Q There we go that should be recording. And just to say I’m also working from home so if I mute myself it’s because the dog’s started barking in the background or something like that, so carry on talking. Before we start do you have any questions about the research or the project or anything which haven’t….?

A I don’t think so. I think like the form and the information was pretty kind of…like gave me quite a lot of background. And I appreciate there might potentially a different…like not a different stage, another stage in which you’re like recording people, but I know that I don’t have to do that kind of thing so….

Q Yeah, brilliant.

A Yeah I know I like kind of….exceptional and stuff so…

Q OK yeah, and that you can stop at any point and kind of pull out if you want to. Sorry the dog’s already started barking. What was it which made you interested in taking part in the study, or why did you get in touch?

A Yeah, so I found out about it via [name] charity. And so for the past couple of years I have been part of one of their like online support groups and I only kind of, within the last few years found out that they existed. And also realised that I probably am a carer but didn’t realise.

Q OK.

A So I think all of this kind of like realization led to joining them, and then obviously they send out newsletters and things and I thought it might be quite an interesting thing to chat about more. And I really do think like research into is really important because it really is definitely…not underappreciated but under like research ???

Q Yeah and kind of under-understood, understanding from kind of the wider society and communities about the caring roles and….yeah. Can you tell me a bit about your caring role then, or kind of….

A Yeah. So I have an adopted brother who we got, which sounds weird but he was 2 when we got him.

Q 2, yeah.

A Yeah, so this was I guess….when was it, 2002, yeah because he was born in 2000. And when we got him we were told that he had like a developmental delay, but obviously he was only 2 so there isn’t that much you can work out about a 2 year old. But he’s recently, at the age of about I think 19/20 been diagnosed with FASD, if you know what that is?

Q OK, Fetal alcohol….

A Yeah that’s it. And so we knew that his birth mum had a problem with drink throughout the pregnancy but the more children she had like the worse it got. So he has brothers and sisters but the first one is OK – if that makes sense – and he was one of the later so he’s the most affected out of his siblings.

Q OK yeah.

A And so, yeah each of them were taken away from the birth mum and adopted. And yeah so he currently has a diagnosis of FASD, Autism, Psychosis and ADHD. So yeah there’s a few kind of interacting things going on there.

Q Yeah, yeah. And what has the impact then been on you kind of, you know growing up? I guess how old were you when….if he was 2 how old were you when he…..

A I think I worked out that I was 7.

Q You were 7, OK.

A About 7. And I have a sister who is blood related who is 3 years younger.

Q OK. And so yeah kind of growing up and right up to the present day kind of what has been the impact on you?

A Yeah I think…it’s tricky because I feel like without realizing we were very protective of him. He initially started at the same…well not started, went through the same mainstream primary school as me and my sister, and then obviously we came to the realization that that wasn’t the right setting for him but we didn’t know his difficulties. And so I think me and my sister were very protective of him – as you kind of are over sibling brother. So I do think we were trying to look out for him all the time and trying to keep him safe, because he is quite vulnerable and I think we just didn’t really realise until recently – neither my sister or even my mum has only recently realised that she’s a carer and that actually it probably did have quite a big impact on us growing up. And also individually on our own like mental health kind of level as well it’s been quite a struggle.

Time 5:30

So our lives revolve around him, which is fine and I don’t know any different, but again recently coming to that realization has put a lot of stuff into like perspective. And also you know kind of growing up and moving out and stuff, like me and my sister have felt very guilty for moving out because we feel like he’s….he’s not a burden but that sort of word in that my mum is left with him 24/7….

Q The responsibility then lies completely with your mother.

A Exactly. She can’t hand him off to one of us. And it also got to the stage I moved out because it was getting unsafe to be in the family home, so that got difficult as well. So it’s just like layers of things.

Q Yeah, yeah. So whilst you perhaps wanted to move out you did so under kind of a bit of a negative….a difficult situation.

A Yes exactly. And also it’s just quite hard because my parents have recently like had the conversation that me and my sister will be joint power of attorney if anything….

Q OK.

A …. happens to them and we’re still quite young. It just feels like a lot. But I understand it because we know him and it’s important that as power of attorney we know him, but it just feels like at some point in my life that’s going to be a thing, a responsibility. So yeah I think just the fact that it doesn’t ever stop impacting, even if I’m not there.

Q Yeah there’s kind of bigger things in the future kind of.

A Yeah.

Q Yeah. I mean I think the future is often a difficult conversation for carers and particularly, you know thinking ahead when your parents might no longer be around or in a position to care. Kind of what do you feel about that, if you don’t mind because I do appreciate that it’s a difficult topic, can you expand a little bit more on how you do feel about that?

A Yeah. I think it’s tricky but it feels like quite a big responsibility that’s coming, but I think in the past year or two they’ve realised that actually if they can’t manage him any more, a residential setting would be better. So I think we are all on the same page with that, which I think is good because it will give him some form of independence, he’s now 22. And also it will give my parents this respite, because they have no form of respite. We did initially have…I think it was a charity called Shared Lives where they can do short respite, but after a couple of stays they said that my brother was too difficult and that they didn’t have him back. Which obviously he’s difficult, he needs respite ???

