K So we are recording and now I’m going to mute myself, hide myself, mute you and say goodbye, and thank you very, very much. Bye.

Q See you later. Hi [name] so I’ll be interviewing you today. Did you have any questions you wanted to ask before we start about the project?

A No I don’t think so, it was pretty well explained. And I heard about it through my brother, [identifying information]

Q Oh I didn’t make the link.

A So I think, he said you know I don’t know if this is a bit weird with these worlds colliding but I think you would be really, really ideal for this programme. So yeah he didn’t know much about it, but yeah.

Q Oh that’s brilliant. Nice to meet you.

A Yes you too.

Q [identifying information]

A You don’t! That’s amazing.

Q I know, it’s just like I’m in awe of him.

A I don’t see enough of him. He lives up in [location]. But he was down last week for a few days. I’m in [location] and so….oh he’s just one of life’s good guys I think, he’s great. And so it’s really nice. But because he was down week days and my work was so hectic I think I saw him for an hour and a half in the 3 days he was here. But anyway.

Q Oh that’s amazing.

A [identifying information]

Q So that’s great, yeah. So I’m going to ask you some questions but this is going to be very informal so, you know just talk about what you want to talk about really. And then I will send, or [name] Smith may send you a form that will just be a demographic, anonymised demographic tick box so we can just collect some background details about you. So I think if we could start off by just, if you could tell me why you wanted to be involved in the project that would be good.

A I think because it’s a full hidden world. And because my daughter is in her early 20s now but also I’m Chair of a small charity, so we….a Chair, not Chair, a director of a small charity and we create arts projects for anyone who faces challenge. But I’m also Chair of Governors at the local special school. So I’ve had a couple of decades now of my own experience but meeting other parents and carers of children and young adults with learning disability. And we’re invisible and they’re invisible in society and in the community – I think that’s because their- children largely are too. So it was just so amazing to find something that was actually trying to gather some information or start to go to actually quantify how that is and what it’s like. And in a wider sense that recognition. I think for all carers, whether or not they are with people with additional needs, that it’s recognised almost that contribution that carers are making. So yeah I was thrilled to think that was being set up.

Q Oh that’s good. [identifying information] and that recognition of that hidden-ness is really important isn’t it? But why do you think that you are hidden?

Time 4:38

A I think because disability and additional needs, educational needs, are something that society doesn’t want to acknowledge or face up to, even though people with disabilities are the biggest minority in Britain. So I guess that if people who are caring for them equally can’t be acknowledged it is almost like it doesn’t exist or it’s not real. But also I just feel that as a society – and I’ve felt this more and more as [adult child]’s got older actually, it’s got more difficult for her – that as a society we are just not geared up to the difference, whatever that is. And it’s very hard for people not to be frightened of other, or of something that isn’t what they perceive as normal. So you know from the school gates to trying to be flexible with work, or trying to find employment, or me trying to find work that fits with me caring for her - because I’m a single parent I’ve had this since she was a year old – it’s just not….yeah it’s not what people want. I wonder why. I don’t know people just are scared of other indifferences instead of actually celebrating that difference. But also finding out what we can all offer society. You know we’d be a lot better to actually go with the strengths – and everyone has their strengths and everyone has their skills. But yeah, that was a ramble, sorry.

Q No it was important points you were making there. You said that for [adult child] things had got harder now she’s in her 20s, is that because you think things have got worse or is it harder because she’s got older?

