2020, and then I started with my childhood trauma in the May 2020. So I’ve kind of been in 6 years in therapy but for different reasons obviously.

Q Yeah, sorry I’m not….that’s terrible timing to have to wave around.

A I know, I understand.

Q I just don’t want the camera to go again. Yeah, and are you having to pay for it privately then now, is that….

A I am yeah. The other lot was free because it was a charity, and The [Name] were absolutely fantastic, I just don’t where I would be without my counsellor, she just encouraged me to get back into art and like expressing myself. And I’d done photo therapy and stuff at college and I’d done art for 6 years as well and I trained as an artist. So it was really like I’m just so….like yeah, I can’t express how good it was for me. So yeah but now I’m having to pay, so it’s very expensive but it’s just worth it kind of thing. I know I’ve got a long way to go but…yeah it’s brilliant.

Q That sounds kind of positive at least, you know that you’re on a….

A It is really good, yeah.

Q Is there anything kind of else, obviously the therapy is a big thing but have you found anything else then supportive over the years, or kind of what helps with mental health I guess?

Time 25:00

A I don’t think I….I kind of just didn’t acknowledge how it was affecting me at all, I just thought I’ve got to do this, it needs to be done, much like of being a child ‘I’ve got to get on with this, it needs to be done’. And I just didn’t acknowledge the toll it was actually taking on me, you know sitting in meetings with psychiatrists, with commissioners, with support workers, with managers, and remarks you know and loads of….I just didn’t look after myself well enough. And when I started realising you know after meetings ‘I need to actually go for a walk, I can’t go from a meeting to come home to look after my child, I actually need to walk in the park and look at the trees and wind down’ kind of thing. And now I’ve acknowledged that it is a lot easier. But it’s changing my mindset of how I have to detach myself emotionally from it, which is really upsetting you know. But it’s so frustrating I can’t change anything and I find that really frustrating.

Q And is it just you and your brother, do you have any other siblings?

A No it’s just me and my brother, yeah.

Q So I guess you’ve got no-one else as well to share any of it with, either kind of emotionally or you know the actual workload, you haven’t….

A No. I mean my husband listens and he was really good, he filled out my brother’s PIP form because he’s really good at filling out forms, which was great. And he supports me like looking after [son]. And he’s driven me – because I’ve got ME, I’ve got chronic fatigue since losing [son] – so he will drive me to [town] sometimes. A couple of times recently I’ve driven myself, which is nice, I’m getting a bit better. So yeah my husband listens to it all and he’s just as frustrated as I am. It’s just like he’s just kept alive in care. And it seems the country over you know.

And like [charity] groups, I’m on a What’s App [charity] group so that’s really helpful just to know that somebody’s there and I can just off-load. I tried a local [charity] actually, the [city] one, but sometimes I miss the meetings because they’re in the evening and something is happening and whatever you know. But there’s been some away days but they’ve involved like a spa and an overnight thing, and because I’ve got CPTSD like one of my triggers is night-time and I just think I can’t really access that. And I don’t really want to be in a spa and swimming pool with loads of strangers, and it wasn’t really for me kind of thing.

Q Yeah I think that’s coming across in these interviews that it’s definitely not a one size fits all in terms of what supports people could benefit from. And you know the various groups that [charity] organize it’s very much some people feel they didn’t fit in there, and other people feel for various reasons, you know they….

A Yeah because the last, like the big one was like meeting in [city]. And I thought like, you know I’m only an hour from [city], I lived in [city], but like that’s your hour travelling and then you’ve got to socialise. And I highly suspect I’m on the spectrum and I’m kind of exploring CPTSD and Autism overlaps and so on and you know I’m going to go for a diagnosis at some point, my son was just diagnosed a couple of weeks ago.

Q Oh OK.

A So yeah it is really difficult. And everybody’s going ‘oh it was such a great thing but it took me a day to recover’ and I thought I don’t have a day to recover. I don’t want to like put that much onus on myself. So I prefer a bit more low key. And then, you know socializing, it takes so much energy because it’s like really….yeah. So I like the meetings, the meetings are OK sometimes. But sometimes like people just off-load so much shit and you’re like ‘oh I really understand where you’re coming from but I don’t actually have the mental energy to sort of respond’ and then that seems a little bit rude, and I’m like ‘oh….’ So I just have to cut myself off from that as well to preserve. Because otherwise I’m thinking about it when I go to sleep, because all these meetings are at night-time and I’m like…. Yeah so it does get a bit isolating really and you think ‘well I’ve just got to get on with it’ ???