Q That’s why you need….

A ??? So luckily my parents got to go away for a week, which is huge, they hadn’t been away for a week in years, so at least they got to do that. But yeah I just think at least in a residential they don’t need to worry about constantly trying to fund respite, he is taken care of. And I think we will all be happier and it will be better for our mental health, which sounds really selfish but I also think it will be good for him. Because he’s an adult but his kind of intellecutal age is about the age of my 8/9 year old, so that’s quite tricky. So yeah I think….sorry I feel I went off your question.

Q No, no that’s fine, just carry on, I have no problem you going…. I can always kind of go back and remind you….

A Yeah, what was the question? It was kind of future stuff wasn’t it?

Q It was about the future yeah and kind of I guess what you do feel about that and the impact of thinking about the future on you.

Time 9:46

A I think, like I said residential wise I think it will be better for all of us, which is really good. And it will give my parents that kind of freedom, because my mum or my dad always has my brother with them, we cannot take our eyes off him at all. And also it will give them….this sounds really like cheesy….but it will give them their lives back in that at the moment everything is locked away, like keys, knives, medication, anything sharp and pointy, and they’re contemplating the idea of locking the food cupboard because he has an issue with over eating. So you know if my mum just wants to chop something up it’s going to make a huge difference if he’s not there. Their lives will just be easier. So I’m kind of looking forward to that moment being taken off my parents and being able to enjoy each other’s company and not just….they constantly feel like they are just tossing him between them. So yeah I think….

Q Do you worry about your parents then and kind of…..yeah.

A All the time.

Q All the time.

A And I just feel really, like I said guilty for having my own life. And they don’t feel that way, they’re like ‘no absolutely you need to have your own life’.

Q They want you to have your own life, yeah.

A Absolutely, which is lovely but I still feel….I don’t know, it doesn’t come from them, it’s not coming from anywhere but I still feel like….and they still heavily rely on me in terms of my brother’s very interested in technology but neither of my parents are very tech savvy so I am called on a lot. Which is hard and affects my mental health, and he gets very stressed about tech and stuff, but I can’t not, it’s not optional, I have to do it and I keep reminding myself that I’m doing it for my parents as well as my brother. And something that we all kind of say to ourselves as a family is that whenever he has frustrated us or has undone something we’ve done, that he has brain damage, he has brain damage. And if you just keep saying that to yourself it puts into perspective that he can’t help it.

Q It’s not personal.

A It’s not personal, exactly. And every day you start again with him, so it is like I think in terms of like groundhog day. So you can tell him that ‘that behaviour isn’t appropriate’ or ‘you shouldn’t do that’ or such and such, but you start the day again the next day and he would do it again despite having done it yesterday. It’s so frustrating. And yeah I think the kind of sense of freedom would be good. And also my parents put locks on both me and my sister’s bedroom door because before we both moved out….and things like that, you know they won’t have to worry about that because they were worried about our safety as well as my brother’s safety for himself and others. Yeah it’s just a lot of ??? things but I really think it will give them time and energy back.

Q Yeah. It sounds like you kind of feel you’ve got an innate kind of responsibility to because he is family and your parents are family, you’ve got this just…..you know like you said they’re not putting pressure on you but you just feel a sense of kind of responsibility and duty to be there….

A ??? myself I guess, yeah. But yeah.

Q OK. Have you ever had any kind of support for yourself as a sibling? What kind of support have you had and what has helped?

A I guess I’ve had a lot of mental health support like since I was like 18 I’ve always suffered from mental health.

Q OK.

A And actually I was diagnosed as autistic at the age of 25.

Q OK.

A So that was interesting. And obviously I think my mum felt really guilty because she was like ‘ooh we should have spotted it’. And she said to the assessor like ‘why didn’t we’. And it was just the kind of generation and time I was born and that wasn’t a thing to do with girls as much, which you probably understand. But my mum felt really guilty, and I think actually maybe it was because my brother took up so much just time etc. And I have nothing against that but….

Q The way it is.

A Yeah. And I was well behaved at school and I went under the radar. There was never anything picked up. So I do kind of think, you know maybe if we hadn’t adopted my brother I might have known things about, you know being supported in school earlier and stuff like that potentially. But I don’t know, and I’ve managed so far. But yeah I do think that mental health wise it has made quite a big impact, especially on me but obviously I have….you know I’m autistic and that will not help. But yeah I just think like you know there’s stuff that….you know maybe I was quite good at masking things and I’m very good at bottling things up, and my brother has always come first. That’s just how it is, and it’s fine but I don’t think I realised that until I kind of grew up and looked at it.

