Q And sorry just to say I am working from home so if I mute myself it’s because there’s background noise, not because I’m not listening. Sorry do you mind carrying on then, you were just saying that you think your work is related to your background.

A Yes. So when I was listening to [name]’s description of all the projects that she’s been involved in with ??? then it really struck a chord with me how much…well how many projects there are that go on and how many people are willing and want to get people with learning disabilities involved in all sorts of things, but how difficult it is actually. Well although she….I notice that talk feeling like it wasn’t so difficult and you just have to get on and do it don’t you. And then I guess as I was saying, I’ve come here for a job as a music therapist to set up a new centre because there’s very little on the island for children and young people to access any kind of arts, whether it’s therapy or just arts in general, music, dance and drama if they have any kind of special needs or learning disability. So it’s a really exciting new project. And yes the other thing I was saying was, I’m sure I’m in this profession has a lot to do with my own family experience and having brothers with disability.

Q OK. Can you perhaps tell me a little bit more about your background and your family experience?

A Yeah. So I’m the youngest of three. And my two elder brothers, we’re all quite close, I’m 55 they’re 57 and 58 I think, and they have fragile X syndrome. So my mother and her sister are carriers of that gene and so I have a cousin with the same.

Q OK.

A So we’re a really close family and there’s huge amounts of love and support, and almost like pride in ‘yes we’re different’, yeah we make known that everyone makes odd sounds or flaps or does this, but this is our complete normal reality, so it’s not weird – but then of course it is weird as well, so there’s two parts. And I think….sorry is that the dog? I’ll shut him out of it. Yeah I mean it has had a huge impact on me like everybody’s siblings do, but I’m realising all my life, even now, I was 55 on Tuesday, you know that it’s so….there’s something so raw about the experience that I can still get really emotional, I can still get very confused, I still have guilty feelings about doing what I want to do. And I think I said in the initial email, I’m not really a carer in the way that we would often see a carer, I don’t have any responsibility for my brothers but the family situation and then how I am with them is always on my mind. And at some point you know my parents will die and I won’t have to look after my brothers in that day to day way, but I might do; or I might feel the need to go and live near them. But again there’s this kind of guilty voice talking, you know ‘I haven’t really got it that bad’ or ‘it’s not really difficult’ or ‘my life is really….compared to others’. But you know also it’s not useful to compare.

Q Do you have conversations about the future with your family then?

A Well I’ve been reading on the [charity] website. I had a flurry of wanting to think about this since coming back. And I haven’t been involved with that [charity] organisation, I don’t know if you know it?

Q Yeah.

A So I was just reading through some of their stuff and recognising some of it. Like it is difficult to have conversations. And if I start a conversation like that with my parents it’s very easy for them to say ‘oh well just because we’re in our 80s do you think we are going to die tomorrow’, you know there’s a humour about it but it’s very ‘keep off, we’re still fine’. And they’re not fine actually, both my parents have got quite big health problems just very recently. And you know they won’t be there and I need to know, I need to know some things, like are my brothers….is that a life long thing that they are looked after by the state; or is it….are the places they are living in, private companies that could change and go bust, you know who has responsibility for that. And I do know quite a lot of the things but my mum and dad are probably always really trying to protect me so there’s been a reluctance to talk about the reality of things.

Time 5:15

Q OK. Is there kind of….if you were to think about, I know you’ve said you’re not a carer in a typical sense, but if you think about your situation is there one particular story which comes to mind which kind of epitomises being a sibling of your brothers and the impact it can have on your well-being?

A On my well-being? Well…I’m not sure I can find a particular story. I suppose from a very young….when I was a child there was a lot of….yeah this is all going to be anonymous isn’t it, there aren’t going to be any names?

Q Yes. And just to reassure you, we’ll anonymise the transcript as well and you’ll get a copy of it so you can take out anything which you kind of….yeah which ??? or anything.