Q Yeah, if going to a meeting then becomes more work and more effort and more kind of emotionally draining, then the kind of….yeah, you want the benefit don’t you but you don’t need to add to your difficulties, yeah. Is there anything which you would find helpful? Obviously the therapy you are accessing, but is there anything else which you think… and like you feel your [charity] What’s App group kind of.

Time 30:00

A Gosh, I mean it would be really helpful if the government paid support workers the correct wage for the job. And that the support workers were adequately trained, they knew what they’re doing and knew what they were talking about and they came to me in meetings….I mean I’ve had managers and commissioners come to me and suggest all sorts of ridiculous things that you’re just like ‘how did you get that job, I should be doing your job and you’re getting paid 100 grand a year, why are you suggesting stupid things’. And you have to sit there and just talk very politely and not get angry, which takes a huge amount of energy as well. But yeah I’m not too sure really. Yeah so I mean the training would be really good. I mean sharing the responsibility would be really, really helpful with [charity]. I don’t know. I mean you see these pamper days and all this other stuff don’t you and whatever else and I’m like….I don’t know it’s….I don’t know, it doesn’t really help me in the needs in front of me kind of thing. It’s nice to talk about it but then I’ve got to listen to somebody else who wants to talk about it. And I’m like well I don’t really want to because, you know, it’s that, I don’t want to like carry your shit as well as my shit kind of thing, you know.

Q Yeah, and it’s still there for you to get back to after the pamper day isn’t it, it’s still….

A Yeah, and then I’ve got to recover from travelling and then recover from the socializing. I mean it is great and then you know I do miss….I don’t know, when I’ve done things like that it is nice, but then it does take a long time to recover. It’s really difficult. So I think having the resources for my brother there in the first place that didn’t make my job so difficult, or make more sense, because then you wouldn’t need those things would you? But that’s a governmental ministerial changes isn’t it really rather than….you know you’ve got to get the correct workers in the job.

Q So fixing the actual issues rather than kind of putting plasters on the top isn’t it?

A Yeah. I mean I just don’t understand why you would send somebody in who doesn’t know what they’re doing to look after somebody. You don’t do that anywhere, in a hospital nurses don’t get….that doesn’t happen with nurses or doctors, and my brother needs the same level of care.

Q I mean it sums up doesn’t it kind of what’s wrong with how people can be treated.

A Well it’s a hangover from 1900s and the psychiatry system and stuff, it’s all the same isn’t it, it’s like labelling women, it’s just all….I understand it but it’s just like it would be nice if somebody could….or you know ministers could step in and change it really.

Q Yeah. Do you think – I mean feel free not to discuss it if you don’t want to but do you think about the future for your brother and for you in your role kind of….

A Well I just….I mean the other night when we were called I thought ‘God if he dies’ like how the fuck is that going to happen? He can’t even go to the hospital you know he has to wait in A & E. And I thought for the future, you know people with learning difficulties die at least 10 or 13 years, so I’m expecting that within the next 5 years probably. So I’m just worried about how that’s going to happen, especially if it’s like cancer or something long and drawn out, how will they keep him sedated in hospital and stuff? I mean it’s really difficult. I don’t really see….I just see him happy in his car go to McDonalds, the car’s on wait, and there’s nothing, it’s just the same old, same old because they’re not being very pro-active. And if I wasn’t there….because they say ‘oh gosh I wish all our service users had a sibling like you’, and I’m like ‘my God, poor fucking people’ like they must be desperate. Because it’s just basic for my brother, it’s nothing unusual. So no I don’t, I just see the end almost. I know it’s….I just see him plodding through each day and every week, and he likes going out in his car.

Q What’s that kind of like I guess seeing that for your brother?

Time 34:40

A Oh it’s horrible. I mean it’s been horrible for years. But it’s just now acceptance because the government doesn’t want to change anything, they don’t want to make autistic people’s lives any better really. I mean if they did they would have done it – and I’ve seen it, I’m 54 and I’ve been seeing it for 40 years now. So yeah it’s very, very disheartening. And at one point I thought well I’m going to start a campaign to get this changed. I thought ‘actually I’m not going to do that’. I would have been really good at doing that but I’m not going to do that because actually I don’t have the energy to do that. You know I’m 54, I’ve probably got another 35 years or so, what do I want to do with my life? So it’s really, really disheartening to think what it could be and what it is, and that’s horrible. But your hands are tied, you know it’s just how it is, you just do the best to keep him alive, fed, warm and as happy as possible really in his own way, you know. So it’s very disheartening.

Q How do you kind of make those decisions then, kind of you know ‘I need to prioritise this’, which is you know absolutely you do, but how do you do it?