A I think it’s harder because she’s got older. I think that there is, certainly where we live and it’s one of the reason that I moved here because this county has very good support for children with disabilities. But there is quite a good level of support, especially medically because [adult child] has physical disabilities as well as learning disabilities and there’s a very good…no not very good, there’s ??? network of care around that but as soon as you hit 18 that all stopped. So all of the pediatric stuff stopped at 18 so she then….and from then onwards we found it very, very difficult if she had to have any medical. Especially hospital, she’s been in and out of hospital probably once every two years since she’s been 13 or 14 with different things, some of them were quite serious, and when she was a child and she could be on a children’s ward I could stay with her, they were very geared up to the fact that she had additional needs. But as soon as she turned into an adult I had to sort of, it’s very patchy as to whether they have….they’re supposed to have people for folk with additional needs but sometimes they don’t turn up. And I have to plead to be able to stay with her. And there’s no….well I just have to sit on a chair, so sometimes I’m sitting on a chair by her bedside day and night for a couple of weeks or however long it is that she’s in there. But also I find that there were….and she’s in an amazing school. She went to mainstream school as a primary and started mainstream in secondary, and then it all went badly wrong. And then we managed to get her into this fantastic special school in our local town, which is the one I am now the Chair of Governors at. And it was….all schools should be that way, special or not, all schools should be that way. But it’s just incredible. And it was a bit of a bubble really. So they had a Post-16 which she went through as well and then as soon as she left there the real world ??? employment just doesn’t cater for anyone with additional needs.

Time 9:53

And [adult child]’s fairly able I would say, she’s actually now got a little job which is just a few hours a week with the County Council as a Youth Representative helping other young people plan their futures. So she’s now a representative who is a voice for young people have disabilities or have special needs, she’s very much about equality and causes and fundraising and so on. And that’s absolutely amazing. She needs a huge amount of coaching to be able to do it but she is developing and learning all the time. And it’s paid work, which for her is just fantastic. She does loads of volunteering, but there’s something about getting a pay cheque at the end of the month that….it’s not so much the money for her, it’s that ‘I’m working and I’m contributing’. And it’s maybe 3 or 4 hours a week. I mean she’s coming up to 25 and they’re 16 to 25 year olds, so I don’t know after that.

Q Are you the person that has to do the coaching or is there support for her?

A Yes, yes I am. So I’m a single parent but I’m really lucky that my lovely sister, my older sister, looks after [adult child] and helps with the care of [adult child] when I’m working. Because I also work, as freelancer I have a whole variety of different areas of work, and I work maybe 80 hours a week just to bring the money in. So I’m freelance so that I can work from home and so that I can do all [adult child]’s appointments and help her with her job. My sister doesn’t drive so I drive [adult child] to all the things because she failed travel training not once, not twice but three times so she can’t travel independently. So I do all of that as well. But with the job coaching, in a way it’s one of the skills I have I guess in part of my work which is the charity thing, I do other work as well. It’s very much bringing my skills to the fore. And she responds very well to it. And it’s very light touch. And it is just that thing of knowing what she needs for her to be able to grasp it and get it and then she can go off and do it. And then it’s the next thing that she needs to help her. But it’s lovely and I enjoy it. It’s just for me trying to make sure I’m not too kind of on her, I let her do her own thing and I let her develop for herself. So I find I’m doing less and less. It’s great.

Q Yeah that is good. Does she have any other support apart from your sister?

A No. No we don’t have any….no. She had encephalitis 7 years ago and was in hospital for a couple of months and was very seriously ill, and ever since then she’s had psychotic episodes every few months. So they just last for a few weeks at a time. She has total ??? chain, becomes hyper anxious, very aggressive, often thinks things are happening that aren’t happening, doesn’t sleep. And she has decided that she doesn’t want medication during those episodes. She said ??? prescribed anti-psychotics and we felt they make her feel worse and they almost highlight the symptoms. And by the time they kick in she’s coming out of it anyway. She said she felt like a zombie, they do zombify her rather. So I totally supported her in that. So again it means I have to support her through that whenever it happens. But what I’m finding is they are getting….there are longer gaps in between, which is great. So it used to be every month or so, I think the last one was about 4 months ago. So I’m hoping that she’s gradually coming out of it. But when she came out from the encephalitis we did have some psychiatric support for her. So she would go and talk to someone and she was on medication which gradually withdrew for about 6 months of anti ???

