Q ….saying that we are recording. So let’s hope that that’s working OK. And so if I just explain what’s going to happen. So I have got some questions but it’s not like ‘this question, this question, this question’, the interviews just tend to roam around a bit. So I’ll ask a question and then I’ll probably ask a question about what you said. And yeah, the stuff about anonymity and stuff Ruth has spoken about and you’ll have a good chance to think about what you want to share and what you don’t want to share. So I guess I just wanted to begin by asking you why did you want to take part in the study?

A Well I saw it advertised through [CHARITY] and I’ve been involved in [CHARITY] – not involved, I’ve kind of been I suppose a member or whatever you call it for probably over a year. I think it was probably in the pandemic that I heard of them, maybe a couple of years. And then I had kind of seen it advertised. Also my research aligns very much with the study and I’m really, really interested in the issues and stuff, care, familial care, families and disability. And having worked for disability rights I’m always interested in that. And then because I’m a sibling I was like ‘well, this is really interesting’ and I’m really glad ??? selected ???. So it was a mixture of all those things. And also to kind of…I’m very interested in the research that this is involved in and the approach that has been taken to research. So I was quite pleased to see that [university] are involved from a critical disabilities perspective.

Q OK. I can’t not ask you this question. Tell me about your research.

A So I am looking broadly at disability activism, but in activism? principally by mothers of children with disabilities but in the [[South America]n] context. So I’m looking at….yeah I’ve done case studies of mothers of children with various disabilities in [South America] and how they’re politically organizing and working, or not, with disabled people’s organisations.

Q That sounds really fascinating. So as an academic I have to now self-promote when you said that and tell you, have you come across a paper that Sara and I wrote years ago, From Activist…. hang on, From Advocate to Activist?

A What did you say the name was?

Q From Advocate to Activist.

A From Advocate to Activist, yeah and who wrote it?

Q I did, with SaraYeah.

A Yes I have, yeah yeah I’ve got it, it’s in ???

Q It’s quite old now. But yeah it came from just being just to keep you aware of the work that mothers typically are doing. How interesting to, in a different context.

A

Q Yeah, and the other thing that’s in the back of my mind is, there’s Francisco Ortega’s work around autism. Do you know his work? So he writes from [South America] I think. And they have a…I might not be remembering this very well, so they are anti a bio-medical model of autism in the context of [South America] because of the different kind of psychology.

A Yeah, because autism was only recognised in [South America] in 2014 as a disability, so it’s super-super recent the kind of like autism, but it’s very strong, so there’s quite a lot of it…

Q That’s really interesting.

A Yeah…autism advocacy in [South America], but not so much for it ??? I did focus on autism quite a lot on Zika but not on other kind of disabilities. So I was trying to do a kind of cross-disability to get a bit more of a….

Q Yeah, yeah, not just focus on autism. But I think it’s just there’s been such a like….autism wars in [South America], you know about understanding what it is.

Time 5:00

A Yeah it’s really interesting. Yeah kind of like care. Well I think there is that anyway isn’t there, there’s kind of parents that are adult self-advocates, there’s lots written about them in the autism context. So I’ve looked at a lot of that literature but I’m kind of interested in that in a more general…like generally across the disability rights movement, how it’s very much kind of the parents’ movements. And then there’s, yeah there’s self-advocate adult movements. Pamela Blo….is it Block and Scotch have written about that as well, that they’ve got a….oh what’s it called, it’s something about parents – ah! Allies and Obstacles.

Q I don’t know that.

A I think they brought it out in 20….oh it’s really….I mean it could be better written to be quite honest, but it is really good, they give a very broad overview of kind of looking at parents’ movements but focused in the US. So again looking very much at middle-class white organizing in a Western context, which is where I’m hoping to kind of bring another perspective.

Q I always want to call her Judy Bloom and it’s not, I think she’s Linda Bloom, Raising Generation X, that’s quite an interesting book.

A Oh no I don’t know that.

Q It’s really interesting because she talks about insectionality in terms of class and race. And I felt a bit ??? reading it because she says ‘these middle-class mothers are so angry because they’ve never experienced this level of discrimination before, you know they’ve had their privilege taken away and that’s why they’re so angry’. And I think, ooh.

A Yeah it’s very interesting, right, you’re like ‘oh ??? bad’.

Q In that book she talks about race, class, gender but she doesn’t talk about disabled mothers, which is really interesting isn’t it?

A That is really interesting that we know ??? got a choice ???

Q It’s a really, really good book, I really liked it. But, yeah, gosh that’s really interesting that you didn’t go there.

A Not surprised though, that’s why.

Q And so what’s your qualification, what are you doing, are you an undergraduate or a Masters?

A PhD.

Q PhD, oh! And when’s that due?

A For my sins! I’ve got about a year left so I’m just starting to write up. Yeah I’ve just got back from fieldwork.

Q Oh do you know I wish I’d never spoken to you because then I could have examined it! You’ll have to get Sara to examine it because she….you know.

A Oh yeah that would be good. Well actually I was thinking I need to find someone, we need to start thinking about external examiners, but yeah I’ll keep her in mind.

Q Are you allowed international people now, because I’ve seen….

A Yeah.

Q Because Patty would be really good as well.

A I hope so because….Patty?

Q Douglas. I’ll send you her details.

A Patty Douglas, yeah.

Q But Sara or Patty.

A That would be good.

Q That’s a good bit of life admin.

A Yeah, I’m just thinking about all of that. I know, yeah, I’m sort of getting more out of this than you are. Thank you very much.

Q And that’s why you’re interested in writing? You asked about writing.

