Q …and then it will be transcribed and we will send you a copy of the interview. You don’t have to read it at all, you don’t have to open it again, it’s up to you whether you want to read it or not. And then if you want to remove any bits that you don’t want us to take forward into the analysis just cross them out and send it back, that’s fine. If you decide you want to stop in half an hour’s time, you’ve had enough, that’s fine. And it will be anonymised going forward into the analysis process. So yeah that’s cool. So [Name] shall we kick off? Have you got any questions before we start? My sheet says that this is going to be more like a conversation around stories around being a parent of somebody with learning disabilities and people’s experiences of mental health across the time, over time. So if you wanted to start off by saying what made you want to take part in this project?

A Yeah I thought it was interesting because the focus was on the parents’ mental health. And I suppose part of what was interesting is because often, particularly in my experience, particularly my son, that tends to get overshadowed. And yet it’s really important because if you’re going to look after that person, support that person, you need to have good mental health. So that was the reason.

Q OK. Why do you think it gets overshadowed?

A I don’t know really. Always has. I mean I’m autistic as well so that….at times we have to try to remind people. Or certain people in my son’s team, there will be one or two who have to remind the rest of the team, yeah that I’m on the spectrum.

Q And so are you sort of saying that being autistic means that mental health is pushed even further back?

A Just that they forget it. So they forget that things my affect me in a certain way. Or if I attend a meeting it’s going to affect me in a certain way. Or they don’t see that some of the things that happen to my son are likely to have a traumatic impact on me, perhaps more so than they might have on someone else. Like even just with him being an inpatient, they don’t always think that for an autistic person like myself those places can be extremely frightening and distressing, and they don’t think to ask my own history.

Q OK. And can you tell me a little bit about your experiences of being a carer, because I don’t know that much to be honest.

A Been incredibly hard. Because obviously I had [Name] quite young. He’s my only child. I had a miscarriage before I had [Name], so then I had [Name]. So he was my first child with no experience of bringing up a child. And he got diagnosed quite early. So he got diagnosed with autism at 2, epilepsy at 2. It was quite apparent from quite early on that he’d got a learning disability. So everything was quite….you’re just doing everything for the first time. So I don’t know what it’s like to parent a child without a disability. It was hard. I mean in the early days he was having between 25 to 30 seizures a day and I’d just be stuck in the house dealing with that on my own. And I’d gone from being kind of a working woman to just being stuck in. And there was quite a lot of prejudice as well. Yeah it was tough going. But I think the hardest part came when he ended up being taken when he was 16, that was the toughest part I’d say.

Q What happened then?

Time 4:30

A So we got him to the age of 16 and he seemed OK, you know he seemed….he was alright. He had his birthday in like a zoo, like he fed the ??? took them out, fed them carrots and stuff. And then somewhere between then and, his birthday was in the February and in the September something just went horribly wrong and his behaviour deteriorated. And I don’t know why, I can’t put a finger on it. But you go back and you think ‘can’t you picture where it went wrong, there must have been some point you could….’ I know that at the school, the special school where he went to, there was environmental stuff going on and they were doing building work and I often look back and think ‘why couldn’t I see that was probably a factor in it’. But he started absconding from school and his seizure activity went out of control. And looking back, the idea was they wanted to medicate. But there was no sort of ??? social interventions. And in the end they said they could no longer support him and he was stuck at home with us 24/7. And then it was, well we couldn’t keep managing the way we were, we couldn’t go out, we couldn’t do anything. And they basically said to us, ‘well you’ve got a choice, he either goes to this place 205 miles away in [place name] or he goes to [place name] there’s a place in [place name], that’s your choice’. But it’s not a choice is it. And that was it. And we chose the one nearest to us simply because it was the one nearest to us. But when I went to look at it I hated it. So imagine having to send your son where you don’t like. But you know you can’t keep going. So yeah it devastated us that did.

Q OK and how long ago was that now?

A 2019. And they restrained him not long after he went in there.

Q Yeah, been there.

A I know.

Q So he’s been there for 4 years now.

A Was, until they sectioned him. Yeah.

Q Is he in the same place, or has he moved?

A No they sectioned him in ??? Because he went through an awful lot. Because he hadn’t been there very long, and then he almost died from sepsis. Then we had the ??? case trying to fight that. So he’d only been there the November, that happened in the February/March. And after he survived that, he’d only been back into the place a few days when the lockdown happened and we were told that we could no longer see him. We went 15 weeks and one day without seeing him. And he’d only just been discharged and his weight was 7 stone 1 pound. It was devastating. And he was still a child legally. But no-one ever told us what our rights were around seeing him. And he ??? deteriorated. He was self-harming and asking other people if they’d be his mummy and his daddy. That had a huge effect on us, particularly on me. And he had to say goodbye to his nanna on a Skype call because my mother was dying because I was a ??? in COVID. It was just a really horrific time.

