Q I’d like to ask you, but just feel free to go in the direction that you want to go in, it’s not like a police interview and we’re going through it in that kind of really strict kind of way. So we are just interested in your experiences, really. So would you mind telling me why you wanted to take part in the study in the first place?

A Well I’m a sibling carer and my brother’s quite complex. And I’ve only been sort of doing projects with SIBS for about a year or so, I only found them back then. And whilst I’ve met some really wonderful siblings I am still yet to find anybody that has a brother like mine, a situation like mine. So I think it’s important for projects like this to get a view of maybe a situation or a person that isn’t very… like a common kind of situation as ours is with family and things. UNIQUE SITUATION, ISOLATING?

So I have given up work to look after my brother. My parents are still, you know, fit and well at the moment, my dad works and my mum is a parent carer. But we have no other outside support, there is no family support and we don’t have, like, a social worker. He has a day service that he goes to 3 days a week, but other than that there is no outside support. And my brother has quite a rare condition, well he has several kinds of rare conditions really, so again I’ve yet to find anybody that’s like my brother that has the same complex needs as my brother. So I think by sharing my story I guess it can give you maybe a new insight into something, or just give you more, a better overview I guess of disability as a whole. Because we hear a lot about autism and we hear a lot about complex needs, my brother is in the middle and he has both along with a few other kinds of rare conditions thrown in. So yeah I guess it’s just to hope that I’ll bring something to the table that’s kind of missed otherwise possibly. NO SOCIAL WORKER OR EXTERNAL SUPPORT. EMPHASIZING RARENESS OF HER BRO. WANTS HIS/THEIR EXPERIENCES ACKNOWLEDGED/INCLUDED.

Q Do you mind telling me about what prompted you to become a carer and give up your job? What happened that led to that?

A So I was working in a Special Needs school, I’d been working there quite a few years. And my brother is 28 now, so my parents have been caring for 28 years. He went with the school system, absolutely fine, and then went on to college for a few years, and then it was like services just dropped off the face of the earth, you know. So my parents kind of struggled a little bit. And we finally kind of got on our feet with this day service he’s at now, he loves it there. And because it’s only 3 days a week for the other days mum was having carers come in. And there would be one that would come for a few months and then they’d say ‘no it’s not for me’ and then we’d have somebody else. And it was just kind of one after the other of people that just weren’t right for him because of his autism and, you know ??? and things. And it wasn’t great for my mum because she couldn’t relax because she was always sort of training new people [support workers] or in the back of her mind she’d be thinking ‘they’re going to leave soon’ or whatever, you know, never got settled with anybody. LOSS OF/LACK OF SERVICES. IMPACT ON PARENTS, PARTICULARLY MOTHER. STAFF COMING AND GOING IN HOME.

And then she broke her elbow. She’d actually broken it two years previously, hadn’t dealt with it and she got calcification in her elbow and it was causing her a lot of problems so she had to have an operation on it. So it came from her saying ‘is there any chance that you could kind of help out while I’m recovering’. So I went to my boss and she said no we can’t give you that kind of time off. So we went down the route of would I be able to take on the PA role, people don’t usually employ a family but in this instance we can make an exception, kind of thing. So to be employed full time and looking after my brother – what better job is there in the world, you know? So I handed my notice in at work and I’ve been doing it ever since. And that was about 5 years ago. BACKGROUND TO BECOMING A CARER. THE TURNING POINT (INJURED ELBOW). ANOTHER EXCEPTION. BEST JOB IN THE WORLD.

Time 5:00

Q Do you live at home?

A No I live separately with my partner but I’m at my parents house about 6 days a week.

Q Gosh, so that’s quite a big commitment isn’t it?

A Yeah. Because it’s sort of done flexibly, so there’s a budget and then you are allocated hours. So it started off as a few days and that mounted up to 6 days. Like the time at his day service I might take mum shopping or, you know, take her to see friends or whatever because she doesn’t drive and because she’s quite isolated. So it’s her as well. PAID CARER FOR HER MUM TOO?

Q And so you say at the moment you don’t have a social worker, but how does your set up with the Direct Payments and the day service?

A I’m not sure to be honest because I wasn’t around when it was set up. INTERESTING GAP IN KNOWLEDGE. DOES THE CARING THOUGH PARENT STILL LEADS ON THE BUDGET/ADMIN.

Q Your mum might know.

A But I think we’ve got a learning disability nurse now, we’ve never had a social worker. I think mum just manages things really well, she’s really good with that kind of stuff. NO SOCIAL WORKER.

Q Yeah. I think at some point there must have been a social worker who signed off on the Direct Payments, I don’t know? I would have thought there would have had to be someone. But you know you don’t….so we….well I don’t think we do have a social worker at the moment because my son’s 28 like your brother and he’s had 9 social workers since he was 18, so like that shows you how ??? they are. So I don’t know if we have a named one at the moment. But they come and they kind of re-evaluate the care package sort of annually.

A Yeah we don’t have a social worker that is like allocated to the family, somebody might come and do a yearly….they come and do an assessment.

Q A yearly review.

A Yeah, ??? who it is that comes.

Q And they don’t come in between times?

A No. Like I say, we’ve got a learning disability nurse now but that’s about it, we don’t really get…. COMPLETE LACK OF SOCIAL WORKER. HOW IS THIS POSSIBLE?

Q And often do you get to see the learning disability nurse?

A I think the last time we saw her must have been about a year ago. But she does regular phone calls and just checks on how everything is and what support she can give and…. Yeah, they’re not very hands-on physically with my brother because he’s very challenging but they stay in contact, you know there’s good communication there. GOOD SUPPORT BY DISTANCE.