A How do you do it? I mean I haven’t done it for years, that’s the trouble, I should have done it a long time ago. Probably because of my upbringing and my conditioning as a woman, I’ve done that. How do you do it? Over time. You do it over time with the realization that’s nothing’s going to change, it’s not actually going to change. If it changes before I die, great, but I really can’t see it changing. It’s not changed in 50 years, is the government suddenly going to turn round in the next 5 or 10 years? What are their… you know all their Bills that they put through, is that changing, is it changing support workers, is it changing people’s general outlook – no, it’s actually got worse. Yeah it’s not changing.

Recently I applied for a job with someone called the [name] Foundation and it was a perinatal support worker for…and it was with the NHS but with also the charity. And I got an interview and then I was like ‘I’m turning this down’ because I know what it’s like to work for the NHS. I know what it’s like because I’ve been working in this voluntary role for a long time. And they want to give women CBT who have lost babies, and I go ‘CBT doesn’t work for trauma’. And I thought I know what I’ll do, because it’s already been written and they’ve got their 5 years, 10 years funding for this project, I thought why would I bang my head against a brick wall trying to change something. So you just go ‘that’s them, I’ll leave it, I can do nothing about it, I’ll carry on. And there’ll be other people and pockets of people and organisations who will try and change it too, but actually what do I want to do?’ So yeah it’s very gradual I think, that realization, the sort of listening to your own needs. Which is really difficult because I’m not conditioned to do that. So it’s really, really hard but it is worth trying.

Q Yeah, and it sounds like there’s obviously still challenges, because something that you said earlier that you had to miss appointments because something to your brother crops up so you have to miss important ones for you. So it’s obviously….

A Yeah I had to miss that one, I thought I can’t sleep. Because if they phone up and I have to go in the middle of the night I thought ‘oh my God I can’t….’ I didn’t want to do it anyway, the sleep study, so it was quite opportune but I wasn’t able to do it. So yeah.

Q Is there a kind of….you’ve mentioned your partner, your husband is very supportive. Is there an impact on your family of kind of your caring role and the stuff you do for your brother, is there….

A There has been when my girls were growing up, they’re 27 and 22 now. Yeah there was a lot of stress. Because I was very disregulated about it, I wasn’t in therapy and I was taking it all on board, very personally, emotionally sort of like digesting absolutely everything. So yeah. So they had to listen to it kind of thing. And then I kind of expected my eldest daughter to take on the role that I was doing, and she said ‘I’m not doing that’. And I was upset about that and I thought ‘actually why is it your job, it’s not your job, he’s your uncle, you’ve met him once in 27 years’. And that’s another thing, they’ve never….my other children, they’ve never met him because you can’t have children there where he lives because it’s not safe because he might lash out, you know it’s just not safe. He’s hit me once since he’s been in another place.

Time 39:46

So yeah it has taken a mental toll you know because I have to process what’s going on and then reading reams of reports. And then doing research for my brother, like for Irlen Syndrome and about Autism and about his medication, and they won’t take him off some heavy psychotics, they still haven’t done and so I’ve given up trying to persuade anybody. And you think about that, I thought well that’s there call isn’t it with the psychiatrists. So yeah. Recently it’s not been so bad. Although we had like our first holiday after COVID that my brother’s place phoned up as we were having our first meal out together as a family in like 3 years. And like the paramedics had been called out because there was a choking incident because some idiot had given him bread and he has a dysphasia diet and….

Q Oh my gosh.

A I was like ‘oh my God’ like. So I thought I had to leave, I think we were in [seaside town] and I thought oh God I’m going to have to drive to like [town]. But he was OK and I just left it, but I’d kind of learnt by then to kind of like ‘right he’s there, I can do nothing about it, if the shit hits the fan I will go and obviously do what I need to do’. But yeah. So it is, it does have an impact on them because then their holiday is interrupted. And then I’m getting phone calls when we are travelling to the seaside and everybody has to be quiet because I need to listen to the paramedic talk and….it’s like ‘oh my God, this is like never ending, never ending kind of thing’.

Q And it sounds like it kind of lurches from one thing to another.

A It does yeah. There’s been a few instances in his new place. He’s had the paramedics call out about 4 times now and he’s been hit by the ‘service users’ as they call them, which I’m just like that’s not humane is it you’re ‘service users’. Well it used to be ‘mentally handicapped’ and then it was like you can’t use that any more now, it’s like autistic, which I think is….but anyway. So yeah it does, it impacts sort of every area I think. Although recently I just don’t talk about it so much because I’ve managed to sort of park it there when I need to. But I don’t want to like burden the rest of my family, you know.

Q Yeah. It’s tough.

A Yeah it is really tough and it’s like unseen. And when I went to the Turner Prize, it wasn’t last year it was the year before I think – or was it last year….no the year before, and Project Artworks, I don’t know if you know them?

Q No.