A Yes, because obviously I’m thinking about publishing. Yeah, because I know that a lot of disability studies people kind of co-author and I’m planning on co-authoring with my research partners and things like that. So I just was thinking generally about co-authoring anyway and thought I’d ask. But I don’t know whether that’s your plan or whether it’s….

Q Well we have….so if I tell you a little bit about how the project is structured. We’ve got a tea and cake group which is a group of people with learning disabilities and carers of people with disabilities. We meet with them, well every two months and sometimes outside of the meetings because some people meetings work for and some people they don’t, so some people have different arrangements. And we tell them what’s going on and we ask them what they think basically. And then we have done a literature review, and what we did with that was we made an accessible version of it. So the themes that emerged from literature review we shared with the tea and cake group and they fed back on, and so on that paper they are named as the tea and cake group because they didn’t want to identify themselves.

Time 9:40

And then we had this phase planned and of course we did talk to people, and we’re all carers but it didn’t go down well. So we had some workshops where we said ‘right, we have all of these surveys about care in mental health, what would it look like, what would the questions be if we wrote the questions ourselves?’ And the people at the workshop went ‘another survey, you must be joking, that’s the problem, tick boxes are the problem, we’re not doing that. What we need is an online exhibition’. So we’re in the process of doing an online exhibition. So they’ve had control of that and they have….we’ve written a paper about that and they have been able to comment on that. So it has all the way through, we’re happy you know.

And I think in a way, especially if people have got these concerns about anonymity and confidentiality and what happens to your story, if you’re involved with the telling of the story from beginning to end that’s probably the most ethical way of doing it. And you know we’ve got this digital story-telling workshop phase as well.

A Yeah that looked really interesting.

Q Yes. So the first workshop if you can make it is on Saturday the 7th October.

A Do you know what, that’s the same day as the [CHARITY] conference and I’m due to go to that.

Q Don’t worry. So we can work around that. We can work with you, when it suits you. So people have been a bit like ‘argh’ making a film. But you get loads of support to think about what the film is and with actually making it in terms of the technology. But that might be another way of thinking about your writing, because one of the things that we have done as part of another project is, we wrote an academic paper and we made a digital story to accompany the paper. And the aim of the digital story is not to map directly on to it, it’s sort of to give a sense of it but access to the ideas in it in a different format. So you could think about your digital story. And I could send you a paper as well about a digital story that we made, and we wrote a paper about how we made it and the processes that we were going through and the decisions why we used certain things, imagery and that kind of stuff, and we wrote a paper about that.

And that was quite hard because not only were you having to think about making the film but we were thinking about documenting the making of the film, and it did like ??? a little bit. So you might not want to do that. But it will give you a sense of what’s possible. And it’s your story, you have control of your story, you can make your story and you can publish your story or not publish your story, or put it into an article you know. So it would give you something very easily that we could write about.

A That’s really interesting. And even as like a methodology, right. Because I’m thinking about like how to make academic outputs accessible to the audience I’m working it with and to kind of like feed back to them. So yeah, just kind of seeing how you do that and make a digital story would be just really interesting in terms of….

Q Yeah. I can send you the paper. So there are two different things. So that making memory is one, it’s about how we made the story. But I’ll send you the other one, it’s a bit grim, it’s called When Father Christmas is the Gaslighter. And it’s about how the special education system gaslights mothers, and that’s the one that’s got the story. And the film is even worse than the article. And I haven’t been able to share it at conferences yet because I….

A Is it really critical of the special education system?

Q It’s really critical. And I did the presentation at the School of Education at Exeter, and basically you could feel the academics seething. Oh God I’m really sorry I’ve just got to let my son in – one second, hang on. Sorry I just had to do a quick handover from [my son’ts] support worker. Yeah so they were like seething. And there were 5 mothers in the room and they loved it. The academics were…. I’ll send you those. The gaslighting one isn’t published yet but it is due out, so please don’t share it but I’ll send it to you just so you can see what we did.

A Thank you.

Time 15:00

Q OK so after all of that.

A Yeah sorry.

Q No it’s really interesting and it’s really relevant isn’t it you know. And my life is entangled with it, it’s not like they’re separate, we’re not talking about something that’s not relevant, it’s all just entangled together. So can you tell me a little bit about your experience as a carer, your life as a carer?

A Yeah. So I mean I’ve kind of….it’s taken me a long time to kind of identify with the label of ‘carer’ but I think it’s so broad isn’t it, the label, and obviously I’m not principle carer because that’s my mum. But I have been involved from being kind of like a youngish….I mean care in general actually. My parents, just very briefly to give you the time length that my parents started doing foster care for disabled children when I was 6, and so I had always kind of been involved in kind of…yeah in care, whether it was being directly involved or kind of witnessing it from a really early age. And we had foster children doing respite care from when I was 6 to when I was probably a teenager, I can’t remember how old I was when the last….when we stopped. I was probably 17 because….oh no maybe it was a bit earlier than that. And then we adopted, my brother and sister are both adopted, I come from a huge family, there are 6 of us and the 3 youngest are adopted. When we adopted my second brother, which is also why I was worried about anonymity right because of that in itself. 2 brothers are also internationally adopted, which is also very much meshed with my work research as well so you’ve got that whole issue. So when we adopted my second brother….sorry….

Q Sorry I think we’re slightly out of sync. Is that what led you to [South America]?

A Actually no, they’re adopted from [Asia] and I did my Masters research on Disability Activism in [Asia] at the University of [name]. So that was that, but then I decided to step away from [Asia] partly because it’s very, very emotional for me because I’ve spent a lot of time there and done a lot of work and worked for disability organisations and….yeah. So stepped away from [Asia] but still interested in kind of international disability rights and activism. And then this opportunity just came up randomly with [South America]. And I had no connection with [South America], I had never been to [South America], I didn’t speak Portuguese – this was in 2018, and so that was actually a bit random really the [South America] thing.