Time 15:40

Q Yeah of course, hindsight is….it’s easy with hindsight isn’t it to like reflect back on what’s happened, yeah. So obviously you said you were diagnosed at 25, what mental health support did you access before that point then, or how did mental health kind of play out for you?

A And so I think from secondary school onwards I had like a homeschooling worker and I was under CAMHS. And that kind of went up through my teens until I became an adult, and then obviously that’s taken off you. And I did have some private occupational therapy that I paid for, and also private just talking therapy. But I felt that it never really helped because it was always like CBT, and I think I struggle a lot with labelling feelings, like I think it’s a lexi thing I was told.

Q Oh right OK, I’ve not heard that term before.

A Yeah I think it’s quite autistic where you can’t label feelings or emotions from being yourself. So that makes therapy hard because you’re constantly being asked, you know….I just cannot decide how I feel, I don’t know what an emotion is kind of thing. So it’s quite tricky. So I think basically that sort of therapy, it’s just not suited to me as an autistic person. But yeah I was actually having private therapy and like paying for it obviously I think in my early 20s when I was at university and my therapist said that she couldn’t take me any further because I was displaying autistic traits. That was the first time I had heard the word autism in the same sentence as me. It’s kind of frustrating because obviously I was paying to see someone, and then that’s when I went, like referred through the NHS and stuff. So yeah I’ve had kind of continuing mental health support and I do pay for a private therapist now as well who specializes in autism, which does help. So she actually has that background and she knows how to get to the bottom of things with me without going into feelings and emotions and stuff, so that has suited me much better. Obviously I didn’t know I was that thing until later on in life, so yes.

Q Yeah. So it sounds like it’s kind of quite difficult to unpick what’s related to your autism and being autistic kind of and how you process these things, and what’s related to perhaps just the way you grew up with your brother and that family situation. It’s kind of everything’s so interlinked in terms of experiences that it’s difficult to unpick what’s what.

A And it’s so just like realizing that actually it wasn’t a very universal experience of other people my age growing up. I think I didn’t really realise that that wasn’t other people’s normal. Not that it was, you know I guess sometimes it was a little bit traumatic but it wasn’t a bad childhood, it was just different.

Q Different, yeah. And you said, I mean that links back, you said how you didn’t appreciate you were a carer until recently and your mum didn’t appreciate that they were carers as well in that sense. Would it have been helpful do you think to have known that before that, to recognise that you were carers before?

A I think so. Also I was discussing this with my sister. She’s a primary school teacher and she said that like nowadays there’s like after school clubs for sibling carers and stuff. I was like ‘oh my God that’s amazing’, like that would have been lovely because I kind of feel like between me and my sister, you know we didn’t really bring my brother up in conversations or he wouldn’t be kind of around us and stuff. And it would have been nice to have even that, just to know that ‘oh someone in the year above knows what it’s like’ kind of thing. So I do think that really would have helped and we would have….I don’t know I think it would have helped me in terms of cutting myself a bit of slack if I was feeling a bit overwhelmed, or home was a bit eventful and I couldn’t do my best on my homework or something like that. Like you kind of feel like also if you had that understanding of your teachers as well would have been amazing, like you know not expecting special treatment but….

Time 20:36

Q Just to be aware there are mitigating circumstances.

A Yeah, yeah, literally that. And just also that I kind of feel like when siblings ??? from you kind of thing.

Q Sorry that just froze then. What was that last…..

A So I almost feel like if you have siblings coming up through the same school as you your teachers expect the same level of, I don’t know if it’s ??? or misbehavior and stuff, and that each person should be seen as an individual rather than part of a family you know. Because my brother wasn’t like me and my sister. He was linked to us and people didn’t understand, and people didn’t know he was adopted, and it was like ‘why does he look different’. So it’s tricky I think, especially adoption wise, he….

Q Yeah I mean that can be tricky to navigate at any age let alone when you are a child and have the additional difficulty of perhaps related behaviours and things like that kind of.

A Yeah. So yeah just a little bit more understanding I think, nothing really more than that that I can think of.

Q Yeah so understanding from others, and maybe some kind of practical support when you were younger in terms of being with like-minded people in similar situations.

A Yeah that would have been nice, yeah.

Q And you say now that you’re in touch with [charity] and go to some of their online kind of support groups and things, is that something then which is beneficial now and that you are tapping into very much that kind of….

A Yeah massively because I feel like obviously we’re all in the same boat, we do obviously have siblings with varying difficulties. But it’s really interesting because people are also talking about Power of Attorney and residential and getting older, and then worrying about their parents, and worrying about you know whether they’re going to be responsible in the future. And it sounds really like heavy – and it is heavy topics – but it’s really nice because other people get it.

Q Yeah, yeah completely.

A I don’t feel like I could talk to anyone but my family and my partner about this sort of thing other than those group people because nobody else is in that world of looking for a really good residential place that ticks all the boxes. So yeah I think it’s been really good and it’s just….yeah I think a sense of community is really important.

Q OK.