A It’s just a little bit about how my dad in particular raised….you know needed to….I mean he had grown up in a time when you got beaten as a child unfortunately – and he didn’t beat us but he did hit my elder brother in particular. So I think as a little girl with these two quite….I mean they were very physically able but mentally disabled, and there’s a lot of confusion and fear I think that my dad would….you know he’d just be very angry with the misbehavior or the challenging behaviour of my elder brother in particular. And I do feel very aware that as a little girl, you know I was hiding a lot, I was extremely quiet. And I didn’t get hit but I think that makes you into somebody who really, really is watchful, really toes the line, ‘I can’t do anything wrong I’ve got to be good’, ‘I’m the one who can think straight’, ‘I have to….’ you know it’s my absolute duty to be really, really good and never do anything that’s going to get me into trouble or add to the difficulties of the family. And there’s that responsibility I think really, that’s the word, you know the responsibility is weighing quite heavy. Yeah.

Q From a young age.

A Yeah. And it’s a kind of imagined responsibility as well because I know that my parents have always….their goal was for me not to feel that, that their goal has been….because they wanted the situation in our family not to ever affect me. But of course you can’t help that. And then more as an adult I think it’s a shame but I have to admit that I think these guilty feelings have just plagued and plagued and plagued me that I should be there, I should ring them more. I don’t really want to ring them because it’s not….I mean I really love them, there’s huge love there, but yeah there’s a lot of guilt. And I’m still working through that. And I think I work through that by doing the job that I’m doing because I’m with families every single day with learning? disability? children, I love that job because I love the music. But you know it’s a bit entrenched you know like working through lots of stuff, and I was hoping I might have worked through it by now though. And it is just going to be there all the time.

Q Do you access any other kind of support, or have you over the years?

A Yes, yes, loads. Psychotherapy. And I mean I’ve an interest in that world anyway so it’s always been a professional interest and my experience has helped my work. And also to be any kind of therapist I think you….well in our training we needed to have personal therapy anyway and then I’ve carried it on intermittently over the years. Yeah. And the therapy is….I used to be really angry and resentful that the therapy topics were just about them again, my brothers. You know how can I get away from them?

Time 10:00

Q Mmm. That’s interesting, that came up in another interview I had with someone. They were saying that they wanted the therapy to be all about them and not their sibling for once.

A Yeah. I think it has moved on for me that, and I’ve gone through enough of that to bring the impact of being in that kind of family dynamic, you know to understand the impact of that and then you can move on and take decisions about what you want to do. And I find like I’m always looking for people like me in my situation but I just can’t find any. I mean none of us probably can find somebody like us. But I want to find somebody who is the youngest, because often a family has like a youngest disabled child and then end up having ??? children. But my mum and dad, in hindsight there were milestone delays and stuff but the disability of their two boys wasn’t immediately obvious. But they say that if they had had a diagnosis sooner they would never have had a third child. And then all the….I mean I’m so lucky in some ways because all the kind of ability and hope for the future has been piled into me and it is really difficult to put hope in the future for a disabled person because…. I mean I think it’s a shame when it’s like that but it is hard to think ‘well what will this person do with their life’. So that’s another thing. I’m sure I’ve piled loads and loads of pressure on me to do academically well, and make sure I get married, and OK I’m going to have 3 children as well and kind of not disabled ‘here you are, here you are mum this is your good family’.

And then something that’s happened very recently, probably to do with coming here, I just kind of ran away from everything sort of. I came for a job and it’s ended up in me divorcing my husband just in the last month or so. And he is a wonderful, wonderful man and he’s been so good for my birth family, and my brothers love him because he’s a real man and, you know that has really set me back because I’ve kind of broken….not just for me, not just for my family but the impact on my brothers and my mum and dad has just been horrendous.

Q Oh gosh. I’m really sorry to hear that. Yeah and so you’re constantly….

A It’s repercussion ??? you know a divorce is not a happy moment in any way for anybody but, you know what do I tell my brothers, my mum and dad say. They won’t understand, just don’t tell anything. And then if I ring one of them they love….so their first question is ‘how is [ex-husband], how is [ex-husband], how is [ex-husband]’, and I just pretend it’s just ??? I’m not sure what we’ll do though in the end when we tell them.

Q So just extra layers of complexity and kind of worry to everything. And constantly the decisions you are making, the ramifications that they have for other people as well.

A Yeah.

Q Over the years what do you feel….what kind of support or what could you have had which would have made things easier for you and kind of your well-being, your mental health?