Q Yeah. And what prompted the access to the learning disability nurse, because you didn’t have that for a while and then you did?

A So I think just….we didn’t know that we could have help really, there’s no kind of guidelines, there’s no guidance. And like I said, because we don’t have a social worker there isn’t anybody to sort out these things on our behalf, it’s very much kind of you turn up to an appointment and somebody mentions it and you go ‘oh, interesting’. So yeah. And my brother had a lot of medical investigations, so because of his challenging behaviour and because he’s non-verbal and you can’t explain to him, he has to be put under general anaesthetic when he has any tests done. So it should be that every few years he goes in and has his brain scan, a bowel scan, he has his teeth done by a dentist and various other checks, his heart and things. And I think possibly through having all those investigations and coordinating that we got the learning disability nurse involved to coordinate all this. You know a lot of professionals have to be in one place at one time, it takes a lot of organisation. NO GUIDANCE OR INFO.

Q Yeah. I imagine when he was a child you were maybe not involved in this back then, but it would have been the community pediatrician who would have done all of that. And that when you get to 18 it goes back to the GP is the person who is supposed to organize it. But like [name] had never seen a GP because we’d always seen the community pediatrician, so that’s often a tricky…

A Yeah. And also people change all the time, people leave, people….you know so you are seeing locums that don’t know him and things like that, so there’s no continuity because….

Q No it’s really hard.

A And you’ve got to start again. So there’s been lots of times where things probably should have gone a certain way and they haven’t, but I guess that’s true for everyone at some point I guess. STAFF CHURN, CONTINUALLY STARTING AGAIN.

Time 10:00

Q Yeah, and it sounds really good that you’ve got a learning disability nurse because the other thing she may be able to do is the annual health check, because you are supposed to have an annual health check.

A Yeah.

Q Yeah. Gosh that’s a lot of stuff going on. And you are right, I mean we’ve only just started speaking to people but I think we’ve been speaking to people in interviews but we have a group of people who are guiding the research and they include sibling carers, parent carers, people with learning disabilities, and I think we have talked to a lot about the kind of where care happens. So the idea that you can be a carer and not live with the person that you care for. And we were thinking about for a lot of siblings they care from somewhere else, they’re not living at home so they’re caring from a distance. But I don’t think that we were thinking well actually a sibling might also be a paid carer of a sibling, I don’t think we were thinking of that.

A Yeah it’s not the norm, it’s not a done thing generally I don’t think. UNIQUE.

Q No but I have heard of it before actually.

A In specific situations they can, yeah. I think you take a risk of people taking advantage of it don’t you? You know when it’s family and, depending on the dynamic there, it can be taken advantage of. And also I suppose it can leave carers quite vulnerable because if your boss is your family member, without kind of understanding the relationship in depth, boundaries and things like that can be an issue. And then obviously if you’ve got a bit of a volatile relationship I guess, I imagine that would cause problems. POTENTIAL RISKS OF PAID FAMILY CARER. SHE SEEMS TO BE SUGGESTING THE RISK TO THE CARER RATHER THAN HER BRO.

Q Have you had to kind of talk things through, have you been quite good at communicating with each other and saying ‘this is working for me, this isn’t working for me’ or…?

A I think yeah for the most part. I struggle sometimes because I’m not very forthcoming with things sometimes and I don’t like to rock the boat, I don’t like to upset people – that’s just me as a person, I’ll kind of keep people pleased and I’m ‘yeah it’s fine, I’ll do whatever needs doing’. ‘PEOPLE PLEASER’. DESCRIBING PERSONAL CHARACTERISTICS AS AN EXPLANATION.

Q Do you think it’s partly because it’s your mum and there are things that are quite tricky to say to your mum?

A Sometimes I guess, yeah. But I think generally I’ve always been like that with anyone, certainly in work and…. Because I specially work in a Special Needs school, you know if somebody sort of said to me ‘well it’s for the benefit of the children’ I would absolutely….you know so I’d stay late or I’d do extra hours when probably there wasn’t a need to and things like that. But I’d be quite happy to do it because it benefited the children. And I adored my children. But again, like I say, when you’re in an emotional kind of job role in any kind of situation, I think if you are a very empathetic person as I am, it leaves you open to being taken advantage of maybe. SHE DOESN’T REALLY ANSWER THE QUESTION ABOUT HER MUM.

Q Yeah. And I’m hesitant to ask this question and you don’t have to talk about it if it’s too tricky, but I wonder what you are thinking about the future?

A Well I try and think about it but it is difficult, because we can’t really say. I mean we’ve only recently had kind of official diagnosis for my brother, and even that’s kind of….it almost asks more questions than it answered. So we don’t know what his future is. We don’t know how limited his life is. I mean he’s got a great diet, he’s really well looked after health wise, I mean the way he eats, how kind of his physical…. I mean he’s got cerebral palsy but because of the cerebral palsy he has to work harder almost to move around, you know so he’s slim built but he’s very strong. And we feed him well, he has an all pureed diet, mostly sort of vegan, he doesn’t snack, no junk food, you know no fizzy drinks or anything like that. He’s super, super healthy. So in theory my partner jokes that he’ll outlive us all. But certainly in terms of care and stuff my mum is very anti care homes and any kind of residential setting, just because he is so vulnerable because he’s non-verbal. He has so many complex needs she just….and he’s been hurt before in a residential setting. She’s very anti. Obviously we know there’s some great homes out there, there’s some great caring, but it took a long time for us as a family to trust that he’d be safe in the care of other people. That’s another reason why there was sort of a bit of gap between college and the day service because it was difficult to kind of let him go after that happened. PREVIOUS TRAUMA, BROKEN TRUST SO FUTURE PLANNING IS DIFFICULT. REGIMENTED DIET. LATE DIAGNOSIS AND UNANSWERED QUESTIONS. SO MUCH UNCERTAINTY.