A Obviously there’s only so much a support group can do, but just knowing that you’re all in it together is nice.

Q Yeah. And you mentioned your partner, does…I guess your caring role does it have an implication on them, does it affect things between you guys?

A I think so, I think just in terms of I’ve moved out but I’m still massively linked to home and making sure that things are OK there and keeping, you know my brother happy, which keeps my parents happy, which means I do go back and forth a lot. Whereas I feel like he’s almost lucky in that he has that separate life and doesn’t have that level of responsibility – of course he still checks in and visits and stuff. But I don’t like going home because I know that there will be a list of things for me to sort that my mum will have said to my brother ‘we’ll wait til [name]’s home’.

Q OK.

A So I don’t go home to see my parents, I go home to sort things. And my mum feels terrible about it but there’s no….there isn’t….

Q It’s a way for them to manage the day to day things make or happen.

A Exactly.

Q But then it puts a lot of pressure on you then when you go….do you go home to resolve these things for your brother.

Time 24:50

A Yeah exactly. And my mum, like recently my therapist was like ‘I think what you might need to do is maybe just check kind of What’s App or Messaging Apps once a day in the evening’ because you are constantly….I don’t know if most families do, probably chatting on their family chats, but some of that’s is about my brother and what’s happened during the day. And actually it was getting too much for me because I need to sort the stuff.

Q Yeah so you’re constantly reminded of it and thinking about it.

A Yeah exactly. And I was just like actually I was waking up and worrying about what my phone was going to say, which feels a bit silly to say but it was this kind of anxiety of, you know ‘what has he undone now’ or ‘what has he broken now, what do I need to fix now’. And also protecting him, like he can’t go on the internet, he’s just not safe on the internet but he constantly finds ways around the blocks I put in. So unfortunately I have been the designated tech support person and I should not have agreed to that.

Q Do you know what, I realise just how untech savvy I am. We fostered some young…we went through a period of fostering young teenagers, and because of some of the risks some of them couldn’t access the internet and weren’t allowed to by their social workers and you know there was various things in place. But yeah they found ways around it, like I….

A They’re always bound to.

Q I know. Like I was so out of my depth. And I thought like ‘I’m a young person, I know how to use the internet’ but like I was completely out of my depth.

A Yeah. We are always saying that we think my brother would be a really great ethical hacker because ask him to find a way on to the internet and he will get there.

Q Yeah, he’s determined that he will.

A Yeah.

Q Is there….and this kind of I guess links to the other part, the digital story telling workshop if you did want to take part in that, but is there kind of one particular story or one theme which kind of springs to mind in terms of kind of talking about your life as a carer and your carer’s mental health which kind of stands out for you?

A Yeah I’m not sure, I’m trying to think particularly. I think also because at the moment my brother goes to an autism day centre and it just caters for that one diagnosis. Because out of the other 4 or 5 that frustrates me and upsets me a lot because the council have seen one side of him and have put him in this place, and it’s not suitable because of all the other things. So I kind of feel like that’s the thing that I worry about the most is like the suitability and the effects on his mental health, but also the effects that that has on the mental health of the rest of the family worrying if he’s being cared for properly. Because there have been lots of incidences at this day centre where he hasn’t been looked after properly, and it wouldn’t have happened if he was in our care because he is watched 24/7. So I don’t know if that could be translated into a….

Q Yeah interesting, yeah. If that’s your kind of main concern at the moment I think that’s really valuable to keep hold of. And also I think it sounds….the fact that you hadn’t realised you were young carers, you were sibling carers, that sounds really key as well because that could have changed what support you could access as a child and kind of steps in place. So yeah there’s a few things which seem kind of quite key to your experiences to date, yeah.

A Also my mum has said to me, she had a conversation with me to say that she thinks that nowhere is going to be able to provide the level of care that we do for my brother and that we are just going to have to accept that. Pretty terrible feeling that they have to let go in order to live their own lives. So that as well feels a bit….it just doesn’t feel right. Doesn’t feel like actually it’s going to be less about him and more about us as a whole being better off….yeah there’s a lot to unpick there.

Q Yeah I can imagine that can have a….yeah those feelings are quite complex then aren’t they in terms of because you are talking about your parents being perhaps a bit freer and being able to live their lives just in their own home more easily, but it comes at then a cost you’re saying for your brother.

Time 30:00

A Exactly. So it’s just there’s so many pros and cons. You know I do my best for everyone but it’s not quite possible.

Q Yeah it’s an impossible situation, yeah. Are there any other kind of sources of support which you feel would be beneficial or that you could access? Because you are paying for your therapy yourself but is there anything else that would help you?

A I think it would have been nice to maybe have some support around the adoption side of things as a young person I think. Only from now potentially because you know over the years we’ve learnt more and more about kind of, you know like attachments to a birth mother and understanding….like he is in contact with half-siblings and things and navigating that, but also keeping him safe. So for a long time we also had to make sure that we didn’t say anything about him online and stuff like that so that he couldn’t be found. So I think just like, I don’t know almost like a crash course in ‘you’ve adopted a person’ for…obviously like it would be great for parents as well, I do think that obviously we have like a social worker, but you know you have the person, they settle in, the case worker checks in every so often, and then you live your life. So I just kind of feel like even just like a yearly check in or like a….