So I was 17 when we adopted my brother from [Asia] and my parents didn’t realise how complex his needs were until we adopted him and it became apparent. I think it’s quite common with international adoptions, right, because the assessments aren’t accurate and their access to healthcare is really appalling and assessments and things like that. So yes. So from being 17 I was a lot more involved in his care, especially because I was living at home until I went to university. And I went to university but I stayed in [city]. So I stayed close to home mainly because of him, because I was very, very involved with him and he was much more attached to me than he was to my mum, partially because I had spent time in [Asia] and I had got to know him and my mum hadn’t.

So yeah very, very complicated specifically, but because of that I was always his favourite, and I still am, we are really, really, really close. So I speak to him every day, usually once or twice a day on the phone. But now of course I live in [city], he still lives at home. He’s 22 now. And yes, so I was always kind of very involved in his care and his upbringing, less kind of….now it’s less hands-on obviously because I don’t live at home but very much kind of emotional support I think for him. So he will talk to me about things that he doesn’t talk to my parents about. He will ask me for help when he needs to come and negotiate things with his parents. He relies on me, and I think to some extent my other siblings as well very much for kind of his, I suppose kind of like his social life as well and to kind of, yeah get access to his kind of social life and what he wants to do in that. Find out information – because my parents are in their 60s and, you know they’re just not cool to be quite honest, and he’s 22 and he wants to have fun and go out and he’s got siblings who are in their 20s and 30s, and….yes.

Time 20:22

And then my younger sister, she started out….she’s adopted from the UK, but after my parents adopted him my mum had to give up work full-time, she was a teacher and obviously looking after him and being a teacher do not go hand in hand. And so she gave up work, became a foster carer because, you know why not, give yourself more care work! And yeah and so we ended up with long term, the first long term foster care placement we had was who is now my sister, so she was a long term foster child and had also significant and complex needs – not physical disabilities but fetal alcohol syndrome and yeah learning disability. So fostered her for a few years and then decided to adopt her because she wasn’t going anywhere, and that’s what my parents like to do. So yeah. So then was kind of less involved with her care because I never really lived at home for very long with her like I had done with my brother, and she was very much more attached to my mum and my mum is much more involved in her care. Yeah, so those two.

Yeah, and then more kind of like in the last few years, especially since COVID, my mum got long COVID and is still recovering and is not great to be quite honest. So then getting more concerned about my role with supporting her and supporting my siblings, also because they are transitioning, my sister has just left school and started in full-time day centre, she’s got a full-time day centre placement very recently. So them transitioning and trying to kind of support my parents, and support my siblings and kind of be this in-between advocate I guess for my siblings but also understanding the very difficult position of my parents. And then also anticipating becoming more involved in their care as my parents age and having to take over responsibilities, yeah which I imagine is a theme that’s coming up quite aligned in the research for people who aren’t already doing that.

Q Yeah. I think with lots of things that you are saying that are familiar, I think that the way that you’re talking about caring from a distance is really important because I don’t think that’s properly understood that it doesn’t matter where you are physically. And especially with phones and digital technology, I think really that hasn’t been spoken about enough. The fact that people are telling me that all the time that it doesn’t matter where you are you are still a carer whether you are living in the same house or not in the same house. So I think that really resonates. And I think the thing that you are dancing around and I think that everybody including me finds it difficult to talk about is the future, you know and what’s going to happen in the future. Have you had conversations with your siblings and parents about it?

A Yes and no. So it’s been quite difficult. Recently me and my sister have spoken about it quite a lot, I think because we are becoming increasingly concerned about my parents and about my siblings, and because my brother has been a bit more vocal with us about like his wants and needs. And we have been trying to put more pressure on my parents to get them into independent living and these kind of things, which they say that they are on board with and blah-blah-blah but obviously it’s…. I mean they’re still young aren’t they, 19 and 22, they’re still in their transition period and most 19 year olds are still living at home so it’s…. but we’re hoping it’s kind of in the imminent future. But it’s quite difficult to talk to my parents about it I think partially because my mum is just not very well and they’re finding it very difficult to have any conversations about anything serious. It’s been a little bit easier to talk to my dad about it, but still kind of hard because he’s like a huge…he’s very much, you know in alliance with my mum and kind of will back her up, which is great but…. And I think partially because they sometimes feel a bit attacked, especially because I work in disability rights; my sister works in mental health, she’s doing her PhD in mental health, children’s mental health; big coincidence, much. So yeah so I wonder if they feel a little bit intimidated, because obviously now we’re kind of like coming at it from a professional point of view as well so that can be quite difficult.

Time 25:30

Yes but I have spoken to my sister and started to speak a little bit to my brothers, one brother lives at home. Like I said there’s 6 of us, one brother’s married and has a baby and he has not been very involved at all in their care or upbringing; and then the other brother lives at home and he is, that’s my other adopted brother, right, who is also adopted from [Asia], he lives at home still, he’s 25 and he is a lot more involved. So I’ve started trying to talk to him about it a bit more because he’s at home, he also has an opinion about things and has started to be a bit more critical about kind of the way things are done and thinking about the future. And he’s now got a girlfriend and obviously they are thinking about things and their future. So yes trying to have conversations.

We said we are going to have a big family meeting at some point because they are trying to get the deputyship for them and that is a load of paperwork which apparently we’re all going to be signing, but we haven’t actually sat down and had a conversation about what does that mean, what does that mean to us, what are the actual legal implications of it and, you know who has a choice in this or is it just all that….you know. So I’m hoping the conversation will happen soon, but actually me and my sister said that conversation needs to happen after the [CHARITY] conference because there’s a part of that conference which will look at legal ??? and so it will be an opportunity for us to try and find out more about that. So yeah talking about things is difficult but we’re trying to push for that and for more open conversations.