Time 15:05

But that was because she was on the cusp of pediatric and adult services. As soon as we went to adult services it just stopped. And there was one incident when she had to go to hospital for a routine operation and reacted to the anesthetic. And the pain, she had post-operative delirium, which they didn’t recognise in the hospital, thought that they’d left something in when they were operating, and actually went back in and made it worse by giving her another dose. So she was really, really disturbed and in a state after that. And the GP, who has been amazing, and he is an amazing support actually, sent a crisis team out because she was ??? and violent and I just couldn’t cope, I didn’t know what to do. So I phoned him and he sent a crisis team out. But that wasn’t very helpful, they were talking about sectioning her. And I managed to persuade them to give us a couple of days, maybe come and visit her once a day for a few days, and actually I managed it and it was fine.

I think those are the only bits of support, apart from the GP who is amazing and she sees him regularly, more for the medical stuff really because she isn’t on any medication for the psychosis. So yeah that’s it. My sister is amazing, absolutely amazing, and probably a year, two years ago, no a year ago I’d say, I was finding it really difficult to cope. Work is very full on. I love what I do but there’s too much of it. [adult child] was going through a difficult period. COVID had been awful for me financially because I work in the Arts and I work for a charity. I managed to keep the charity afloat by not taking a wage through COVID, and the other work I do is in Public Art, and it just collapsed basically.

So I was really, really struggling with everything, with finances, with [adult child], with work, and she offered to take [adult child] for a respite one night a week. And she actually lives next door now, which is amazing ??? medieval ??? and that’s been a lifeline for me, absolutely. So once a week, and it’s on Fridays in fact, so I can settle down and get ready now for their Friday afternoons, Friday afternoon she goes round to [my sister] and then she comes back on Saturday lunchtime. So I have that time, like 24 hours that’s just for me and when I don’t have to be….because she often has problems at night time so I’m on constant kind of meerkat lookout at night time on whether ??? the stairs or leave her upstairs. So that’s incredible support. It’s amazing. I don’t really know how I’d have continued without it really. But yeah that’s it.

Q So did you speak to the GP about when you were struggling to cope, or was it that you solved it with your sister?

A I don’t really know what they’d have done. I can’t think what they’d have done. It’s just in a way it’s just what life has dealt me. It’s just no-one else can take responsibility for things and make a change apart from me. And so it’s just how it is. And in general I feel very blessed with my life. I have two lovely daughters and, you know a great job. I worry hugely about what will happen to her because I’m a single parent. But I need to ??? tackle, it’s another thing, it’s another thing I need to set off ??? But no I don’t know what I would have said. And they’d have just said ‘oh have some anti-depressants’, which I wouldn’t want to do.

Time 20:10

Q Yeah I suppose….

A It wouldn’t work.

Q It wouldn’t work did you say, sorry?

A Well I couldn’t carry on working I don’t think. Because you know I absolutely need to because…. And I pay [my sister] to help look after [adult child] when I’m working, so she’s in a way a dependant as well as ???

Q So on your 24 hours break each Friday do you just catch up with stuff that you should have done, or do you create some time for you?

A The idea was that I would, yeah have Friday afternoons off, but it’s now just become another work day. But it’s quite nice because I can clock off a bit earlier in the evening. So if I finish about 7 o’clock or whatever then I have the rest of the evening, which is really nice. And then I take all of Saturday off because I tend to work on Sundays. So I take all of Saturday off which is lovely. So Saturday morning I might go ??? look for other jobs – I say that but I haven’t done that for quite a long time, but I could do. Or I could just sit with a paper, you know ??? and read a paper. And then when [adult child] comes back we have Saturday afternoons together and that’s really nice and we spend the rest of the day ??? So it is really special. And having that night time when I’m not on mummy watch is…oh, just bliss. I sleep so well on a Friday night.

Q That’s very cool. So how would you summarise your experience as a carer, because obviously it’s been you and then your sister for a long time now, so what would you say about your experiences of being a carer?