A They’re in [town]. And a lady called [name]…I can’t remember her second name, anyway [name], she’s got a son who is in his 40s with learning difficulties and she set up art workshops so basically people with autism and learning difficulties are artists, you know they can do their work. But anyway, so I went to….I was with Mothers Who Make [town] which is like a grassroots sort of like mothers artists kind of thing, I went on the tour, and as I walked into their exhibition space they had this thing called….I think it’s called Circle of Care. And it was this thing that [name] had drawn and it was all the roles. Like you’ve got your person in the centre and then it was all the roles that are created, or all these things that are needed to support one person with autism. And I thought oh my God there I am, I’m represented at last in some artwork. It was really good and I’ve been friends with her ever since and we’ve had several workshops. And they even tried to get my brother to come to [town], which they drove him there to try and take part but he wouldn’t get out of the car to take part. So yeah, so how have I got to that?

Q Yeah it sounds like very much then that kind of….you started off about kind of when I said about kind of why you are interested in the research and it was about, you know you’re not represented anywhere. And I guess again if you found this artwork and it’s about representation that’s obviously a key thing about sibling carers, it’s about being representated is it then, and it’s about people understanding kind of ??? or…?

A Well you’re not represented. I don’t feel I’m represented anywhere in the media. I mean you get programmes about autism don’t you, like David Tennant and whoever. I avoid those like the plague because I just think they’re just not my life at all, my life is far more horrific with my brother’s behaviour at the time as we sort of knew it. It’s just not representative at all, it’s very, very airbrushed. I think the closest you get is Katie Price and Harvey with his very obvious needs. And my brother is like that, you know breaks things and everything because he’s distressed and so on. No it’s not represented. Which is really difficult because then you forget, you know you are getting on with your everyday life and people are walking around like normally and you’re like ‘what?’ It’s difficult.

Time 45:10

Q Yeah. What if there was greater representation I guess, what would that mean or how would that change things? I don’t know if that’s a tricky question.

A I expect more people would understand wouldn’t they really. So if you talked to someone they would get it straightaway, rather than having to speak to a specific group of people on a What’s App group.

Q Yeah OK. So which is ???

A Yeah I go out with friends and like they’ve got normal kids as such, neurotypical. One friend’s son is autistic and lives at home and so on so she gets it kind of thing, but the other two just don’t. Yeah one of her sons is autistic but he’s like studying physics at [city university], so he’s the other end of the spectrum. And it’s almost it’s still really secretive, it’s still very like a shameful thing, it’s very like ‘what do you mean he does that?’ People just have no comprehension. Like baby loss, you know you mention that and they’re like….

Q Yeah.

A I get it, you know I completely get it because I’m on the other side of it, but it’s the same for really severe autism, you know it’s like people don’t understand the behaviour, they think it’s badly behaved. And if they do understand or they try to they’re very quiet and they’re like ‘I have no idea what to say’ kind of thing.

Q Yeah, yeah.

A Yeah so understanding, like books, God books at school for kids. I mean the thing is we’re almost segregated at 5 aren’t we, we’re all put into like our little pockets and then we just don’t meet anybody apart from ourselves. And if you are different you get bullied.

Q Yeah, it’s that like representation that’s not only for you but for your brother as well, a kind of….if they….yeah, and reducing that isolation then.

A Yeah it is very isolating, I mean I can’t really see that changing to be honest apart from like the small pockets with [charity] and….and that’s all I know really, I don’t….yeah. I’m part of the Autism Society but I don’t really do anything. I post some things on the group sometimes, I haven’t done it this year so it’s very rare. And I do a lot of….I mean I’ve done tons of research on autism, like God I should go and like do something with it, but mainly into sort of women and sort of masking and so on. You know I do like research. I think that’s why I wanted to take part in this, I thought ‘oh that sounds great’.

Q Yeah. How did you get in touch with [charity] then or how did you come across them, if you kind of hadn’t before and you said it was years ago?

A I don’t know if it was just on Facebook, or maybe I was searching for my brother’s stuff. Because once you know the internet took off years ago and ??? and then I found out about Irlem Syndrome and then I realised I had it, and that’s why I wear coloured glasses. And then I started researching loads and loads and I was like ‘oh OK’. So maybe it was….it was probably on the internet. ??? is great, I so wish I had that. And then you see a picture of like children and go like ‘where’s me?’ like I’m 54 and that should have been me like 45 years ago or more. And it’s just not, it wasn’t, and it’s….yeah. And I dare say there are still kids the same now that are slipping through the net, you know being brought up with people who are neurodiverse. Which is fine isn’t it but it’s just their needs are not being met if they are so severely challenged.