Q What’s kind of ordinary is that, you know my parents aren’t alive any more but as they aged there is a kind of….power balance shift isn’t quite the right thing but do you know what I mean, things that they needed help with that they didn’t need help with before, and it was always very difficult to know how far to go. But that was without all the complexity that you have thrown in. And I think having those conversations is super difficult and I think….has anybody offered to help with those conversations, like do you have social workers involved or anything?

A Well I mean they do both have a social worker, I think they have the same social worker which probably isn’t great but maybe makes it a bit easier for my mum. And we haven’t….I mean of course because my mum deals with everything and she’s there and we’re not there, we’re not involved in those conversations. Like we don’t know when the social worker is coming, we don’t know what….and she doesn’t communicate kind of what’s happening really. She’s communicated less and less actually I think since COVID telling us what’s going on and what decisions are being made and all of this kind of stuff, which is quite frustrating because decisions are being made that potentially will impact our futures, right. But no there hasn’t been kind of…I was there once when the social worker was meeting ??? had my brother, he had ??? he decided he wants to date and he wants to find a girlfriend. ‘Great [brother’s name], which ??? doesn’t want to do that, it’s not quite that simple mate, sorry’.

But we said this is the kind of thing he needs to talk to a social worker about and say and ask her about independent living and ask her what these things and kind of, you know if you want these things you need to be voicing them because it’s really important that you’re able to stand up for yourself. So we kind of were able to kind of like, yeah to get him to speak to her. But we’re not involved in conversations with social workers and things for them, yeah there’s not really anyone else who had broker those conversations.

[redacte

A Well I think, honestly I’ve got this sort of idea. I’m going to speak to my sister about this because I think having some kind of….I mean this is exactly what we’re like, we’re thinking about now right with this deputyship and I think that needs to come into that conversation on ‘what happens if…’ And not even a death plan but a ‘we can’t cope any more’ plan. Like ‘what is the plan’?

[redacted]

A I know, this is the thing, trying not to ambush [parents] but getting them to actually engage in the conversations that need to happen, right, that kind of very fine balance. I think my dad would be more receptive, it’s my mum I think bearing the burden of kind of the care giving and the admin. Although my dad doesn’t work, he does voluntary work but he doesn’t work full-time and he’s very supportive and does all the housework and all of the cooking and shopping, blah-blah-blah he’s like very hands-on. But yeah exactly, it’s trying to…it’s really difficult I think having those conversations and knowing kind of like how to navigate them and knowing that emotions are very high and there’s a lot of….yeah. But no I think that’s a good tip.

[redacted

A Yeah, maybe [anxiety] is something we need to explain to them and just say. Because they probably haven’t even thought that far because they’re just…I think my mum, she just can’t, she just….yeah it’s too hard.

Q No-one’s going to help you. I mean that’s one of the things that we’ve discovered, that people are so worried about the future when we ask the question ‘does anyone help you, does anyone have a conversation with you’ usually the social worker isn’t in the picture, you know people coming out and there isn’t that support to have these conversations. And I think the thing is that those anxieties about the future really impact on you now. So it’s like we have to try and convince other people that they need to offer that kind of support I think.

A Yeah.

Q So we’ve got this focus obviously on mental health so I wondered if there was anything you wanted to say about mental health in particular, whether you had any support or….

Time 35:00

A I think…yeah I mean definitely post COVID/my mum got more poorly it’s been a lot more difficult. I think obviously it’s a ??? everyone thinks the same thing that COVID had a huge impact on everyone’s mental health, yeah on everything. Yeah I mean I did try. So last year I managed to get support through the uni just because I was…I mean I was stressed a lot with loads of different things, I was stressed about my research, I was stressed about…yeah about them and the family situation, yeah. I mean that’s always there, like that worry is always there, but then other things kind of can add to that.

So yeah I did manage to access some sessions with the uni, so like counselling that you can get as a student, right, because that’s the only way really you can get free counselling. And it wasn’t…I mean it was fine, it’s kind of like CBT type stuff which is fine, like I did a few sessions and then I went and did a couple more maybe a few months later. I think that was 2021, yeah that must have been 2021 maybe a couple in 2022. And then I did, I think was it late last year – no it must have been earlier this year because I was also again kind of feeling really worried about things and a few people on the [CHARITY] group had talked about getting counselling and specific counsellors who had training to work with families, disabled children/siblings.

And there were a few lists posted and so I had a look through and contacted a few people, and I think only maybe two got back to me; and one said ‘oh yeah I don’t have any space at the moment’ – and this is to pay privately, right, this is to like…yeah. I think some of them give like subsidized rates for students or whatever, but yeah. But I just think there’s just not a lot available to be quite honest. I mean I wouldn’t even bother approaching the NHS because I know for a fact that I would not even reach anywhere near priority on a waiting list, do you know what I mean, to access any kind of…. I mean I might get referred to like an online CBT course, which I have also access through my work actually. So through my… I work part-time and through my work we’ve got access to the [name] It’s like a general health, you know one of these big companies that provides cover for big organisations.

And again I tried them, that was the other place I tried to see whether I could get some counselling, just to talk through things right because it’s so complex and there’s so many different things that are all interwoven. And because my work is very interwoven with my life and kind of my personal experiences – and that’s everything I do, from my research to my job, everything is all kind of like interwoven, linked to disability, care, race, gender, all of this like intersectionality stuff is what I work on. So it’s kind of difficult because I don’t get to escape it. Obviously I’ve made these decisions but I’ve chosen some quite ??? things but can’t really blame anyone for that. But you know it’s almost like there’s no escaping it, everything I do is about that – which my partner likes to point out!