Time 15:38

Q Absolutely.

A Yeah, so long term, there isn’t a plan as such because we just don’t know what his health will look like; I couldn’t tell you what my parents’ health will look like. SO INTERESTING, FOUND THIS IN GROWING OLDER. ZERO PLANNING.

Q Sure.

A So it will kind of fall to me really. My partner is Greek, so in his mind we will save up, we will buy a house in Greece and we’ll move there. But I try to let him have that dream but there are times when I’ll go ‘you know that probably won’t happen’. And whilst he’ll say, you know ‘regardless of what happens I’ll never leave you, I’ll always be here to support you’, wanting to go home is a very present feeling for him. Because ‘England’s alright but it’s pretty rainy and people aren’t always very welcoming’ and so, you know. And he comes from a really small fishing village in Greece, a really small community where all your family and friends are within a mile of you, and it’s a really nice life, it’s very laid back. The sun is always shining, you’re right next to the sea. He’s got a small fishing boat, you know he goes and takes out his boat and goes fishing for the day, I go out with my friends, it’s lovely. So in an ideal world I guess that would be the plan. But we just don’t know what’s happening this side, and I couldn’t just sort of leave my family to it. And the thought of putting my brother in a home and me leaving the country just….I couldn’t do it. TENSIONS BETWEEN CARING AND PERSONAL RELATIONSHIP/LIFE. SO DIFFICULT. OVERRIDING LOYALTY TO HER BROTHER.

Q It’s massive isn’t it? I know it’s a real massive thing in my daughter’s life, you know, and she feels the same way. So she’s got this plan, we call it The Compound. It sounds military! But she’s got this plan that when the time comes she’s just going to move us all in together.

A Well that was kind of….that was something, I mean we are renovating our house at the moment. We bought a house with a downstairs bathroom, that was the kind of planned theory. The driveway would be wheelchair accessible and it would have a downstairs bathroom for my brother. And we bought this house and when [name] stayed over he absolutely loved it, but the three times he had a bath, three times he had a huge meltdown in the bathroom. And the bathroom’s tiny and it would be really dangerous, you know, the bath is there and you turn around there’s a sink ??? there was just too much for him to bash his head on. And one of the first things he does when he gets angry is he bashes his head. So it was just a bit dangerous. So we looked into extending the bathroom, we couldn’t do that because obviously with drains. So then we said ‘right, if we extended on the back, put a kitchen in, we could turn the kitchen into a good sized bathroom’. So we started doing that about 2 years ago and we still haven’t got a bathroom. But we are basically adapting our house so that it suits my brother. ADAPTING HOUSE AND LIFE FOR HER BROTHER. And I’ve got to that point where people say to me ‘this has gone on forever now and it’s not good for you to be living in a building site’. But at the same time they sort of go ‘well why are you doing it’. But at the same time they haven’t got brothers and sisters that require that extra help so they couldn’t possibly understand the drive behind it. So I guess the plan is eventually that he will certainly come and stay with us regularly, if not move in. FUTURE PLANS TO SUPPORT. LACK OF UNDERSTANDING BY OTHERS WITH NO SHARED EXPERIENCE. EXPRESSED NEED TO SUPPORT AS A DRIVE.

Q Yeah. And we’re interested in your experience as a carer and your experiences of mental health as well. So I wondered if there was anything you wanted to say sort of specifically about mental health? I think it does link to the idea of the future, because I know sometimes that can be a big worry. So is there something that you want to talk about specifically around mental health?

Time 19:43

A Sure. I mean I do suffer with anxiety quite severely and depression as well and certainly the first time I kind of actively experienced anxiety it was when I bought a house – so buying a house was a huge trigger because none of my family had bought a house and it wasn’t something that I’d grown up with that kind of plan. It was that we were in a position to and we thought that was the best. LOVE THIS EXAMPLE THAT SITS OUTSIDE THE TOPIC. MENTAL HEALTH RELATED ISSUES.

Q Sorry just one second, I’m just going to close the door sorry because I’ve just heard them all come back and…..sorry, yeah. So you were buying the house.

A Yeah, and it was around that time that I first experienced that feeling, like kind of feeling ??? and I couldn’t breathe. And I said to my partner ‘I can’t breathe, I think I’m having either an asthma attack or a heart attack’, I thought something medical is going on. And I was, you know close to ringing an ambulance it was so overwhelming. And then from then I’ve just had anxiety attacks and just that feeling of anxiety quite often. And there doesn’t have to be anything wrong, it will just ??? you know be when I’m sat sort of watching TV or whatever, it doesn’t have to be triggered by something. ANXIETY ATTACKS.

Q Yeah.

A And then with sort of depression and just low mood, again it just comes on at various times, just overwhelming, you know I’ll sort of have a lot of things on my mind that maybe I’m not dealing with, just get a bit….you know your emails come through and you think ‘I’ll deal with them when I’m in a better sort of state of mind’ but then not dealing with them adds then to your worry. And yeah sometimes the worry is about the future a bit more at the forefront of my brain again. And yeah just the worry is constant. And it’s not just the health of my brother but the health of my family. It’s, you know my partner has got his dreams and wants and maybe my kind of commitments will stop him doing what he wants to do. They’ll all be kind of at the forefront of my thinking. And then that some days can just be really overwhelming. And it can just be the weather, you know we’ve had a long winter, it’s not stopped raining. OVERWHELMING DEMANDS, OBLIGATIONS, COMPETING TENSIONS FROM DIFFERENT LOVED ONES, FEAR OF THE FUTURE PLUS OTHER STUFF LIKE THE WEATHER.