Q Yeah. Has there been anything offered to you kind of as a sibling or to support your mental health which hasn’t worked and kind of you wouldn’t recommend?

A Well not much has been offered apart from through [charity], and like I said that day away really didn’t ???

Q No.

A I expect it’s just talking about it one-to-one maybe, like I’m talking to you about it, and like not having to do the other person’s life because….

Q I am not going to tell you all my problems!

A Yeah. No but because you understand and it’s just….yeah. So no I don’t think….no. Yeah there’s just not much out there really I don’t think.

Q Yeah OK. And kind of would that be as a younger child but also now as an adult as well?

A Yeah. I don’t know. Unless I’m not looking. I mean maybe I should go back on the internet and have a look and see if there’s anything else.

Q Yeah it sounds like you’re doing a lot of work kind of looking and researching and stuff so I’m sure you’d have found stuff if there was.

Time 50:00

A Well I think I would have found it, yeah you would find something. And the [charity] group, they must know loads of other things as well because they’re sort of in with everything else. And when things do come up you know they say ‘let’s have a festive evening’ and blah, blah, blah. I just think, oh God I just don’t want to kind of thing, like I just don’t want it because really what is it going to do at the minute, at the time and…yeah. I think it’s just off-loading to somebody about it, not in therapy because that’s a separate issue kind of thing. Because when I saw Project Artworks and I had a chat with [name] who runs it and she went ‘oh do you realise you are suffering from a trauma from like childhood with your brother’ and I was like ‘I think yeah, I must be’ kind of thing, you know like I didn’t realise….because it was normal, you know it was normal for me. I knew it wasn’t normal as such because nobody else was like it, but for me it was, you know accepted kind of thing, you didn’t ??? this kind of thing. So yeah.

Q It sounds like as well kind of strategies which really helped you really come from you and your kind of self-development for ???

A Yeah I’ve had to assess my situation.

Q Yeah.

A Yeah and say ‘actually these things aren’t working for me’. Like meetings specifically, but thankfully I don’t have to go to them in person at the minute. But the other thing is, like I visit my brother and I can’t really sit in his place because he can’t really tolerate people in his environment, and if I do it’s always with two other support workers and they’re always talking to him in a funny manner and I don’t like it. So that’s really….it’s really horrible. And I’m probably going this Sunday actually to drop his present off, so yeah.

Q And how would you like the visits to be like, or how could they….could they be done differently?

A Yeah we have talked about that. Because I bought him some art materials because he does like doing things on paper and so on, and I said ‘oh how about if we do that, have a little bit of a focus kind of thing’. But for [brother] it’s what kind of mood he is in the day. I mean I might turn up and he’ll see me for literally 30 seconds and then ‘see you later [name], see you later’, because he uses ??? borrowed phrases and so on. And he’ll go ‘bye now’, like ‘bye now’ and literally I could be there for a minute. But sometimes I could be there for 30 minutes, 10 minutes, and then I’m just hanging around in the cold standing outside. And I think I can’t really do this, I haven’t got the energy to do that. So yeah we had talked about sort of meeting in a park, but then he doesn’t always get out of his vehicle. Because he’s got trauma and I’m trying to….because they don’t have a psychologist anymore, like a clinical psychologist, so a speech and language therapist, so I think, well I’ve given up trying and I’m just like ‘well when you get one like let me know’ this kind of thing ‘because we need to address his trauma’, because he’s got trauma from his….well abuse that’s happened to him in the past. So yeah. I don’t know, it just plods along I think. So I don’t know how to do things differently I don’t think, because it’s almost like there’s not the opportunity to do it really – or we haven’t found it.

Like he used to love going to soft play when he was in [city], but they haven’t found one. That’s the trouble, like I suggest all these things and ask all these questions and whatever else and then I forget about them because I’ve left it with them and then I go six months later at the review and ‘oh what happened to that’ and they go ‘what was that’, I’m going ‘yeah but that was….’ And then a learning disability nurse says ‘well why haven’t you done that’ to the organisation, and they go ‘oh we’ll look into that and get back to you, we’ll do an independent report. And you don’t get the report and you go ‘oh fuck, I was meant to chase that up’. And I go you can’t keep chasing up adults like who are paid to do this job, just drop it.

Q Yeah it sounds like you really have to kind of pick your battles then in terms of what to pursue with them or…

A Yeah you do with them really, I think so really. Because then when you do get a bit testy kind of thing you know you get….and I had one woman, like I really challenged them and then they accidentally sent me the email, like a private email and I shouldn’t have got it, and they said ‘oh well we really don’t want to be like in that situation with his sister again’ and I thought ‘oh’. And then they had to apologise and then review why that email got sent to me instead of….you know it’s just.