Q Yeah.

A I know! ‘You need to do something else’.

Q I think in a way though sometimes I think, because I’m the same, but I think that at least I haven’t always been able to change what’s happened but I have been able to get some different understanding I suppose, and I have found that really useful. Even if, you know it sounds ridiculous doesn’t it, but to say I’m aware of the processes of ableism and disablism at work. You know it’s almost like it’s happening, you know you are watching this thing that you’ve read about, playing out in front of you.

A Yeah from the fold ???

Q And there is something about understanding that but also I agree you can’t do it all the time, you have to find maybe other things some of the time. I don’t know.

Time 39:45

A Exactly. Exactly like you say, right, it’s almost like you read all these things and then you can’t un-know those things. So I know about ableism and I can’t un-know it and I can’t look at things in the same way. And you learn about intersectional discrimination, I work on it and I’m constantly working with activists from around the world who are in different situations who are also kind of recognising it. And then I’m thinking about my brother who is not white, right, he’s not white and he’s disabled, got a complex disability, and I’m just thinking there’s no way his life experiences are coincidentally. But you know even when you can’t prove it, you don’t have very specific examples, I think intersectional discrimination is like that, where it’s really difficult, it’s really tricky to pin down. But you can’t kind of uncouple that can you once you learn about these things and you’re like ‘oh right, yes that makes sense’. And it’s difficult to kind of separate. But I think also as you said, it’s helpful and in a way it’s therapeutic because then you understand these things and you know that you’re doing something to kind of, hopefully, change it and make progress. But yeah at the same time it’s a lot to deal with at the same time.

Q I think that that’s what those mothers that you were talking to are doing too, you know in their activism. The fact that there are so many ??? of mothers of disabled who are working in disability studies, we’re all trying to do the same thing aren’t we and we’re all trying to make sense of what’s happening to us. It’s kind of weird isn’t it to think of academia as like a mental health intervention.

A Yeah right, especially when it’s such a hostile place I guess.

Q Even worse than CBT I think!

A Yeah definitely.

Q People ??? on CBT, that’s for sure, that’s come in for a bit of a bashing, CBT.

A Oh I’m glad it has, yeah.

Q Because people feel ??? sorry….putting things on your ‘worry tree’ is not going to cut it. Sorry, you go.

A Yeah it kind of annoys me a bit when people, you know I sometimes worry with like ??? saying it ‘oh let’s create a support group and talk about this’. Well that’s great and that is helpful, I’m not saying those support groups aren’t really, really important and having that is important and that’s ??? what they ??? And it’s like well if you aren’t going to do anything about it and try to change the underlying systems or….you know some kind of policy change or do some kind of campaigning or advocacy, then I don’t see that much point in it. Because you know it’s almost like you’re just kind of pulling at the wound, right, you’re just ‘yeah let’s talk about this and let’s do that’ without actually doing anything else. And I think that’s probably why a lot of mothers end up going ??? some work, it’s like that you know, exactly as you were, right, because you’re kind of almost left with no choice.

Q Yeah, yeah. So I think that thing that, the other thing that we’ve kind of been talking around, what people understand by mental health and what they’ve ??? do. People have different understandings of what it is. So some people feel that maybe they’ve always had mental health difficulties and how it’s become entangled with those; some people feel that mental health is something that has been done to them by engaging with the system and they see their responses as a logical reaction to the experiences that they’ve been through. Do you have anything to say about what you think mental health means?

A I mean mental health is just, for me it’s kind of just like a way of describing your general mental state, right, and it doesn’t necessarily have to mean poor mental health or you’re in mental distress. But it means just kind of like….and I think it’s constantly in fluctuation, like nobody is completely constant all the time even if they appear it. And yeah but I understand why people do think of mental health as being a very specific ‘oh you must be mentally ill’ or….there is so much stigma, a stigma on mental health, like so much stigma on mental health even that we don’t talk about it. And yeah. But I don’t know, to me I just think mental health really should just be about kind of it’s relevant to everybody, right. When we’re talking about mental health it doesn’t mean necessarily that you are suffering, it just means that it’s something to be aware of and to kind of consider.

Time 45:00

But I don’t know, from my personal experience I didn’t ever feel like I had any kind of like….I always felt that I coped really well and was very, you know didn’t have any kind of like mental distress or anything until probably quite recently in the last few years. And I think partially that’s been the pandemic, partially that’s been PhD, and partially that’s been like worrying about the future and also recognising my experiences and the experiences of my siblings in a different way. So yeah. And then that’s caused a lot of anxiety, which when I was younger I just…I think also probably age, I think when you’re younger you….you know some young people really do get anxiety and I understand that but I think for other people it’s the kind of thing where as you get older then you end up just worrying more about things and life becomes a bit more real because you have more responsibilities, right, or you understand the world better.

Q Yeah. OK sorry I’m going to go back just to see…yeah I will go back to one of our proper questions.

A I’ve gone off track.

Q So we ask about change, I mean God it’s massive. If you could wave a magic wand what would you change? Is there any, I don’t know a small thing or a big thing that….I mean mine would be smashing ableism, you know, I don’t know. What just needs to change.

A Yeah definitely smashing ableism, racism, sexism all of those would be a massive help I think. Yeah just general understanding of people of kind of how insidious ableism is and that it’s to be taken seriously in a way that, you know people just started maybe taking racism and sexism a bit more seriously a bit more recently. Yeah I think that’s definitely one thing. And kind of recognition…I don’t know, yeah I mean personally in terms of my life obviously getting rid of ableism would be hugely advantageous for like my family situation. But you know like kind of more opportunities I think generally, which obviously comes hand in hand with getting rid of ableism.