Q Does anything help? I mean have you found anything that supports your mental health?

A Not really. I mean I talk to my partner about it but he’s a typical Greek, he’s very laid back and ‘oh don’t worry about it, it will be fine’ you know. I did have….what’s it called, CBT for a little while but that wasn’t…I didn’t find that very helpful. And then I’ve been on medication before, but again whilst I didn’t sort of feel as anxious, I didn’t feel anything at all so I wasn’t enjoying anything, and I thought surely that’s counterproductive. So it was a bit kind of take the extreme highs with the extreme lows, or just plateau.TRIED CBT WHICH DIDN’T WORK. MEDICATION REMOVED FEELINGS SO STOPPED IT.

Q Yeah, a complete blunting thing.

A Yeah.

Q Yeah, I know.

A I didn’t like that. I didn’t like the idea of being reliant on medication and not being….my brother the same, we’ve got him on very minimal medication. Yeah I’d much rather heal things holistically. STIGMA? AROUND MEDICATION USE. HOLISTIC APPROACHES.

Q Yeah. And what prompted the time when you were having CBT, and what prompted being offered medication?

A It was around when the anxiety kind of started really and it was just getting overwhelming. And I went to my GP about it and ??? self-refer, and it took about 2 years for me to even get a call back. But when they did call me….

Q But what was the self-referral to?

A Well I think it’s Better Minds now. But back then there was a self-referral through the GP. He would send you a link and you just clicked on it and filled out a form and it sort of said somebody will call you. LONG PROCESS TO ACCESS SUPPORT (THAT DOESN’T WORK).

Q Was it called Instant Access to Psychological Therapies?

A I don’t know. It was something to do with Nottingham University Hospitals they were doing it. And I can think of the kind of image that was on the emails but I can’t remember the name.

Q And did they offer you CBT?

Time 24:47

A Yeah. So it took about 2 years. And I got a phone call from this, let’s say company, and yeah I was on the phone for a good sort of hour or hour and a half. And she just sort of asked me what was going on, and it was just like word vomit for a good hour ‘well this, and this, and this, and this’. And yeah and then she said ‘what’s funny….’ I just remember her saying ‘what’s funny is’, she says ‘you’re telling me all these awful things’ she said ‘and you’re laughing as you speak, which tells me that actually you’re quite unwell’. I thought ‘oh, OK’, I never thought of myself as unwell. So she said ‘right, well I think the first sort of port of call would be getting you some CBT and maybe talk to your GP about going on medication alongside it to try and get things moving so that you’re not overwhelmed by this anxiety’. THIS IS SO ODD. WAS IT COVID TIME? A PHONE CALL WITH A STRANGER TO UNPACK MENTAL HEALTH ISSUES SEEMS BIZARRE. HER UNAWARENESS THAT SHE WAS UNWELL (THIS CONTINUING TO CONTINUE ON REGARDLESS - THOUGH NOT SURE OF THE QUALIFICATIONS OF THIS PERSON).

And that’s what prompted the medication was because she sort of said if you just do the CBT it might be OK while you’re doing it but then if you have the medication alongside it would just get things moving, and then maybe when the CBT, you know it helps, just stay with the medication after the sessions have ended. But I think I was supposed to have 13 sessions, and on the 10th session the lady said to me ‘well I’m going travelling round Egypt so I’m going to have to cut our sessions there’, and I sort of went ‘oh OK’. And that was the end of that. THIS IS SO POOR.

You know, NHS for you. You get what you’re given don’t you and you’re just grateful for that. ACCEPTANCE AND BIDDABLE. And that was it. And I never had anything else after that. I came off the medication, it made me really ill coming off the medication which put me off ever going on it again. And I think, yeah, that was it really. And then ever since then I’ve tried to just do things kind of as holistically as possible. So I have like CBD oil for when I can’t sleep and that’s really helpful. But yeah, just day to day, as I say I just get anxiety and it will just come on at random and I try and do maybe breathing technique and things like that. But as far as kind of ever living without it, I can’t imagine it at this point because I don’t think those worries will ever go away. And certainly as I’ve got older.

Q I understand. I think it’s like volume, it can get turned down on it can’t it, sometimes the volume is a bit down and then there are times when the volume’s back up again.

A But I think as you get older as well the worries of the future become a lot sort of more magnified. Because when you’re younger, it’s like anything, when you’re in your 20s you’re not thinking about bad knees and bad backs you know, but when you hit 30 you’re thinking ‘oh better start wearing better shoes and getting a support for the sofa at home’ and those kind of things. I think as you get older you start thinking ‘gosh, my parents are ageing, I’m ageing, my brother’s ageing, what about their health, what about my health’. IS IT RESILIENCE TO DITCH THE PILLS, THE CBT AND JUST ACCEPT YOU ARE GOING TO HAVE TO GET ON WITH IT. THERE’S SOMETHING ALMOST NIHILISTIC IN THESE ACCOUNTS WHICH IS AN OUTCOME OF THE UNDERSTANDING AMONG PARTICIPANTS THAT SUPPORT DOES NOT EXIST AND NO ONE ELSE IS GOING TO SORT THIS. THEY ALMOST HAVE TO SET ASIDE THE ‘LUXURY’ OF MENTAL ILL HEALTH TO GET ON WITH THE JOB AT HAND. WHICH IS NOT GOING TO CHANGE OTHER THAN EVERYONE GROWING OLDER.