Time 54:50

The other thing is like you know you don’t want to like upset the apple cart because you don’t know how they’ll treat [brother]. Because I’m not there, there’s no cameras there’s nothing, and he can’t self-report. So you then think ‘well I don’t want to say too much in case they take it out on him’. Because these are just ordinary members of the public that apply for this job, they could be anybody, they’ve not had any training. And they’re….what’s the word, not racist, they’re just as sort of prejudiced against people with learning difficulties as the next person with autism because they’re different. And we’ve had that a huge amount of time with remarks about my brother and so on. So it’s like do you say anything? You know you really want to say something because they’re so stupid but you can’t because I’m not there to supervise his care. It would be great if there were cameras there to sort of supervise what was actually happening. But yeah.

Q Gosh. Yeah. It’s a horrible situation to be in.

A It is horrible. But the thing is it doesn’t have to be like that.

Q No.

A That’s the thing. And it’s government, it’s up to government to change something about it isn’t it? Yeah.

Q What….does he ever….sorry if you’ve mentioned it, his situation, does he have a social worker now?

A No. No I asked for one a while ago and they just said there’s not the manpower to do that, and if there was I would be telling them everything they needed to do. I’d like to explore it. I did ask the commissioner, well she retired, I would like to explore that again.

Q I mean you haven’t even got that out there have you to raise, flag concerns with or to….

A No I do email the commissioner privately, and then she sends the email to everybody else and it’s like ‘oh God’. So that becomes a bit awkward then because then you haven’t told somebody else that you’re telling somebody else and it’s like….my God. This is why I go ‘right I’m dropping it’ because really why is this system like this, why is this system working like this, this is not the right way to run the system, you’ve got it wrong. Yet the commissioners are getting paid a fortune. And the trouble is, like the support workers then become the managers of these places and they’re still no more trained than the support workers. And then the managers then leave because it’s such a high turnover industry and then you get these people coming up through the ranks who actually know nothing about autism and yet they’re running the centres. And you go….there’s something wrong there, you know there’s something very wrong. And you know they’re getting paid, what, 50 grand a year and you’re like ‘oh, what are you doing’ kind of thing. It’s very frustrating.

Q They just need to give all the money to the families don’t they and….

A Well what they need to do, and it’s [name] who runs Project Artworks, they got a grant to build an annex in their garden. I mean they’ve got a big garden which…. But really what they should do if families want to stay together – and our family did want to stay together, we didn’t want [brother] to go initially when he was 14. Because he went to a Steiner School for the mentally handicapped ages ago, and then he became a Ward of Court because we couldn’t cope. Like with me, I was a child but my mum couldn’t cope. But really what should happen is, yeah we didn’t want him to move, we had grandparents and cousins and uncle and aunt and stuff, is build a separate place for us as a family where he’s annexed in a special place and we could live next door and then the specialist service come in. It doesn’t take a brain scientist to work out what needs to be done with families who actually want to stay together and don’t want their young? people put in seclusion and ???

Q Yeah much nicer, there’s a much nicer way to do things than take….yeah.

A Yeah if you want to do it, not everybody wants to do that.

Q No, no.

A With the change in puberty, which is massive, you just can’t cope sometimes. But yeah we would have liked him to stay. I mean he stayed as long as he could at home, yeah.

Q Yeah. Is there anything that we haven’t covered that comes to mind? I know we’ve darted about a bit but is there anything….

A I don’t know, I don’t know what more research you need kind of thing. Yeah I don’t know.

Q Is there anything particular which stands out about your kind of role and your position as [brother]’s sister kind of, is there anything in particular which….

Time 59:50

A I think the…oh there’s several things. I think it’s the lack of support from any external agencies. Which I mean safeguarding ways, you’d think that’s a bit wrong in some respects wouldn’t you because I could be really bad, like I could be spending all his money and stuff. But I have to report it, but I could probably ??? kind of thing, so that’s strange. Yeah so no support, I don’t feel there is enough support at all for the job I do, emotionally….

Q Sorry, is that for the kind of physical task and the emotional kind of….

A Yeah, I don’t get paid anything. I mean I can’t even claim Carer’s Allowance, there’s nothing, it’s a completely voluntary role.

Q Yeah, but you are doing so much.

A Yeah it is. And it’s a mental load. Because it’s not like you go, at the end of the day you can close that down, you don’t, it’s there living in the background. I think the other thing is, the big thing is, like this is actually able to change and it’s not changing. And it’s like why should I go through this when maybe people with other siblings aren’t doing that, and why is my brother not able to access things that he needs to access when actually he can. So there’s obviously some mismanagement going on somewhere. And the support workers, they need to all have mandatory training, you know like apply for a proper job and be paid correctly. So yeah I think that’s the….yeah.