Like for my siblings I think that’s one of the biggest worries is that they don’t have the opportunities that I have had and you know I’m constantly trying to look for things for them and think of what things they could engage with that would like enhance their quality of life. And also you know mean that they just weren’t a recipient of care, I think that’s a real thing I have an issue with, thinking of them as just being you know in the system, in the social work system; in the special education system; in the day care system; a recipient of Universal Credit; you know a reason why my parents get carer’s allowance; and not being kind of like a person in their own right who might have hopes and dreams and goals and things like that if they were given the opportunities. Because you know they are definitely capable of achieving things in their lives if given those opportunities and have the support.

And the frustrating thing is, also seeing when opportunities are available for people with learning disabilities but then not being available in my area or the area where my siblings live; or they are available but my parents are so flat out from caring that they do not have the brain capacity to kind of engage with those things and to facilitate those opportunities for them. That’s really frustrating for me because I think also being exposed to those things and being kind of like, because of my work being kind of switched on and knowing what things are going on and thinking ‘oh God that would be so good for [brother’s name]’ or ‘that would be really amazing for [sister’s name], she’d love that’ but knowing that my parents would not be able to facilitate that because they just do not have the time or head space. Yeah that’s definitely something.

Q Yeah I think it’s really hard, all that….yeah having that feeling that you have to make something happen. No-one ever comes and goes ‘here you go’ you know, ‘have this, do this, here’s this’, you have to constantly fight for it and make it happen. And if you don’t have the resources to do that that’s really hard.

Time 49:45

A Mmm. And if you’re constantly fighting for the basics then, yeah, anything else is a kind of ‘oh that would be nice’ but you know I haven’t got the time or the energy to make that happen because it’s however many more hours of research and however many more social interactions and fights to get funding, fights to you know…. And then at the risk that it won’t be suitable, it will be a bad experience or whatever, or it will fall through and then it’s not worth it because of the mental health risks also to my siblings.

[redacted]

A Also probably because trauma builds up I think. So you have these experiences, you have a bad experience and then you’re scared of having the same bad experience and so then you don’t want to engage in it again.

[redacted]

A I know, yeah exactly.

Q So yeah I think that’s one of the things that happens over time as well really.

A Definitely.

Q Do you know what, it just popped into my head I’ve given you the wrong date for the digital workshops, they’re actually going to be….I’ll send them to you, they’re going to be after Christmas, because the siblings one….so we’re doing parents now and siblings later, so it might be that you can come, but I’ll let you know when they are. One of the really useful things about talking to [CHARITY] is, we were doing the proposal was they’re like ‘they can’t be in the same room’.

A No.

Q And everybody goes ‘no, no, no’.

A It’s not a good idea.

Q And I really, really understand. I really understand that. I think parents will probably be less worried about it but I can really understand why siblings don’t….it’s hard isn’t it to talk about it in front of other parents.

A I’ve thought of another thing before you move on. So another thing that I would change is – and this is something that I feel quite passionately about and also I’m quite interested in in my own research is – I would….I don’t know how to phrase this….I would like to see more parents understand about disability rights and ableism because I think that is hugely lacking. And I would like to see more coalitions between disabled people’s organisations and parent’s organisations. This is a huge issue that I see in the disability rights world and this kind of like joint learning. And parents learning that they can be also be ableist too, and other family members I’m not just saying it’s that, but ableism within families I think is huge. And it would probably be very useful if parents….obviously no-one gives you a manual when you become a parent, but just if parents were kind of more aware and have more outreach from disabled people, from disabled activists who are adults, right, about what it’s like to be a disabled adult and what the disability history is and what the disability rights movement is, and you know what the debates are going on so parents would be a little bit more mindful of that. Because I just think – and I’m not saying it’s the parents fault because obviously you’ve got enough to deal with, but I just think so many parents are completely clueless when it comes to disability rights and they’re about ableism and it would make a huge difference, right.

Time 54:25

Q Yeah I really agree with that. I always remember in one of Carol Thomas’s books, I think it’s the 2007 one, there’s this specific phrase where she says ‘the agents of disablism are often close to home and that includes other disabled people, parents’ - I can’t remember who else is in the list. And I think yeah that is really true that that happens and it’s really important to be mindful of that. And I think one of the things that, I mean because I’m so lucky in my job, I get to work with self-advocacy organisations of people with learning disabilities, and that’s one of the most positive aspects of my job. But it’s like the counter? to everything else. So working with people. I don’t really know what learning disability means when I’m in those rooms because I think I don’t really understand why anyone would describe you as having a difficulty with other things ??? you know they’re just the most amazing people who are speaking from their experiences. And that’s really powerful. And most parents don’t have access to that because the first disabled person they’ve met probably is their….

A Is the child and they’re in a child/parent relationship and it’s really difficult for them to reflect on that. So yeah I think definitely when it comes to learning disability, right, to have learning disabled self-advocates talking more to parents and having that as a kind of….yeah.

Q Did you follow the Rosie Jones thing? Do you use Twitter?

A Yeah, because she said something didn’t she that was conceived as being really ableist.

Q Well it was really sort of distressing all round. So she did a programme which was called I Am Not a Retard because she has that said to her. And parents of children with learning disabilities who wouldn’t be able to engage with that had a big reaction about how you use the word ‘retard’.

A I saw there was a reaction but I didn’t realise it was the parents.