Q So you mentioned that you’ve been in contact with SIBS and that you’ve met other people but their siblings weren’t quite like your brother, and I guess they’re not in the same situation. But has it been useful to meet other siblings, has that been….

A Yeah. I don’t think I’ve ever met another sibling – I probably have and we’ve kind of, you know I’ve been talking to her and I’ve said ‘oh my brother’s disabled’ and they’ve gone ‘oh my sister’s disabled’, ‘oh fab’ and that’s kind of been the end of it. But in January SIBS did like a retreat, I don’t know if you saw that, for siblings. THE IMPORTANCE OF THE SIBS WORK AROUND BRINGING PEOPLE TOGETHER TO TALK IN SAFE SPACES

Q I saw it advertised, yeah.

A Yeah. And they asked for people to kind of apply for that and then they picked 20 people. I was lucky enough to be one of the 20. So I went to this retreat and it was fantastic. It was a sibling only environment. We had talks and you know it was a bit like school I guess where they sit you in a circle and you say ‘my name’s Tyler and this is my thing, this is how I feel about that’. But it was just this lovely kind of open discussion about things. So we’d have a topic that we were speaking about, so one of them was like what are the challenges to having a sibling with autism specifically. And we would just discuss it. It was just this lovely open group and discuss things. And things would come out that you’d thought but never said because it felt safe to say it. And then there would be people that would say things that would resonate so deeply with myself and with others around.

Time 30:00

And then on the last day we had a discussion about care in the future. And they said we’ve specifically left this until the end because obviously it’s a really tough subject for a lot of people. And as we were talking, things were being said and people would just sort of burst into tears. And we were like little emotional bombs in this circle, each of us just suddenly crying and the tissues were passed round. And we just had this group kind of cry together you know, and we discussed….said what we were worried about. But there were very different views. THIS IS SO REVEALING AND DEVASTATING.

So the lady that was sat next to me, her brother is already in residential care, and she said ‘my family got better when he went into care, we couldn’t be happier now and he couldn’t be happier now’. And there was another lady that said, you know ‘the thought of my brother going into care keeps me awake at night’, which really resonated with me. And she began to cry. And I thought everything she was saying it was like hearing my own thoughts said out loud, which then made me cry. And we just, all of us just sobbed. But it’s like it was therapy in itself. And just to have the opportunity to be in that environment was just magic, and you wouldn’t get that anywhere else. IMPORTANCE OF SHARED EXPERIENCES WHILE ALSO REVEALING THE DEVASTATING ISOLATION THAT SEEMS TO CHARACTERISE PEOPLE’S LIVES.

Q Yeah. Did you make any….are still in contact with any of those people?

A Yeah we’ve got a What’s App group for people that were at the retreat and we keep in contact. A lot of them were…I mean we were from all over the country. So there’s one lady that’s up in Scotland. And then there’s a few that were down in London. I’m in Leicestershire. You know there’s people that came over from Wales. All across the country. And a couple of people have met up in London, which is really nice. There’s talk of, you know there’s a few people in the Midlands that were talking about possibly meeting up. But the irony of it is when you’re a carer it’s finding time when you’re free to do it on the same day isn’t it? THIS CONUNDRUM WE’VE FOUND IN THE PROJECT MEETINGS ETC. YOU CAN’T ACTUALLY MEET BECAUSE OF CARING COMMITMENTS AND ZERO REPLACEMENT BODS.

Q Yeah.

A So yeah we keep in touch and that’s really nice.

Q I think social media has become really important to me, because of course it wasn’t around when [name] was little. But now, you know I know people all over the country and I feel like now if I have a question about something I could ask and someone would say….I can remember when [NAME] was leaving school, it was something about his educational health and care plan, going on Twitter and saying ‘the local authority have said this’ and someone going ‘no, no, no – Section 2.1.2.2 - you can say this’. And I….that’s just brilliant. Sometimes it’s really practical.

A It’s like a cheat code isn’t it, it’s about you going ‘this is my problem, how do I deal with it’ and you get at least 2 or 3 people going ‘this is how you do it’. A CHEAT CODE… ALWAYS FOUND OUT THE MOST IMPORTANT INFO FROM OTHER PARENTS. WHAT DOES THIS SAY ABOUT SOCIAL CARE?

Q Yeah ‘this has happened to me, this is how you do it’. And yeah I think it’s so important to me. And I think that people think ‘oh God she’s Twitter obsessed’ and I guess I am, but I think I have a particular need that other people don’t have.

A And there’s very few people, friends – and you know you don’t always want to talk to family about things, or when you do it’s so emotionally fused, sometimes it’s nice to talk to somebody that’s just impartial, that’s go no emotional input in your situation, but they understand. INTERESTING. CAN’T TALK TO FAMILY, BETTER TO TALK TO OTHER PEOPLE. WHAT ARE THE BARRIERS TO TALK? WHAT DO THEY MEAN?

Q Yeah. And I think you said that thing about saying the things that you can’t say to anybody else, you know.

A Yeah, or all those things that just sit in the back of your mind and you never say them out loud. For some reason you feel safe to say them in a sibling environment. THE THINGS YOU NEVER SAY OUT LOUD OTHER THAN TO OTHER SIBLINGS (IN A SAFE ENVIRONMENT). VERY TANGLY FAMILY INTERACTION/RELATIONSHIP STUFF GOING ON HERE.

Q Yeah, I went….

A Go on, sorry.

Q Sorry, it’s just I went to a thing at the university where a sibling PhD researcher was talking about his research which is around siblings and humour. And he was talking about family humour. And he said that…

A Vinny? Clark?