Q OK, they are the things which need to change, and then I guess if those things change you would kind of….your role would be easier and then you don’t need kind of perhaps the same level of kind of emotional support perhaps if the day-to-day kind of running of things was smoother and easier and you can ???

A Yeah. If my brother’s life was better and he accessed more what he needed. He doesn’t even have a clinical psychologist now and his trauma’s not….nothing’s being looked at, he’s just being managed. And you know to sit in a meeting year in year out where nothing changes and I still get the same information. Because I ask questions inadvertently to see if they actually know, and they don’t, and then I have to pick it up and then they get a bit like arse-y, like they a bit like ‘oh, well why are you asking us that’, ‘well because it’s your job’ you know.

Q Yeah.

A So I think it’s the fallout from that, because then that kind of disregulates me and upsets me because then I go ‘oh [brother]’s….his nails aren’t being cut, his teeth aren’t being looked at’. You know he hasn’t been to the dentist for 10 years because he can’t go to the dentist. So then we have to go through ‘well he needs to go and have an appointment first’, I was like ‘he’s never sat in a dentist’s chair all his life, and I’m telling you that now. he needs a GA, he needs a General Anesthetic’. ‘Well we can’t do that because then we need to go through the protocol’. And I’m like ‘well that’s not going to work and he’s going to have the experience of that being negative, and then they’ll cut….and then in a year’s time, do you know what you’ll do, you’ll do a GA and then we’ll have to go to Best Interests’ Are you like numbskulls, like it’s just so frustrating. But I have to go ‘OK’.

Q Yeah.

A So he didn’t go to the dentist. And the dentist was Monday. And then I said you need to look out for signs, he’ll start hitting himself in the face and he won’t eat his food, and then he’ll bolt his food, and then you might need to call the paramedic. And they go ‘oh’ and then they go ‘oh could you tell us about his trauma’ and I go ‘it’s all written down’. Like it’s just so frustrating. So then I just think ‘bugger it’, he’s alive. But it is like that, very much that spiral, which is really frustrating.

Q Well yeah, it sounds like you have to actually be there doing everything for them kind of, that’s the alternative isn’t it?

A Yeah, and then I report them. I’d say ‘well I am going to take this to the commissioners’ and then going to take it to the commissioners and then the commissioners get in touch with them and then…. It’s just like meeting after meeting and yet nothing actually changes on the ground for my brother. So you think well actually one person can’t keep doing that can they, it’s just not feasible kind of thing.

Q Yeah that makes sense. Thank you. I appreciate it’s perhaps difficult stuff to perhaps talk about.

Time 1:04:45

A It’s just frustrating kind of thing because I know nothing’s going to change. And it would change for us as neurotypicals living in this world wouldn’t it? If we wanted to change something and we wanted a holiday we’d go and book one if we wanted it, or whatever. Whereas my brother’s looked after and he hasn’t got a voice and so it doesn’t change. And it’s like it just tells you how like systemic it is in our society where we don’t want to look after people, you know.

Q Yeah it’s no fault of theirs. Just how little is thought of their lives perhaps. Yeah.

A Yeah it is really frustrating.

Q Mmm. But yeah thank you, I do really appreciate you talking, not that this research can change those big issues at all.

A No, where does it go to eventually, I’ve forgotten, I’ve probably read it.

Q So we are looking at kind of producing kind of resources. I guess it’s about representation about others understanding the position of carers, parent carers and sibling carers are in, and so looking at resources for people who come into contact with carers. So GPs, therapists, nurses, social workers, you know people who come into contact and yet don’t fully appreciate, or where things could be done differently or support could be offered differently. I guess it’s kind of trying to get to them. So something which has come up in so many interviews is about therapy and about therapists not even understanding the carer’s role.

A Yeah my therapist doesn’t, I have to explain. And I just go ‘I can’t be bothered’. It’s so tiring, I haven’t got the time, I haven’t got the energy to like spend £50 explaining something that does nothing for me – well it does obviously, she gets to know, but I don’t want to spend 50 quid doing that. I’d like someone who understands in the first place.

Q And again it’s almost kind of telling them how to do their job isn’t it almost, or you know you shouldn’t have to do that.

A They just don’t understand. Neurotypical people just do not understand what it’s like to be brought….you know I mean I feel really sorry for kids today even, you know having to live like that. Because although the parents try most of the time, they just can’t, you know it’s just too much – unless you’ve got some live-in help, or something, or the child can go somewhere else. Because a person like my brother, you just can’t have….it’s almost like you can’t have another sibling because really they just take up all the time and space. It’s not their fault, it’s just how it is kind of thing.