Q Yeah parents. I don’t know if it was other disabled people. The people on my timeline. So parents that I know and I like absolutely piled into her saying ‘you can’t use that word’ and ‘what you’re saying is that you’re not like my child and my child can’t speak and understand? the ??? that you have’. And then Frances Ryan who writes for The Guardian, she’s a disabled journalist, she interviewed Rosie Jones. Usually I love her too, and she didn’t challenge her on that issue. But then all the parents of disabled children piled in on Frances Ryan, and I was like….

A Rosie did bring a video out didn’t she explaining like her….like defending her use of the term.

Q Yeah and I don’t think it was defensible and I do think that Frances should have challenged her on it in the article. You could go and find it probably. But what was awful was the absolute pile on on two disabled women by mothers of disabled children primarily – there were a few dads in there as well. And Frances Ryan even to things like say ‘this is having an impact on her mental health’ and they were like ‘never mind, we just tell you why you’re wrong’. It’s like… And Frances said that disable people need to lead the movement. And these parents were saying ‘but you can’t lead on behalf of my child because my child has a profound and multiple learning disability’ or whatever it was.

A You know which is usually the argument.

Q Yeah and I kind of get all of it and I wanted to say, I thought Twitter is not the space to say this, but I wanted to say ‘look, look, just stop, everyone just stop, let’s get in a room and have a proper conversation about this’. But I was too frightened of Twitter to do that.

A Yes exactly because it’s just a horrible space isn’t it and you don’t want to weigh in on a debate where no-one’s going to listen anyway and it doesn’t resolve anything. But yeah I think that is the issue, that those people are often not in rooms together. And to be quite honest, like exactly as you just said there is a lot of ableism within the disability rights movement especially towards people who have got learning disabilities. And I hear from physically disabled activists, you know kind of like…or from other people as well, but kind of like, you know you say ‘oh my sibling’s got a learning disability’ and it’s like ‘oh I’m sorry’ or ‘oh’. Or people think….that kind of attitude, or ‘thank God I haven’t got a learning disability, like that would be terrible, I’m physically disabled but that would be awful’ and just this kind of stuff. And you think ‘oh God, no’. And at the same time you see this stuff from parents and you’re like how are you so clueless about the disability rights movement and you feel like you can say things like this. And why are we not aligning.

Time 1:00:06

I just see this, it’s like divide and rule isn’t it, right, you divide people. Actually so many of the goals are shared, which is getting rid of ableism, and yet we are so divided and fight among us. And there seems to be these two separate camps or two separate movements, which to me just seems completely bizarre.

Q It happens to me, that thing happens around autism. So people are telling me all the time…. it was twice last week where somebody said ‘I’m autistic but I don’t have a learning disability’. And somebody said to me ‘I’m autistic but I have a really high IQ’. And of course I want to say ‘like I give a shit about that’. And I think as a non-disabled woman, or perceived to be a non-disabled woman, because as you age I don’t quite know who is ??? anyway, but as a non-disabled woman I feel like I can’t ??? It’s complicated.

A Yeah it’s very complicated, yeah. But I think yeah definitely more conversations between parents and disabled people. And you’re dead right, like and understanding and just people open to learn and open to be wrong.

Q Would you like conversations with parents who are not your parents? Do you know what I mean?

A Yeah I do that with my work anyway, right, I’ve just had two months interviewing mothers. But yeah maybe that would be useful for them to hear from someone who is not their son or daughter maybe. Yeah that would be useful. And to hear from other…probably hear from other disabled people who are not my siblings, that would be really helpful.

Q Yeah. Well these are things that have happened in the project. Because we have people with learning disabilities on the group with carers is that they carers have said ‘I’ve never heard that before’ you know, and that has been really powerful. And the other thing actually that’s come up that I don’t think has been written or spoken about very much is the care that people with learning disabilities give.

A Yes I saw that actually in a blog that you wrote, and I was like that’s really interesting because I think that a lot, especially about my brother. But also about my sister, right. My grandad died. My mum’s mum died earlier this year and then he was in kind of like the early stages of dementia and my sister who is verbal but she doesn’t speak a lot, she hasn’t got a lot of speech but she signs. So she uses Makaton at school, loves using Makaton and BSL. And she was at the table – he used to come to my parents for lunch every Sunday and she would sit. And it was quite difficult to engage in conversation at the end, really difficult to kind of like talk to him. And she used to sit there and talk to him and sign and sing and do anything. And he would engage with her in a way that he wouldn’t engage with other people. And you could tell that she knew what she was doing and she was really making an effort to talk to him. And I mean this is someone who was labelled with a learning disability and, you know an IQ of I don’t know something very low, probably below 50. But you know she was able to do this.

And the same with my brother, I think he can pick up on when I’m not feeling great or when I’m stressed, because he’s very, very emotionally intelligent and he can…. Oh we took him to Paris two weekends ago and my partner – my partner has also got mental health, he’s got OCD and he’s got mental health things and he is in a great place at the moment but a few years ago he was really not and he had time off work because of mental health issues and been hospitalized because of his OCD in the past and all of that sort of thing. Anyway I think probably he’s somewhere on the….he’s probably neuro-diverse, maybe autistic but we don’t know, but he identified a lot with my brother who is autistic as well, autistic and learning disabled. And it was quite a stressful trip as you can imagine, it was me, him, my sister and her partner all there with my brother because he’d decided he wanted to go to Paris. And so we had to make the Paris trip happen, we promised him that he’d go, that we’d take him, which we did.