Q Oh yeah. And what really, really amused me was that one guy said ‘just to let you know I wouldn’t punch anyone else with a learning difficulty’. And you know you think people are horrified. But how many people have you like…

A I know.….

Q So that was really interesting that he was thinking about humour.

Time 34:46

A Yeah. But our humour’s really dark as a family. You’ve got to laugh sometimes otherwise you’d lose it I think. I mean somebody commented actually the other day on something, and they said ‘you know you’re a carer when…’ and then the comments were all, you know. And somebody put ‘every conversation turns into one about bowel movements’. And I was like ‘absolutely’, absolutely. And I thought that is so spot on. Because my brother’s got issues with his bowels and he’s doubly incontinent, so yeah we’ll kind of come in ‘how has he been’, ‘oh his behaviour’s been really bad’ and we’ll go ‘has he had a pooh?’ You know ‘oh well he did a bit’ and we’ll talk about what time he had a pooh, how big it was, you know. And you think these wouldn’t be normal conversations for most people. But I guess it’s like when you have a baby and the health visitor comes over and you go ‘well he did a pooh at this time in this nappy, and this was the colour and consistency’. But it goes on for 28 years, you know. So yeah. So little things like that. COMEDY RELATING TO BOWEL MOVEMENTS. ‘DARK’ COMEDY.

And just sometimes I think for a long time, like you said with there not being social media around in the early days you know, you almost felt like you were the only one, even though clearly you’re not but it is when you feel like you are the only person. And being able to go on social media and find a group where there’s other people. And what’s been a great feature as well is being able to remain anonymous, I think that’s a great feature on Facebook is that you can put an anonymous quote. So you can just say ‘this is my situation and this is how I’m feeling and I’m sorry if that’s really awful and it makes me a bad person’ but you know. And people share the deep sort of darkest feeling. And then you get people go ‘yeah we feel like that as well, it will pass, it’s a totally valid way for you to feel and that’s alright’.

And sometimes that can be the difference between an anxiety attack and a period of depression, because a lot of it comes from guilt. It’s not just the feeling of feeling that way, it’s the guilt of feeling that way. And in SIBS they talk about the guilt resemblancy ??? sore. So that was really interesting, you know you feel resentful of the situation, you feel guilty for feeling resentful, and you feel resentful of your guilt – and you’re just back and forward. And I thought that’s really interesting. A lot of the time it’s just having your feelings validated isn’t it and just you know you’re not selfish and you’re not mentally ill, you’re going through something that isn’t normal.

Q Yeah you’re experiencing….I think that’s one of the reasons why I, because I’m a ??? CBT, I found it quite difficult because I felt like they thought there was something the matter with me. And I felt like I was just stressed for really good reasons. So the kind of, you know ‘well that’s not logical, write your list’….

A Do your ???

Q I thought ‘no, no, no you’re not quite understanding what’s going on here’.

A Yeah that’s why I didn’t find it helpful I think. They sort of trivialized very complex feelings, you know ‘put them on the worry tree’. And I thought what on earth is that going to do for me ‘write it down on my worry tree’, it’s still there.

Q Yes, make a list, put it on your list.

A I’m still living with it.

Q Yes. I felt invalidated by it I think, yeah.

A And I think it depends on the person that’s doing it as well. If they’re not really interested – and I guess they’re limited to their kind of…you know they’ve got their Section 2.3 that you’ve got to…and they’ve got their boxes they’ve got to check. And a lot of sibling situations don’t fit into that. It’s sometimes, you know you just think it’s not box-checkable, it’s got to be flexible and it’s got to be person-centred. They talk all the time in disability about being person-centred but then when it comes to siblings, when it comes to mental health, they’re not. It makes no sense.

Q Like that ‘it’s not box-checkable’, because the project has like a literature review and then we run some workshops with carers. And our plan was, and bearing in mind a lot of us who wrote the project and we talked to carers when we wrote the project, and now it just sounds like a mad plan. But our plan was that we were going to get carers to design the mental health survey because we thought they could ask the questions they wanted to ask. But when we got people together they were like ‘ticking boxes, what on earth’s that?’

A We do that all the time and it does not get us anywhere.

Q ‘We’re not doing that’. No.

Time 40:00

A And also if you give somebody ‘right, is your sibling this, this, this or this’ and you go ‘hmm, well he could be a bit in that group; and he’s a bit in that group’ you know. But this is why we found it difficult to find sort of a placement, a day service for him. It’s because you sort of get these behavioural kind of units that are for really challenging and extreme behaviour, and then you get these lovely wheelchair accessible calm spaces with lovely lights and calm music where they have massage and it’s…. you know. And my brother sits in both those categories but also in neither, so it’s really difficult to find somewhere in between that can cater for his challenging behaviour but also attend to his medical needs and his sensory needs. So yeah it’s tricky finding the services that can kind of help.

And the same thing with kind of going and getting mental health support. You know somebody who’s experienced a one-off trauma and has PTSD cannot possibly benefit from the same therapy as somebody like myself who has had a lifetime of traumatic experiences, anxiety about future problems, you know the ‘what ifs’ and the whatever else. And then the family trauma, because it’s not just happened to you, this has happened to your whole family, so you can’t possibly be treated in the same way. And yet it’s condensed into these 10, 13 sessions of CBT where ‘this has been printed off Google for you to fill out in the session and let us know how you feel when you come back’. And it’s like well this isn’t going to work for me. But then when I sort of questioned ‘well what happens now, because that’s done and it hasn’t worked, well what’s next?’ And they sort of said ‘well you can go back on the waiting list and have another round of it’. And I said if it didn’t work the first time it’s not going to work the second time. And it took me 2 years to get there, I’ve now got to go back on the waiting list and wait another 2 years for it not to work.