Q OK and some kind of ongoing….

A Yeah, because they could point you to services and stuff. I’m not saying they need to help. But it was like having a new fully grown baby from like zero to that, so yeah it would have been I think helpful and maybe given us a bit more understanding I think, yeah.

Q Is there anything as an adult as well now kind of that you can think of, or kind of any gaps in support?

A I think maybe just it would have been good to have some training around FASD.

Q OK.

A So my mum actually self-funded to do like an online 6 week FASD course. Because realistically we know the basics, obviously we know a bit more since diagnosis, but actually she learnt a lot about how to challenge behaviour and things like that, and also like sibling relationships and stuff. So I do feel like….I don’t know maybe another support group around specific disabilities and things, though I appreciate that’s quite a niche thing. But yeah I think some background on FASD would be really helpful because that’s how we got to the term of ‘remember he has brain damage, he can’t help it’. Before that it was just so infuriating, you know him stealing things and things like that and not understanding that actually it’s impulsivity and he doesn’t understand consequences and stuff like that, which is hard when you’re bringing up a child and they’re pinching things, you like tell them off. But you can’t because that will set him off. So yeah I think just a kind of continuing education, like a continuing background as to how to manage.

Q Yeah that makes sense, that makes sense. What do you think it would mean if kind of carers mental health was taken into consideration by services, and parents views were taking into consideration in mental health services. What would that look like for you if….

A I think it would be nice if they had at least a background on me. Because I feel like maybe my mental health issues wouldn’t have gotten to, you know kind of breaking point, or you know the issues with depression and stuff if it had been caught earlier kind of thing, or appreciated earlier that actually ‘she’s struggling at school because of this’ kind of thing. So I do kind of feel like maybe it would have got that recognition earlier and wouldn’t feel like I’d have to pay for a therapist now in my adult life to keep my well-being OK. So yeah I think that would be useful. And I don’t really know how else….I’m not sure how else they could really tackle it. I don’t know.

Time 35:00

Q Yeah. But if there was an awareness there then it’s having access to services and support in your own right at an earlier time so….

A Yeah, and turning up to the service and them being like ‘right so you have this sort of ??? background’ kind of.

Q Yeah and take that into consideration.

A Yeah, so you’re not always having to start again kind of thing. Yeah I think that would be quite helpful.

Q Yeah that makes sense. Sorry I’m just looking through the topics we have to cover. The support now with your therapist that you get with your mental health then, are they understanding of your background and your situation with your brother and stuff, is that….?

A Yeah. I’m quite lucky in that I actually had a struggle to find someone locally but I found a doctor who specializes in autism and learning disability with like an NHS hospital that has a private practice. So not only does she understand my autism and my brother’s autism but she understands learning disabilities and will connect them all. So I just feel very lucky that I found the right combination of person, because otherwise I have struggled in the past with therapists who haven’t seen the full picture of me and just been like, you know ‘and you have sensory issues’ but haven’t actually thought like ‘why is that’ as a whole person. So I feel like I’m seen as a whole person and she tailors it to me rather than doing by the book CBT.

Q The generic CBT.

A Yeah. And even she said yeah it’s not made for autistic people, it’s made for a kind of, I don’t know typical neuro-typical person. Which I understand, like I can see how it would be useful, but I have very black and white thinking, which people didn’t realise, so it’s helpful to have something that is more tailored to me.

Q OK. And so what were you looking when you were looking for your therapist, you said you struggled to find one locally. Were you specifically looking for someone who had that kind of area of expertise, or what were you looking for?

A Yeah so I remember looking online and there were lots of therapists that were like ‘I do everything from autism all the way to kind of anxiety, depression, sexual health’ like all that sort of thing. And I don’t want someone who is like ‘I can do everything’, I want someone that can just focus….like can just do autism and has that background and does it really well. So I really did have to filter through because a lot of therapists were like ‘I have experience with all of these things’.

Q Yeah how can you have experience in absolutely everything and be an expert?

A Exactly. And some of it was like intellectual stuff, intellectual disabilities like anorexia and stuff like that. But I don’t know that you can do all that. So when I came across this lady and read about her background I was like right, she’s kind of been in the NHS and had that experience and I think that would be really helpful in terms of understanding me. And she is a specialist. I just wanted someone who knew the main issue that I’ve got rather than all of them.

Q Yeah they could get you and they could get your brother and you don’t have to constantly explain stuff from scratch.

A Exactly, she has that bit of background and….

Q Yeah that makes sense.

A Yeah, it was a bit of a struggle to find her but I’m glad I have.