Time 1:04:50

And we’d taken him out to this bar. My sister had bought tickets to a cabaret. He’d done really well, the show hadn’t started on time and he’d been waiting, waiting, waiting. He decided it got too much and he wanted to go home. We were like ‘that’s fine, we’ll take you home, you’ve done really well like waiting around’. So me and my partner took him home in a taxi, arrived back and realised we couldn’t pay on card and we didn’t have the cash. And I was like ‘well I need to get [brother’s name] back into the Air B&B, I can’t come with you, you’re going to have to go and find a cash point’, with a taxi driver who doesn’t speak English and we didn’t speak French. ‘I’m sorry but I can’t, you’re just going to have to deal with this on your own I’ve just got to get him in the house’. So I got him in and then of course he went off to try and find an ATM. And the taxi driver was really annoyed. And this is the kind of thing that will set him off and really stress him out. So he arrived back home and he was really wound up, like so annoyed. And me and [brother’s name] had gone in and like put the telly on and it was like….and he was just so angry. And I said ‘listen, either go out for a walk to calm down or go downstairs’. It was also really hot, it was that weekend when it was 34 degrees. It was horrible. But the basement of the apartment was really cool so I was like ‘go and sit downstairs and cool down’. But he was obviously so wound up.

And [brother’s name] bless him, I think because he also identifies with my partner, because he gets wound up about similar kind of things, right. And so when he finally came back up and he sat with us on the sofa watching the telly, he just like gave him a hug and said ‘are you OK [partner’s name], you were a bit stressed’. Because I was like ‘[partner’s name]’s just a bit stressed like about what happened with the taxi, it’s fine, he’ll calm down’. He was like ‘yes I understand’ and then was like comforting him and like telling him that it was OK and that like he also understood and he ‘I get annoyed [partner’s name] and I get stressed too’. And like that I think is kind of, those kind of actions and things, just exactly as you said they are not written about and they’re not valued. That isn’t valued that community building and that care.

Q And yet to you in that moment it means so much doesn’t it, when those moments….

A Exactly.

[redacted].

A Definitely.

Q I’m aware that I’ve talked to you for longer than I probably should have, but is there anything else that you wanted to ask me?

A I was interested because I work on intersectionality. Are you including indicators of race and are you….yeah are you including race in the project because I think that….

Q Yeah we’ve tried really, really hard and we’ve really, really struggled. So it’s not fully white but…and we were aware of that right from the beginning. So we’ve got two co-aps. So Rosa is from the Roma community, Liz is from a British Pakistani background and has links with those communities. So we are hoping….for some people with a ??? participation are massive, so particularly the Roma community and that was one of the reasons why we are really interested in that community because, you know the discrimination that they face is just massive. So yes we are and we’re constantly trying to do something about that, but we haven’t been as successful as we’d like to be. But we haven’t finished recruiting for the siblings, so if you know any siblings that you think might be interested we’d be up for that.

Time 1:09:40

And the other thing that we are going to do for the exhibition phase is have it in multiple languages to try and counter the predominant whiteness of the ???2 phase. Because this is really interesting actually, we’ve got a load of money to pay people’s carer placement costs, and people can’t spend it because they can’t get any placement. So we’re going to use that money for translation instead. So we’ve looked at the – I can’t remember what they are but we’ve looked at the most commonly used community languages across….

A Yeah like Polish and Urdu and…

Q Yeah and Welsh actually.

A Welsh, oh alright.

Q Lovely Welsh. And so we’re going to try and make the exhibition bit of it as accessible as possible.

A More accessible, yeah. I’m wondering whether, I don’t know if you’ve already thought, but reaching out to community groups in places like Bradford. Because there’s lots of…yeah there’s loads of groups, they’ve got like Purple Patch Arts who work a lot in Bradford.

Q Oh I know Purple Patch, yeah.

A Yeah, they’ve got a research group actually haven’t they which is linked to a PhD project at the University of [city] which was about how to….

Q ??? contact them because I did some work with them in the past.

A Yeah it might be worth reaching out to them. Who else? Purple Patch. Yeah there’s a few groups linked to Purple Patch, probably Pyramid Arts as well in [city], they might but they’re not so…they’re more [city] than Bradford. And then in London maybe ALLFIE the Alliance for Inclusive Education, because the leader is Michelle Daley who also set up Disabled Black Lives Matter UK, so it might be worth reaching out to them. And there’s the…is it the Asian Disability Network as well, if you’re not already in touch with them, or if Liz is in touch with them. Very much South-Asian based but I’m just wondering if they might have some groups. And because they’re, like Purple Patch were an activity it might be a good way, do you know what I mean, of catching kind of carers who are there whilst people are in activities.

Q Yeah those are fantastic ideas. Thank you. Yeah you’re not the only person who has asked about that interestingly.

A Mmm, I think it’s just on people’s radar a bit more, right, which is good because then people are asking about it even when they’re not…obviously for me my brother isn’t white and so, but it’s an unusual situation because I am and my parents are so then….I mean that in itself I think is an issue because we’re not plugged into those communities. And I think my parents are completely, completely….not completely but pretty unaware of like issues of racism in a way that they wouldn’t be if they weren’t white. So yeah that’s good to know that you are thinking about it. But I realise there are huge barriers around it.

Q Yeah. So I think it’s been really helpful having Rosa because she’s just been able to spend loads of time, and she’ll be there with the person when I speak to them and things like that. So there is support, we have built in to have the support available but it’s still been really tricky.

A Yeah, it’s kind of like the Catch 22, right.

Q Yeah. But we just need to keep trying and keep thinking. And also we will translate the resources that we produce at the end. We’re already committed into translating those into community languages too, so we will have….it won’t be that it isn’t accessible to people. And we are working on a range of projects and we’ve been talking about it across all the projects as well, so that’s really cool.

A Yeah.

Q I’m just going to stop recording for a moment and then I just want to say one more thing…..