So you know I just think it’s better off just kind of figuring it out on your own and going on social media and finding groups and finding support elsewhere because I just don’t think that the NHS is cut out for siblings and complex disability as a whole. I mean even autism, which is so at the forefront now and there’s more investment and there’s more research and there’s a lot of funding for autism, but you still see people not coping constantly. I mean medical professionals that just don’t know what to do, they’ve had all the training have got no idea what they’re doing. And you know we get asked really ridiculous questions and think….I mean my mum was just talking about actually a few years ago when she got a letter from the DWP asking if he was fit for work and could we bring him down for a work place interview. And she was like ‘no’, you know cerebral palsy doesn’t just cure itself overnight.

Q No I know, that stuff is so stressful.

A And she had to physically take him down and show them, you know ‘this is my son who is disabled’.

Q It’s outrageous.

A And she doesn’t drive. And it was so distressing for him. It was distressing for her. And it was just totally unnecessary. But things like that, the system just isn’t built for people that are differently able, you know, or their family.

Q Yeah. But you would think they could work….you know that shouldn’t happen again. You know I’m not sure whether….

A I mean it hasn’t happened to us again. Thankfully now we have a….there’s a lady that comes, she ticks the boxes funnily enough, ‘still disabled, still can’t work, see you again next year’, you know. And the silly thing, because I mean it’s not going to change you know, so why not have a box that says ‘indefinitely disabled’ you know ‘going to be that way for his entire life’.

Q Yeah, not a fluctuating aid.

A So there doesn’t need to be a yearly check, you know. So yeah it’s again being treated the same as somebody with sort of limited mobility issues who has maybe had an accident and can’t work for a year, so you assess them again next year – that’s fine. For somebody who has got severe brain damage, autism, is non-verbal, is deaf, they’re not going to be ready for work in a year so just sign them off indefinitely and be done with it and don’t cause stress to the family.

Q Yeah.

Time 45:00

A But these things, they’re not thought about because they’re usually put in place by people who have never experienced it. And yet if you put a sibling in charge of those things the system would be completely different, you know.

Q Yeah. I wanted to ask you about the digital storytelling workshop bit, do you remember that bit?

A Yeah I remember reading it but just talk me through it again.

Q So they are going to be, in October and in January. And in October, well I think it would depend what people want. So when we spoke to you and said we were planning a bid they thought that probably siblings wouldn’t want to be in the same workshop as the parent carers and they might want a sibling only space.

A Yeah, I would agree.

Q So I think that probably will happen in January because I think it will be easier for us to recruit parent carers than it is sibling carers. So I think that probably won’t happen until January. So I will be in touch with you in between times because I’ll send you the transcript when the transcriber has done it and so on. And I’ll just keep in touch but it won’t happen until January. And it sounds a bit….don’t be outfaced by it because I’ve done it and it’s OK, because I am not tech savvy, you’re probably way more tech savvy than I am. So what people do is – I can send you some examples actually of films made for another project. So Patty is doing this bit, she has a project called Restoring Autism, and I’ll just send you the website because you might really be interested in the films. And so you’ve got some people who are autistic who are talking about their experiences; some parents; some siblings; and there are just some beautiful short films. So the films are sort of 3 to 5 minutes and originally everybody went to a workshop and did it over a weekend and it’s quite intense. And then the pandemic happened and they moved everything online, and actually that’s made it a lot more accessible to a lot more people.

So there will be 4 sessions, and then sessions with….though they are like award winning ??? like many film makers but they’re really brilliant artists in their own right. But the thing that I was so taken with, because you know when you’re really, really good at something and you’re supporting somebody who is not really good at something and I think the temptation is to go ‘oh, why don’t you….I’ll….’ And they never ever did that. They would make suggestions and ask questions, and in the end you end up with a film that represents a sort of story about your life. And they are so powerful. I mean there’s actually some I’ve watched again and again and I can’t watch without crying. So be aware of that when you watch the films because some of them, you know there’s sometimes just something in them – a bit like you said about that other person ??? and you think ‘sometimes even I don’t think I’ve fully thought it’ and then somebody else…and I think ‘oh now it’s like….’ now I can think.

A It’s exactly that feeling, yeah.

Q Yeah. So they can be quite powerful in those ways. And so, you know we always had that in mind but really response is not ticking boxes. And I think that at the end of the project we want to develop some resources, so we weren’t quite sure for who because we weren’t quite sure who people are getting support from, but GPs is certainly one. And I think that instead of just having something written, having some visual when ??? will I think be powerful. We’re hoping it will be more powerful anyway.

A Yeah. It’s a bit off-topic but just speaking of something that’s visual and that’s kind of, you know there’s been two programmes recently on BBC, there’s been Best Interests – I don’t know if you’ve seen that; and There She Goes. And there’s been a lot of talk on the kind of ??? of that programme. Now There She Goes in a way kind of resonated with me, but Best Interests, I had to watch that in stages because it was so close to home. And when I watched the last episode I just was sobbing, and I think I cried for about 2 hours afterwards. And I had to have a little sleep because I was just emotionally exhausted from watching it because there were so many things that had happened to me and had happened to my family. And the fact that he’s got a sister and the sister, you know some of the ways that she behaves and the way that she feels was just so relevant. So just having that visual and being represented. It’s a relatively new thing I think, siblings.