A Well I think this [charity] website and the organisation, and I don’t know there probably was something available but…. And I think about it a lot now, like in this centre where we work we have contact with over 150 families and there’s many siblings that I know a little bit as well. And I’m just thinking, you know could I start a side in our centre that’s not for the disabled person, it’s for the sibling. But also being different, so you might not want to be lumped in with them. But yeah I think….I don’t know what I would have done with it necessarily, but just to be in contact. Or for any disabled organisations, like we had a lot of contact with MENCAP in [town] where we were growing up and maybe those, and SCOPE, you know all those organisations, could they have at least a recognitio9n or a bit on their website that says….maybe they do now, but I mean websites didn’t even exist then did they, but yeah just for all those organisations that focus on the disabled person have a section or an organisation or a link or something for the siblings as well.

Q Yeah.

Time 15:11

A Yeah I mean I think it’s really important because in counselling or therapy it could be offered. And I’m not sure what else. Maybe some guidance for parents as well on the things that their other children will be feeling. Like they may be feeling guilty or they may be feeling like they mustn’t take a step wrong, or that they put pressure on themselves.

Q Do you think your parents ever recognised the impact it had on you?

A I’m not sure really. I think things have changed so much anyway because people talk a lot more about their feelings don’t they and the impact, and your circumstances and your thoughts about life, and people have choices more and we can self care and all that stuff. Whereas my parents’ generation they were definitely in that ‘we’re just getting on with it’. I mean it opened up for me when I was 29. I got married in the same year and I started music therapy training, which was a lot about personal therapy and self-awareness and what brings you to this role. So I had a great big opening of what felt like a massive can of worms really from that time, and I probably needed to do it, and then it was my own self-healing of working out how relationships affect you. And I did at that time try and speak a bit to my mum and dad, but they were a bit dismissive and they would say things like ‘well that’s just obvious isn’t it’ or….the parent just playing the drum with their child, they didn’t want to think. And I can absolutely see why they didn’t want to think about the possibility of me struggling or the psychodynamics, you know almost like they haven’t got time for that really, they’re surviving and they are getting on with it and everybody’s OK, and that’s enough, let’s just leave it.

Q OK. Has there been anything over the years – I know you’ve said you’ve accessed and had as part of your job and personal therapy, has there been anything else which you’ve found really supportive or really helpful?

A Well friendships, yeah. I absolutely needed very, very close friends who know my family, it’s been really important. Like even with boyfriends and with the man I married, you know the kind of test was ‘can you manage to be with my family?’ I’ve been lucky, I’ve got amazing friends, a few very special ones, who know my parents and my brothers, so that’s been important you know giving time to those friendships and really valuing. And reading, you know I’ve taken a kind of academic route but I’ve read a lot, even novels, there’s more novels now. There was one recently about a man who took his brother out of his care home during lockdown and he’s written a novel. So I’m just looking for things like that and seeking literature or articles or poems even as well – I haven’t found much but….you know I think intellectualizing it probably has helped me.

Q Mmm, thank you. Has there been anything which hasn’t worked or hasn’t helped, that you haven’t found supportive I guess?

A Something that I’ve tried that I haven’t found supportive?

Q Yeah or….well I don’t know, if there’s been kind of well meaning stuff or well intended but hasn’t quite hit the mark. Is there anything over the years that you can think of which isn’t helpful?

Time 19:50

A I suppose just in general some people’s attitudes. It’s like the society problem I think. Well it’s just a lack of understanding, which is not surprising you know if you don’t know people with learning disabilities you can make crass remarks. Or…yeah I don’t know, I mean nothing in particular. I mean there’s been many instances when I’ve been hurt or felt stupid or taken things personally or felt like I’ve needed to call people out when they are using words, terminology that just makes my blood boil. You know and I suppose I’ve had a lot of fierceness in me, it just erupts, and I try to contain it, but I’m hugely over-protective at that time. But no I don’t think overall there’s been anything I can think of.

Q OK. And where are your brothers living then at the moment, what is their current set up? They’re not living at home any more?