Q Good. And what is your understanding of mental health? If someone said ‘what is mental health’ to you, what is it? This project is obviously about a carer’s mental health, what does mental health mean to you, or what….?

A I think to me it means that you’re not quite running at the right speed or capacity or energy levels, and that there are so many layers of things going on that it just takes a toll on your brain. It’s almost like…to me it feels like a sense of overload, that there is too much going on and you switch off and distance yourself from it. That to me is what it feels like. And also I think having had kind of episodes of depression, it’s getting stuck in things and finding a way out but worrying that you’re going to get stuck again. So it not being a linear thing, it being like ‘I’ve got to keep avoiding this bit’ kind of thing. So yeah I would just say like mental health is something that has to be managed and requires upkeep.

Time 40:25

Q Yeah OK, you can’t neglect it, you’ve got to attend to it kind of, to make sure you stay on an even keel.

A Yeah, because otherwise it will just kind of get you back to a place you’ve already been and didn’t like.

Q A spiral.

A Yeah exactly. So that’s kind of I think how I see it.

Q Are your parents understanding of your mental health, and your sister’s I guess as your sibling, you guys’ mental health….

A Yeah I think my parents definitely are, obviously they’ve had some kind of mental health stuff with my brother. So I think my mum….like both my parents are understanding but my mum has more of a medical and background knowledge in terms of she was like a nurse so I think she’s more understanding and will read up more than my dad does because of just having time and stuff. So I think that that does help. I think they….I remember them saying to me about when they were adopting they were asked if they would be able to cope with mental health issues, ??? their child with mental health issues, and my parents said no.

Q OK.

A So that was kind of written down because they didn’t have any experience at that age, me and my sister were still young. Obviously now….you don’t know what that person is going to change into or turn into. So that was quite interesting, them being like you know we had no idea what we were getting into.

Q How did you know that that was the question they were asked, have you seen that recently written down, or did they tell you?

A So I think like over the years me and my sister have like asked lots of questions about the adoption and stuff like that because obviously like we had to go to court to kind of officially do things and stuff, and it was like ‘what was the whole process like?’ And they explained that it took like 2 years to kind of go through it and do all the paperwork. And I was like ‘what sort of questions were you asked’ and things like that. So over the years we’ve had multiple discussions, and my brother always knew he was adopted from a young age, they thought it was important to talk about it because children are mean and will spot that he is blond haired and both me and my sister are ginger, so we do look very different. So I think it was to just…you know because kids will just look at your visually and be like ‘you don’t look like brother and sister’. So yeah I think that was a really good move from them in that they were open from the start. And he wasn’t questioning or being like ‘I’m not quite the same as everyone around me’, like we made that….we celebrated that kind of thing, that was a good thing.

Q Yeah OK. Is there anything in terms of….kind of anything else which doesn’t work in terms of kind of mental health support? So obviously you’ve said about CBT wasn’t very good for you. Is there anything else which you can think of which doesn’t work, any areas that….

A Yeah group sessions didn’t work for me in the NHS because I’m neuro-diverse and I didn’t connect with people and couldn’t….you know. So I found that quite difficult. And also I’ve had like, I think it’s like IESO?, it’s like online chatting therapy with a few therapist remotely but not via video, and that was really odd. And also just the shortness of how many sessions can be offered. So for example I had some issues kind of October last year and by February I was like ‘I think I need some help’ and I referred myself to just my local adult mental health service. And they still haven’t been able to provide anything – so that’s February this year to now. And I haven’t heard from them, they’re meant to do check in calls every 6 weeks, which hasn’t happened. So it got to a point, I think it was May/June, my mum was like ‘I think we’re going to have to pay for something’, and that’s how I managed to find the therapist. And also they’re not going to have specialists to the extent that I can with a paid person. So I’m still on that. But they don’t check in so like I could be anywhere doing anything. So I do kind of feel like if I wasn’t in an OK financial position with a full time job I would be lost.

Time 45:35

Q And you don’t know what position you’d be in now kind of.

A No. And I kind of feel like that’s worrying, because you kind of wait and then you kind of do an initial assessment, and then you don’t hear anything. And also don’t know necessarily what you’re waiting for, so if they got in contact with me now I don’t genuinely know what they’d be able to offer. And it would probably be four hour sessions or something, and that’s all they can do, which I know they’re stretched but that’s not much.

Q That’s not much.

A To a lot of people, not just me.

Q Completely.

A Because I need to see the same person. And I’ve seen, before I started a new job I saw my therapist weekly and it’s helpful it’s the same person, it’s the same time, place, environment. And I don’t think the NHS could ever do that.

Q No, OK. Have you ever observed or experienced discrimination in mental health care?

A In regards to me or in regards to my brother?

Q Yeah in any. I mean about you and your mental health I guess predominantly, but in any scenario?

A I mean I have. When I referred myself and I was struggling with my mental health and said about my private therapist saying about being autistic, the first doctor I saw wouldn’t refer me. And he was a male doctor and I was like ‘hmm, do you know what, I’m going to try again and request a female doctor’. And she referred me and ‘you’re autistic’.