Time 50:23

Q Yeah. I always have mixed feelings about those films. There are some things I really like in them and other things I don’t like in them. And I had to really kind of steel myself to watch especially There She Goes because I feel really uncomfortable about the non….I know they couldn’t have a disabled actress maybe doing it but I feel really uncomfortable about that. And I was, you know at the end where she met somebody with the same impairment as her, and I thought oh they have tried to respond to that. But I just found….and I found the….

A It’s a bit insincere did you think? Not insincere but….

Q I don’t know what the word is. I just felt uncomfortable about her pretending. And then….it’s very difficult isn’t it because I find the representations of challenging behaviour really difficult because that feels sort of in one way really private, but in another way it shouldn’t be really private should it. So I never quite know how I feel about….I just think the whole thing was a bit like ‘ooh’.

A Yeah. I didn’t feel that that was as kind of reflective as….I mean Best Interests, I think the girl that plays the girl that’s disabled, I’m not sure, I think she is actually, I think she was.

Q Yeah.

A So there was that authenticity there that I thought was missing in the….

Q You see that was, I thought it was really interesting that the character didn’t have a learning disability.

A Yeah, she was kind of able in other ways, it was just her body was physically disabled. And it’s very rare that they represent people with a complex need.

Q Yeah, and I thought actually you know when they went to the school, those are the people that would be at that school and they weren’t represented. You know Lenny similarly, I thought it’s like ‘oh they can’t go there’ do you know what I mean, it’s like so far. But….ooh.

A Yeah, BBC are not ready for all that yet.

Q No but we are.

A We’re ready, we’ve been ready for a while.

Q We’re film makers ourselves. And yeah we can be. And we can have lots of conversations about this, and this is what happens when we go to the workshops and stuff. But recruiting, and it might be too hard to do this now, but if you think about a story, a story of caring, would there be one? In all the multiple….I mean you’ve told me so many stories of caring already.

A I mean my story of something that’s….

Q Or it could be something really abstract. Because you know I thought the way that you were talking about anxiety, it could just be…. So it’s not to go ‘right, now I’m going to make a film on anxiety’ you know that’s not…. But if you think about things you said about that ‘I can think about the sounds and….’ do you know what I mean?

A Yeah.

Q It might be that you think….or with the future, or you know there might be something. There are so many stories that you’ve told me.

A I mean there are times when I will have anxiety and it’s nothing to do with my future or to do with my mum’s future, or my mum’s past. Or you know my dad. Because I think my dad’s in his 60s and certainly he’s of a generation of men certainly that don’t….they didn’t discuss those things. You know ‘you be a man, you provide for your family, we kind of don’t discuss emotional things’ you know. And you know he’s very tough and he’s very supportive of the family. But I wonder sometimes how things affect him, you know he’s only got one son who he can’t play football with. Or you know there’s only one of us that will get married and have children, and all those things. And it’s also that in that then presents its own pressures as well because I’m the only one that can get married and the only one that can have children. Does that mean I must have children, I must be the one that does those things because my brother won’t do it? You know I may or may not have children. But that in itself brings guilt because then your parents now won’t have grandchildren, and that’s on me you know. So everything carries some sort of anxiety.

Time 55:16

Q You know it’s really tricky for me because you know I’m a mum and I have a daughter and I don’t feel that. You need to talk to your mum maybe. I don’t feel….I just want her to have a happy life and if that includes children…. And I think if my son had been able to have children I would feel like that, do you know what I mean?

A I thought so if one had said ‘do you know what mum, I don’t want children’ and the other said ‘I want 10’, you know, great.

Q I can’t think of anything worse than somebody who doesn’t want children having a child.

A Well this is what I think, I’m a great auntie, I’m a great sort of support and ??? for my friends. When I look after other people’s children I love it, but I don’t want it 24/7. And I don’t know if that stems from being a carer from such a young age, I feel like I’ve already done it. Does that make sense?

Q Yeah it does make sense. But I think that, you know maybe your mum and dad are not thinking what you think they’re thinking.

A Hang on just one second…

Q It’s alright.

A I’m coming. I’m just finishing off.

ANO Sorry about this.

A I know. Don’t worry. My brother will be home from day service soon.

Q Oh of course yeah. We’ve talked for ages. So just have a think about….you know you started off with ‘you’ve got a different story to tell’, so have a think about what is the message that you want to tell. And then in those workshops, much better than I can do, they’ll help you to do it and they’ll help with the tech and help with the ideas and they’ll help you with the….you know they do storyboard stuff if that’s what you want to do, or sometimes people just talk to camera. I’ll send you the examples so you can have a think. But thank you so much. I know you’ve got to go so thank you so much for talking to me. I’m sorry about the bit of a wonky start. And I’ll also organize for you to be sent your voucher for participating.

A Ah, how lovely.

Q And just one last thing could I ask you? If you know anybody that would like to participate….

A Oh I was going to say, if you are looking for sort of parent carers then I could talk to my mum, I’m sure she’d be happy to talk.

Q OK yes. So the stuff I sent you, if there’s anybody that you think ‘oh they might be interested’ or other members of the What’s App group or….

A Yeah I can check and share with the What’s App group.

Q And I think you might like to make your film on your own, you might like to make a film with another person that you know maybe, you know, so there are those options as well. So what I’ll do is, I’ll be in touch but there will be a little bit of a gap between the interview and the workshop, so we can have a catch up to talk about the film in the meantime.

A Yeah that’s brilliant.

Q Thank you very much. It’s been absolutely delightful to talk to you and thank you so much for sharing so much, I really, really appreciate it.

A Bless you. Well it’s been a pleasure. Thanks for having me. Thanks for listening.

Q OK thank you and I’ll be in touch.

A OK. Take care. Bye.