Q Yeah. So it’s about kind of resources to help other people I guess understand, and looking at what could be done differently, or where kind of. You know it’s not going to solve those bigger issues in terms of how people with learning disabilities and autism are treated and, you know the kind of poor quality of care workers, but whether it can have some impact when it comes to, yeah if you go to a GP appointment and they like understand that you’re a carer and what this actually means and entails and things like that.

A Well that’s the thing, because I’m not officially a carer, this is the thing. I’ve fallen through the loop somewhere because I’m a distant carer who does all the emails, you know I’m not the everyday…I mean they get paid, they get paid but they still don’t do it very well. Yeah so that’s what I….

Q Yeah. But you’re so much involved, you know you’re very heavily involved kind of. But yeah for that not to be formally recognised then I guess is….

A Yeah well that’s why I think, that’s why all the government likes it cheap don’t they and free, because imagine if you had to pay me to do that job, yeah.

Q But then by you doing it they’re saving a hell of a lot of money aren’t they elsewhere by not having a social worker or whoever doing it and….

A Yeah. I think I’m going to go back to that social worker idea actually just to support me. Because you know I’ve only got 6 years til 60 and I’m thinking ‘actually, if it’s going to take more energy’ kind of thing. So yeah that’s another thing, relinquishing my role will be quite tricky, if I have to, because I know it won’t be done as well kind of thing. But you know you have to come to those decisions sometimes don’t you?

Q Yeah. Who would you…like who would you talk that kind of stuff through with? Is there where perhaps [charity] would come in, you know the What’s App group, or is that your husband, or how would you….

Time 1:09:45

A Yeah I probably would speak to [charity] actually and then just tell AEM and also the OPG. I mean I’m hoping we can like do it jointly. But I think a social worker needs to be involved. But yet again they’re not trained either, they don’t really understand. Because I’ve been involved with them, they don’t really get it, it’s a different kind of social work. Yeah so I think I would talk it over with [charity]. I think it’s the guilt that then remains, you know because you think ‘God, he’s not being….’ But you think well what else can you do kind of thing you know, because you’ve got to look after yourself as well.

Q Yeah you’re in a no-win situation in that respect aren’t you, yeah.

A Yeah.

Q Do you feel guilt about….

A Yeah, I mean I used to feel a lot of….yeah, yeah I do feel a lot of guilt. But I think actually it’s not my job. I then have to be very logical and go ‘actually that’s not my job, that’s not my job, this is the way the system is, I can’t change the system, nobody wants to do that’.

Q It’s not your responsibility.

A Yeah it’s not my responsibility. And I think that’s where I cut off. Which is good because then I can absolve responsibility to somebody else. It isn’t good is it? This sounds really wrong because we actually know what to do.

Q Yeah but it’s kind of you’ve been forced into that position though haven’t you really, it’s not…. in terms of, yeah so if they were doing their jobs properly and….

A Well if they were trained to do the jobs that they are doing, which is like ‘but you won’t ask ones-self like why aren’t they’, it doesn’t make sense. What is the vested interest in keeping people in seclusion, you know for millions of pounds a year, so like it doesn’t make sense, there’s something going on that’s not very obvious.

Q Yeah and how could that money be used differently to better the person’s life.

A Definitely, yeah.

Q Oh thank you very, very much. Yeah it’s been really good, kind of good to talk, ‘good’ is the wrong word given how the impact, but it has been really….we really appreciate talking to you, with you, so thank you.

A Yeah well if you need any more information, if we haven’t covered everything. Because I know I just get quite passionate where [brother] is concerned kind of thing.

Q Yeah. No thank you, and I kind of just really appreciate how open and honest you are and people are in interviews as well, so thank you. I’ll send you…I’ve got kind of an email to send afterwards just to say thank you for taking part. And Martina who has been doing all the admin side of things and there is a voucher and stuff for taking part, she is away, she’s on leave now until the New Year so she’ll be in touch again. But I’ll send you an email kind of just to explain that and stuff to follow up. And if there is anything else you think about or kind of want to reflect on or anything you’ve got our email addresses, so do just feel free to get in touch. Or you go away and you reflect on anything and you think ‘actually….’ you know, yeah.

A When you write your stuff up can I….where will you put it, is it like going in your paper?

Q Yeah so there’s going to be different stuff. We’ve got a website with a blog and stuff which is kind of kept fairly updated, and we would share findings, we would share kind of findings with participants and stuff as well. So yeah we would share that with everyone, and if you keep an eye of the website as well there’s kind of updates ??? and there would be updates on that as well kind of when it comes to the end of the project. They’re doing digital stories, was that something….

A Yeah I’m not too sure, it depends what I’d have to do kind of thing and how long it would take. And I think I’d probably want it….I don’t know it depends what…..