A It’s very rewarding. It teaches you a lot. I’ve become so patient in general as a person and that really helps me. And that’s sort of a gift I’ve been given through the experience of caring. I have this fantastic relationship with [adult child] – although actually I have a fantastic relationship with my elder daughter as well, I was going to say I maybe a bit ??? but I’m very, very close to them both. But what I would say is that it isolates you from some of the things you may have done, friendships you might have made, experiences you might have had. What I feel is that the whole of the rest of my life now is dedicated to caring, and I might have had a different future, I might have had a different life. And it does isolate you I think from being able to do some of those things, especially with people with children who are sort of the same age as your child, because my elder child was 7 and a half when [adult child] was born so all of those things that I did when she was little with the other parents, some with other children, it just ??? it makes [adult child] ??? And I think it also can really define you as being ‘[adult child]’s mum’, so I get called ‘mum’ a lot. ‘So mum’ from whoever it is, the consultant or whoever it is that we are seeing. And I think partly that’s why I work, although I wish there was less of it. But work is really precious because it’s a place where I’m [Name] and I’m a director for a charity ??? or I’m a public health consultant. So I have this whole different world where I’m seen very differently and I can be a different person.

Time 25:09

But also my….both the children’s father and I split up when [adult child] was a year old and largely to do with the fact that he couldn’t cope with the fact that [adult child] had a disability, so that was 23 years ago, I probably ??? or something ??? The thing about being a carer is, I’ve never had another relationship, not one, and I can’t imagine how that could ever have happened. I mean now it’s just wearying to think about it. But it might have happened if [adult child] hadn’t had such intense caring needs. You know I know folk who have children who have such profound disabilities and caring needs that it’s absolutely all-consuming, so I feel relatively lucky in that way. When [adult child] was born they thought she had a progressive muscle wasting disease and that she would die at about 3 years old, so for the first few months, first year, I was preparing to have a child who would die. And she didn’t. So when we knew what it was that she had it was, you know flags out celebration. And I still uphold that feeling really of how it could be. So yeah I suppose I can’t know what my life might have been without that, but I suspect that it would have been quite different.

Q You just said that about not having a relationship or the different ways your life could have been. When [adult child] was young did you sort of assume that you would have another relationship, or was it so engulfing?

A It was so engulfing at the time. I mean again it’s more the physical side. She didn’t walk until she was 5, she was completely locked because she had to be fed from a tube. Yeah it was just all encompassing. And I had two girls and I had to work to bring money in. I was always the main breadwinner anyway, and that was quite helpful when he left because many women ??? don’t have that, they don’t have the finances. But it was very difficult because I suddenly had to get money in, so that was really hard. And we’d bought a house, I’d always paid the mortgage but his name was on the deeds so I had to sell the house to give him his half. And so we had to move and find somewhere else – there was just so much going on for those first few years. So I don’t know really, I don’t know whether I….but I think I probably would have assumed that I might, yeah. That means ??? I’ve never looked for, and I’m trying to think what he would….he would look at me and think ‘oh yeah that’s a good set up, she looks great’ ??? ???

Q So you’ve mentioned the time a few years ago where you really did get close to sort of not being able to cope and then your sister stepped in and this seems to be a good set up. How have you managed your mental health up to that point, was there anything else that you’ve done or….that’s helped you?

Time 29:50

A I don’t know. I think….I have good mental health actually in general. I’m an absolute optimist and I always have been, and I always think there’s a way to solve problems. And I think I’ve always enjoyed taking responsibility. My mum left us when we were all little but [name] and I, my eldest sister and I were only a year apart and we’re the two eldest so we brought the others up really with our dad. But I was the mother hen, you know I just loved it, I just took….I was only 10 but you know the cooking and the cleaning and the shopping, along with school work, you know all of that, I just…. So I’ve always really quite….it feeds me. I don’t know what that says about me but I really do like that aspect. And I sort of think in a way if somebody has to be given a child to look after who needs looking after, maybe I’m a good fit. You know if there’s a universe and a God maybe they’ve gone ‘oh yes, she’ll be quite good at that’. So I’ve always….yeah I do feel actually quite a resilient and happy person. Obviously I’m not always. I mean sometimes things are really tough, but everyone has their things don’t they, all families, all people have those things that they are dealing with, we’re all just….they all…. So yes I’m not….I don’t feel I’m….Yeah, and also I suppose with mum going it made us very self reliant and resilient and mature and all of that and grew up very quickly, so I think there’s probably an element in me that thinks ‘well ??? strong, get on with it’.