Q Yeah OK.

A So the levels of understanding, some GPs get it, some aren’t on board, they’re just ‘no’. So I feel like what if I hadn’t? Because I feel a lot of people would have been knocked back by what the GP said ‘it’s a no’.

Q It takes confidence to keep pushing forward.

A Yeah it really does. And I just think that the fact that I pushed and thought ‘well actually the person I’m seeing has said it, it’s not just me saying it’, but because it wasn’t on a bit of paper or it wasn’t NHS paperwork or whatever they were like ‘hmm’. And it’s just like frustrating. So yeah I think in terms of being listened to and appreciated in terms of my mental health linking massively to autism, it’s not understood at all, it’s seen as a completely separate thing. And I’m like ‘but my thinking is directly linked to my autism and mental health’. So I just think they need to see the whole picture, they need to see the whole person in front of them and not just this little bit. So yeah. And I’ve also been told that I don’t look autistic by a consultant at the hospital.

Q Oh wow.

A Yeah, so that was nice. I was like….

Q Did you say ‘what does an autistic person look like’ or….

A I think at the time I was so shook that I….I was like…eh? And it just kind of planted that seed again, you know not everyone’s on board despite it being 2022/2023. So yeah I think I’m more careful of who I tell, and whether I tell my employers and things like that because there isn’t understanding about mental health issues as well as autism. So I do try and treat it as a kind of private medical thing because I am kind of vulnerable I guess.

Time 50:00

Q OK. And in terms of like your caring role for your brother – and obviously even though you’ve moved out like you say you’re still a carer and very much involved in your family like, do you ever encounter difficulties there in terms of other peoples’ understanding of that?

A Yeah massively. The fact that he looks like a fully grown adult and he is in the body of a fully grown adult, and other people understanding milestones ‘why isn’t he in college’, ‘why hasn’t he a partner’ you know all these things. And it’s hard because especially with him you can’t explain it properly without going into some really private stuff. You know you don’t just want to be like ‘he has….’ you know Fetal Alcohol Syndrome and it’s a completely preventable thing, which is really tricky for him to grasp let alone anyone else. So I do feel like we are very protective over him and will step in for him to help with conversations and things if he is questioned. And I think things like him wearing a sunflower lanyard and things like that, little things like that help my parents in terms of a bit of a ??? or if they are linking arms with him and they’re like ‘that looks a bit weird’ because he can’t cross a road kind of thing. So I think that does, the ??? rules help him whereas I don’t think I would wear…I don’t want to bring attention.

Q Your attention to….yeah.

A Whereas it’s almost safer for them to be like if someone found him or something and he’s wearing that they’ve got, at least hopefully maybe a bit of a thing if he can’t verbalise what’s going on.

Q Yeah OK. Is there anything else kind of…. particularly related to being a sibling of your brother and mental health as well, just bearing in mind that that’s the kind of focus of the research. Is there anything else related to that or your caring role that we haven’t discussed that you think is important?

A No. I think it’s just kind of knowing who to talk to. Because your family – so my sister, my dad and my mum – are the only people that truly get it. Obviously my partner does but hasn’t grown up with him kind of thing. So I do feel like it’s great to kind of vent between us but actually it’s also not very healthy because it brings everyone down and you go round in circles, and there’s only so much you can solve between four of us. So I do kind of feel like in terms of family dynamic we are ‘my brother’s team’ and less of a family the more that I’ve grown up.

Q OK.

A And I also have said to my mum that I feel like I’m not really my brother’s….I’m not really a sister to him, I am a….I don’t know I almost feel like a support worker, he isn’t able to kind of really be like ‘how are you?’. It’s not a sibling relationship, it’s a ‘I help him’ relationship.

Q Yeah transactional.

A Yes literally that. And he has a better relationship with my sister in terms of sibling wise and I’m a bit jealous of that. But she doesn’t have the tech stuff, she doesn’t have that bit. So I’m like ‘is that why’ because I’m on the permission level, I’m the ‘you can do that, you can’t do that’.

Q Yeah, you’re the one stopping his access to the internet for example, whereas your sister isn’t in that, she’s not in that position.

A Yeah, she’s great. But me, I limit stuff. So I do kind of think it depends what mold? you are as to how your mental health is. And like I would say I, ‘suffer’ is the wrong word, I struggle more than my sister because she’s not called upon to sort things, she doesn’t have that so she can have more of a separate life – which I find frustrating.

Q Yeah understandable.

A So yeah I think there’s just different dynamics when you think about it more, and you feel like more of a kind of team than….you know it took my parents like a year and a half to come and visit this flat because of my brother. And it’s just stuff like that, like just being able to like see my new flat and stuff.

Time 55:05

Q Yeah ordinary kind of experiences.

A Yes exactly.

Q ???