A No. I mean that’s the other thing that I think my parents did really well – maybe it was well for them. But when they reached early 20s, my mum didn’t want it really but my dad was really adamant that they find them a care home, you know an independent place to live in to avoid that situation of keeping them at home until the parents die and then suddenly in their 50s they’d have to move. So he had a good vision for that really, but I think it was hard. Anyway so they are all in [county], the family now, and so one is in a [charity] supported home with just one other man. And they get quite minimal support, which is amazing because they can’t….they can follow systems but there’s no way they could manage that on their own, but it’s got to a point where they can have limited support just once or twice a day, so it’s not living in. And the other one’s in a care home, a privately run care home in another part of[county] with about 8 others. But that changed very recently because he managed to communicate somehow that he just wasn’t happy there, and he also now in the last month or so moved to a much smaller place with one other man, with 24 hour care.

Q OK, yeah. I’m just looking through, I’ve just got another laptop here so that’s why I’m looking to the side.

A Yeah, I’ll have a little bit more of my breakfast then.

Q Yeah go for it. What do you think needs to change for carers to be well supported?

A Well it’s hard to think of what needs for….I mean there are so many carers who are actually physically caring for their siblings aren’t there, so I mean I can’t imagine…I mean they are more like a parent really to their siblings. So for them I mean I would want just acknowledgement that that is a massively responsible role and they deserve time off and respite and just like recognition of the toll that that takes. And I think like I said before, just any organisation that is aiming to help or provide support for people with learning disabilities, don’t kind of see them in isolation, it’s a ??? that whoever it is – it might not be the sibling, it might be the auntie or the cousin – they just really treat that family as a whole, well whichever bit of it, it might be an added on or just make sure you see the whole picture as far as you possibly can.

Q Yeah. And do you think, I know it was a while ago but kind of when you were at school as well kind of growing up with your brothers then and you were a young carer at home, whether you saw yourself as one or not but obviously you were taking on this responsibility, like you said you felt more responsible and perhaps do put pressure on yourself to do well at school and stuff. Could school have handled it….could there have been more support at school?

Time 25:00

A Well yeah I think it would have been great to be able to talk about these things. I suppose people were aware at school and they didn’t….my brothers were at a special school. Yeah I think I really agree with the special schools, I think it’s much easier and you get specialist help in the special school, but maybe less segregation, less separation, like visits between schools or…. I didn’t present as somebody that needed counselling I don’t think or anything like that at primary school. No it’s more as an adult that I found it harder. I suppose as a child, like with every family, that’s your norm isn’t it?

Q Yeah you just get on with it.

A Yeah. And in a way, if you offer somebody who is managing OK with counselling and talking, I mean it depends what it is, but maybe that would bring up things more gradually rather than kind of ‘oh my God this has been really hard’ or ‘how has this affected me’. Because you do build up defences, every child does whatever their circumstances, but I think there’s more layers that you put on if you’re constantly around people with disabilities. But I mean I don’t know if schools are changing now, but yes a bit like with gay families or rainbow families, just to have a whole different gamut of books available at school, you have stories, social stories – well not even social stories but just stories available in schools that have disabled siblings or things. But not ones that are kind of deliberately ‘oh this is interesting’ but….

Q Yeah, just the norm, just the….yeah, yeah, OK. But for you then it’s the impact, you’re saying it’s much more apparent for you as an adult and the feelings of guilt which then have kind of arisen.

A Yes. Yeah I think so. I think I just shut a lot of it off. When my brothers went into their homes, I mean I was doing my A levels probably or starting university. I mean I know now that there were terrible issues with especially my elder brother going into this home, he ran away from it and he hated it, I mean he would hit people and come home and be hit, and just awful things that I just didn’t know that my mum and dad were going through.

Q OK. But they’ve protected you from a lot of it then.

A Yeah.

Q Is there anything else that you’d like to share with us, or anything else you can think of which we haven’t….

A Tell me again a bit about what....the project is specifically about the mental health of carers?

Q Yeah we are interested in stories of caring and how that impacts on kind of carers’ well-being and mental health. And so part of that is looking at parents’ experience but then part of that is obviously looking at siblings’ experiences. And really I guess what people can do differently to support siblings today and parents today with regards to their mental health. So we are thinking about sharing findings with, you know schools, social workers, organisations, GPs and therapists, that whole spectrum of people that come into contact with carers really.