Q What do you think needs to change for carers to be better supported?

A I think we need to be heard and seen. And I think that those being cared for need to be heard and seen. And I think we need to be celebrated, not ignored or hidden away. So I always think that as a society we need to say ‘look at this sector of people’ and ‘look at this group of people and the skills they’ve got and the things they’re doing’. and ‘oh that’s good isn’t it’. And that’s part of the work we do to make a society, to make ??? it’s what we contribute and that should be recognised. There’s also some technical things, and [my sister] at the moment because she cares for [adult child] a number of hours a week when I’m working, can get carer’s allowance which really helps because I can pay her a bit less because I know she’s getting that. So she retires, is of retirement age next year and the carer’s allowance will stop. She’s not going to stop caring for [adult child]. At the moment we’re having this tussle where she is saying ‘well I’ll be getting a pension so you don’t need to pay me’, I say ‘well that still won’t cover it, of course I’ll still pay you if you’re working for 17? at the moment.

But things like that are odd, there’s such an anomaly. Because there must be so many grandparents for instance who are caring for their grandchildren while their sons and daughters go out to work who are getting carer’s allowance because they’re caring for a family member. And so it’s partly things like that, it’s almost like very stacked up against you. Yeah. But I think it’s about being seen and heard, and not just acknowledged but celebrated, there are so many positives that we could bring or people could learn from us. Or if we knew who else was out there you know we could pool resources or coming together. I’m not a joiner so it’s like I’m not party….I don’t feel like a carer bizarrely, because I’m a worker. I think so.

Time 35:40

Q But it sounds like that works ??? important.

A I’m not part of carer’s groups or anything like that. But you see if I joined a carer’s group I’d be volunteering to do things for them and set things up – and I haven’t got time.

Q So in terms of, because the project is looking at the mental health of carers which is also something that’s invisible, what do you think it would mean to include carers’ views into mental health services? How would services understand that some carers will have mental health issues or concerns or ill health?

A Yes, I suppose if their voices are represented then that’s the way isn’t it, they need to be able to hear people or hear those case studies or….I don’t know how it could be reported. I suppose through things like this. I don’t know. I’d like to say ‘what do you think’, I’m going to ask you a question, I don’t know if that’s allowed.

Q You can ask me a question.

A What do you think? Yeah. And I want to know who you care for. I want to know about you now.

Q No, he’s died sadly.

A Oh no. Oh [name].

Q I know. I think there’s something where the work of caring is so intense for mothers in particular because of the complete love that is inextricably woven through it, it’s a bit tricky to feel that you can say ‘I’m struggling’ or ‘I feel like I really need a hand in something’, which means that probably the family carers just get on with it and it’s not known about. So we’re hoping this project is going to surface some of that stuff so that there is a recognition that it can be a difficult job even though none of us really say that that often because we’re not heard. So yeah, yeah it’s a tricky one that. That is actually one of my questions anyway, so you can ask me any questions you want, or have you got anything that we haven’t talked about that you wanted to add to any of that?

A I don’t think so, though I feel like I’ve rambled on a lot.

Q No it’s really important what you’ve said, it’s really interesting. I suppose a final question from me would be where ideally would you like to be in 10 years time?

A Well my mind immediately runs to [adult child] where she’ll be in 10 years time. So I suppose…gosh I’ll be in my 70s so it really is about getting her sorted out, whatever that means. So you know I always used to say ‘oh she’ll be independently living’ but I don’t even know what that means. So in 10 years time I hope that there’ll be something in place where [adult child] can be supported to live independently if she wants to. Yeah. And maybe I’ll stop working. I can’t imagine that actually, that’s a bit frightening. Maybe. Yeah, because I’ll be 74 then. Yeah maybe I’ll have a….I suppose I’d like to have a simpler life that’s quieter and to have enough support for [adult child] that she can live independently when she chooses and gets too doddery. That won’t be in 10 years time. My mum’s 90 this year and my dad lived to 92, I’m hoping the genes will hold out.