A They can’t just….they can’t go anywhere without him. And depending on how he is that day dictates what they can and can’t do. So yeah it’s just a weird kind of like….which I know can’t be helped, it’s not ???

Q No but it’s still very much like you’ve said, you’re still very much a carer for him even though you have moved out, it’s very like….yeah.

A Yeah. I almost feel like I still live there.

Q Yeah OK.

A Whereas I feel like my sister, you know obviously she’s still very much involved but she’s that one step removed further than I am, and I’m really jealous of that.

Q Yeah completely. Are you able to talk about that with your sister, or is it recognised? Or it’s a difficult topic to talk about perhaps?

A Yeah I think my parents are more understanding than my sister. I think…yeah I don’t think my sister is as sympathetic, and she was a bit funny about me and my autism diagnosis and wasn’t as understanding as my parents. I’m not really sure why. But yeah I think my parents are more on board and understanding, and are like ‘I really don’t want to ask you to do this, but….I need you to do this’. Yesterday she sent me like ‘here’s a pre warning, these are for things that are going to happen when you walk in’.

Q OK.

A And it’s just like….I just want to go home and be with my parents. And yeah.

Q Yeah that must be really tough. And they’re perhaps things then that you can with the [charity] groups, they’re kind of perhaps experiences that you can take to that group to get some understanding from others.

A Mmm. I’m just finding, like them also finding the time to talk to their parents without the sibling being around all the time and stuff like that and having to constantly choose your moments. I think the rest of the group really get in that we are not a priority. Obviously we’re still important and part of the family but actually we have to work around the sibling. Yeah, this is the group dynamic.

Q Yeah, so all your interactions are kind of considered with your parents in terms of if it’s an appropriate moment to discuss something or raise something or…

A Exactly. One example I have is, I remember I finished…there was a job that I’d finished and I’d been there for 5 years. And I came home and I was upset just because I’m not very good with change, as I ??? And my mum was like ‘right, let’s go out, let’s…’ So we drove to a church car park and I just sat and cried in the car because I couldn’t go in and cry in front of my brother. So everything has him at the heart of it. And I understand, I don’t want him to be ??? But I should be able to go into my own house and….

Q And cry if you want.

A Yeah. So that was a bit rubbish just me sat in the church car park crying. But I know why, I know why, we have to adapt, but….

Q Yeah but it doesn’t make it easier though does it, like it doesn’t change it. You can understand why it’s there but it doesn’t….yeah.

A Yeah. And I just kind of feel like ‘I bet nobody else has to do this’. Like it’s a selfish thought of like ‘hmm…’ But yeah, it works, it’s a way of not involving him and it was just me and my mum which was nice, so I kind of have to take it as a win.

Q A small win, yeah. But then I guess, say yeah, it highlights I guess doesn’t it why then having the opportunity to be able to offload with other people or with your therapist or support groups and stuff, why they are so crucial, otherwise you are kind of just left with those experiences.

A Yeah. And to the extent that when I was kind of freelance whilst looking for another job I would phone my mum on a Friday when she was at work without my brother because he’d be at a day centre, that was our time to talk about my struggles or to have things that were potentially troubling for my brother because they were always like in the same room. So we had like that designated for like our lunch, yeah literally. And that was the best way of doing it, which seems a bit weird that I can’t just….I don’t feel like I can just ring up my mum.

Q So there’s kind of practical solutions and ways around in terms of managing, but underneath it all it’s still difficult.

Time 1:00:00

A Yeah it’s difficult and it’s not quite normal or right.

Q Yeah different to….yeah.

A But I think because I don’t really know any different it’s only with age I’ve been like, like I said been able to be like ‘oh other people have it very different’. So yeah. So I think that’s the only other thing I can think of.

Q Yeah thank you. No thank you so much for sharing all that with us, because it is a difficult topic and so we really do appreciate some aspects of it are certainly harder to talk about than others, so we do really appreciate people agreeing to share their stories and experiences with us.

A That’s OK.

Q Thank you. Are you going back to work now then or are you…

A I am yes, so I’m working from home today, so literally it’s just a different screen, so it’s not too much.

Q Will that be distracting for you from kind of the stuff we’ve spoken about and things, or will you need to be kind of….?

A Oh no, no it’s OK, my partner’s home as well so it will be….don’t worry.

Q OK brilliant. What happens next is Martina, who you were originally in contact with, she’ll get in touch again just to share some….there’s like an anonymous demographic ??? for us to capture some information. There’s a voucher in terms of payment for your time. And she’ll have more information about the digital story telling workshops as well if that was something that you want to take a part in as well, she’ll be able to share more about that with you.

A OK that would be good. OK.

Q Brilliant. And also you’ve got my email address so if you do think about anything else or anything, feel free to share. Yeah I hope this was OK for you as well.

A Yeah it was OK.

Q OK brilliant.

A Yeah it was nice to meet you.

Q Yeah, thank you so much for your time again.

A No worries.

Q Alright, take care.

A Thanks, bye.