Time 29:23

A Yeah that’s really good. I think what we found here in our centre is that the parents in particular are finding a huge benefit to the network. Because often when people go to schools or you take your child to therapy somewhere, ours is a centre where everybody comes to us, we’re not going out to different places to provide music service. And while people are waiting for their child to have their session there’s a lovely garden, chairs to sit on, and it didn’t happen immediately but just slowly, slowly these friendship groups are building. And just that thing like I said earlier, finding somebody who is not in exactly the same situation as you but has got a very similar situation and similar pressures and similar difficulties and fighting for this and fighting for that, we can just see the benefit of that. So I mean any kind of support groups. They are difficult because you have to be in a good enough place to put yourself out there, so people really need encouragement I think. And even if you think you’re OK or you don’t need it, or just encouraging people to try it, try whatever is on offer. And even for GPs or other schools to keep offering it, you know even if somebody says ‘no I don’t need that, I don’t want it’, just keep repeating it ??? because there may be some time when they will be able to say ‘yes I do need help’.

Q Were you….is it only recently you’ve discovered [charity for siblings] did you say?

A Yes.

Q Will you continue to access stuff through them?

A I’d like to, yeah. They had a reading panel thing so that you can read stuff before they put it on the website, and kind of ??? was reading it or saying how it is, so yeah I’m keen to do that. And it seems like that’s a much easier way for me to contribute, than even like ringing my brothers every week. I mean I don’t know it’s a funny thing, I don’t know why it’s a bit difficult, but yeah. You know if I can do something that suits me at the moment then that kind of helps me feel like….yeah feel like I’m doing something.

Q Yeah OK, thank you.

A Are you a sibling as well?

Q No I’m not actually but I’ve always worked in learning disabilities, kind of support work and things and then I’ve gradually moved into research. But no I’m not a sibling. Which I think….kind of I’ve had these discussions with other people and like I’m always very conscious of that when researching learning disabilities. I’m not a parent – well I am a parent but not of a child who has learning disabilities, and in this instance I’m not a sibling of someone who has learning disabilities.

A Yeah but it gives you a good distance though.

Q Yeah exactly, exactly. So whilst I’m very familiar with I guess the area and supporting people with learning disabilities, yeah I am a step removed from it.

A Yeah, no that ??? Because I feel like when I’m talking to the parents at our centre, you know I can really empathise but I don’t know, I haven’t got a personal feeling of being a parent of a….I have only added responsibility and fear I think of ??? Basically the fear is what happens when my mum might die.

Q Yeah and that very much comes through these interviews as well, the future. You know it’s such a big topic and just on everyone’s mind, but something which is so hard to obviously address and to think about for people. And not just for parents but for siblings as well, like you’ve said, you know thinking about the future and what happens.

A Yeah. I mean that could be ??? you know what is the system, a government system, I don’t know how that could be transmitted to siblings. But I think a lot of siblings grow up knowing somehow that they are going to have to support their disabled sibling in the future – but actually that may just not be true, you know, I don’t really know what happens. And yeah it is hard to find out. And I suppose it changes, maybe it changes with governments as well, I don’t know.

Q Yeah interesting. So that actual like working knowledge of the system I guess, which your parents will have had from navigating their way through it but they’ve protected you from that side of things so you don’t have that ???

Time 34:55

A Yes, and it could be that you ask parents to be really clear once they know something and once the non-disabled sibling is old enough or wants to know, then to be clear you know. I heard a story recently about a friend whose non-disabled – well it was a friend of a friend – but the other child had spent ages worrying as a teenager that they were going to have to get ready for a job because they knew they were going to have to support the sibling. And it just wasn’t true. But they developed this fear or worry in their head, hadn’t expressed it and the parent hadn’t known. So yes talking and trying to get stuff in the open is never a bad thing.

Q Yeah, and if there was….I don’t know if there are with [charity] or not, like workshops for siblings to think through what you want to happen in the future regardless of what your parents might want or your brothers might want, but workshops on how things work as well.

A Yeah. I think there are those groups in that SIBS thing. It’s a really good organisation.

Q Yeah, brilliant. Thank you. Is there anything else before…..?

A No I don’t think so, no.

Q Brilliant. Thank you so much for your time and for your contributions. If there is anything else that you think of that we haven’t covered you’ve got my email address, you’ve got Martina’s as well. Martina will be in touch with you because there’s a….actually I can stop the recording now.