Time 40:23

Q Is there anything you wanted to add to any of that?

A No I don’t think so.

Q That was such a good interview [Name] it was really, really, really thoughtful, so thank you for that. This will be typed up by professional transcribers.

A Oh lovely. I always think that’s just the worst job, I really do!

Q Well because we’re researchers we’ve had to go through doing our own. It’s very difficult, it’s very time consuming.

A Yeah it must be.

Q But then we will send you a copy, which you don’t have to read if you don’t want to, we just send it to you so you have the opportunity to….you might not go to sleep tonight on your night off and think ‘oh I wish I hadn’t said x, y or z’, so just cross it out and send it back, that’s not a problem. And then everything would be anonymised when we take it forward into the analysis. And then the other thing which is going ahead is, we will be inviting people who have taken part in this part of the research to see if they would like to take part in the digital story telling workshop. Which is quite an interesting process, it’s a Canadian academic who is leading that part of the project and she’s got a lot of experience in supporting people to sort of share their stories in a digital form, which ends up in about a 2 or 3 minute film which we are publishing online as part of the project. And we are creating new teaching resources for GPs and medical students and all sorts of people from the project. So we will invite you, you don’t have to decide now if you want to take part in that, but there’s four Saturdays in October – each Saturday in October we will be holding a workshop – so we will get in touch probably at the beginning of September, not that long, to ask you….

A I’d love to do it, yeah, it sounds fantastic.

Q Oh that’s good.

A And also I’ve got half a mind on thinking ‘ooh that might be a good format for a project for the charity’.

Q Oh that’s great because you can help with….[name] is so experienced she’d sort of like help you with any questions or anything like that after I’m sure.

A Yeah. I’d pay her for a day or two to help me set something up.

Q Yeah. And [name]’s been through the workshop and she’s created a story, and it’s a really empowering experience and most satisfying. So that’s great. So yeah. And we’ll be sending you a voucher, [name] will be arranging that – or [name].

A Yes. Such an exciting thing to do.

Q So you can spend that on your Saturday morning. No that was really great.

A That was really great actually. It’s so weird because you don’t usually get to talk about yourself do you?

Q No.

A But yeah it was lovely. It’s probably what therapy is like isn’t it? We ???

Q There is stuff written about, you know a research interview should not be an therapeutic encounter, but I can’t see how it can’t be. You get the opportunity to talk about something that you don’t usually talk about.

A Yeah.

Q I don’t have a problem with that.

A Yeah it’s therapy in that sense not in a….you know I don’t mean in a….yeah. Is it really tiring doing them?

Q It is because of the personal thing.

A Absolutely.

Q Do you know what I mean? It’s sort of like….

A And you’re switching aren’t you from….

Q I know, it’s just like….oh. But it’s fine I have to say, it’s just momentary like just sort of where your mind just goes off.

A It must be quite draining, you know when you’ve done a few at the end of the day.

Q Well it’s a ??? isn’t it, it needs to be done, that’s the thing.

A Oh it’s just amazing. When [name] told me I just couldn’t believe it and I thought isn’t that amazing that in however many years nobody has ever, you know I’ve never seen anything. And because of the work I do, it’s not that I don’t keep up with the sector and kind of read around it and stuff for the charity work, but I’ve never seen anything like it. ???

Q No it’s good, it’s a good project and we will be in touch throughout, so that’s great. And it’s lovely to meet you and I’m so excited ???

A Is there any family resemblance?

[Identifying information]

A Yes I will. I really will. A bit more work to do, but yeah after that I will.

Q And thank you for the time.

A Thank you, it was great.

Q I’m going to call [name] back to get the recording so I don’t lose it. I’ll send her a text. There we are.

A I’m sorry to be late.

Q Oh it’s fine, don’t worry about it at all. Cool. I’m going to text her now, so I’m going to sit here.

A Bye bye then.

Q See you. Nice to meet you.

*Interview ends at 46 mins 10 secs.*