And then after all of that he had agency staff coming in and out of his area because obviously staff were leaving. But there’s a corridor that went through his living area and it was a nightmare because people would walk in and out, there would be doors banging, and particularly agency staff who didn’t know. And even when I used to go and visit him I found it really difficult as an autistic person, there were two autistic members of staff who left because it was so bad. And in the end he got sectioned from there because of an incident to do with a corridor. It was during the hottest day of the year, when it was that really hot heat wave, and he wasn’t going out at the time.

And the reason for sectioning, we managed to get the reason for sectioning overturned but not the section itself because they’d lied basically and they managed to get a witness statement to show that they’d lied for the reasoning. So we got all that overturned and put on his record but not the actual sectioning, even though it was all….but basically they did the sectioning without us there. We had to go up, we drove up and it had all been done and dusted. And they woke him from his sleep three days after the incident with this teddy bear, and did it. And they sent him to a horrible place where he got abused. It was horrendous. They banned him from playing with his teddy bears, with his toys. He couldn’t go out. They wouldn’t let us seen him. We had the Health Minister writing to say there’s no reason why we can’t see him. He wasn’t allowed in the garden. It was just awful for him.

Time 9:46

We managed to get him out of there and he came back home, but still there was no home for him because they were trying to find a home. All this time the health authority, the local health authority has been trying to find a home, but they haven’t done it, they’ve been doing it for years, failing him. He came home. Still no home, still no home; he was stuck in, stuck in. And then they contacted us and said ‘you can’t carry on like this’ and we’re like ‘yeah we know’. And they said well if you carry on he’s going to get sectioned into [country of UK] or [country of UK] but we have got somewhere, another ??? catchment in terms of care unit in the county next door, he’ll have his own unit with his own garden, we could put him there until we could find him a home, but you’ll have to have him re-sectioned. And I had my own son re-sectioned to spare him from going into [country of UK] or [country of UK] basically. And he’s still there now, he’s still there now and year on.

Q And how is that place compared to the other places he was at?

A To begin with awful environmentally, but he’s got a good RC, the first RC was horrendous, this RC is actually the opposite, really good, kind, compassionate man. Because [Name] was put in the HDU unit on his own – and this is the big thing about my mental health – so he was put in there on his own because he wouldn’t be safe with the other patients. Because my son has got a severe learning disability in that some of these patients have come through the forensic route and we knew he wouldn’t be safe there, he knew that. So he was in long term segregation but the seclusion room was like near to him, so his only experience of other patients was them being dragged through to the seclusion room. And we were there sometimes when that happened, it was so distressing. And you’ve got some poor patient screaming and crying in the seclusion room, [Name] thought they wanted to attack him and hurt him so he was severely headbanging. You would see his blood on the wall. And it was just the most horrific thing to see.

Sometimes police would escort people in the seclusion room with tasers, and [Name] would wet himself in fear, it was just the most horrific situation. And they RC kept saying to the health board ‘we can’t have this, this is just really unfair on him’. And in the end it was him not the health board who said ‘right I’m going to move him to the step down unit’, so where you step down before you’re discharged. He got all the patients discharged out of step down, put [Name] in there, which means other patients can’t go in there. So he’s in there on his own, but it’s quiet, there’s no seclusion room, there’s no other patents around. And [Name] has improved enormously. I mean he’s still in a hospital but he has improved a lot. And he’s got LD staff to come working with him. And that’s all down to the good RC, but he’s still in the hospital. But the actual HD unit was just horrific. And he had no access….the garden didn’t exist.

Q So he’s got access to the outdoors now.

A A little garden, a tiny little garden. But I keep fighting for him to go out more and to have more space. And it’s a hospital it’s not a home. And every day you wonder what’s going to come, even though things are OK at the moment I wonder what’s going to come next. And because of him being taken so many times, and I can’t forgive myself for having [Name] sectioned, I can’t forgive myself for doing that, even though I knew he was at risk and I’m going further afield, it’s the position they put me in I think. It’s not [Name], it’s never been [Name], it’s the system. They affect my mental health, they do it, not him.

Q So you know it’s affected your mental health?

A Oh yeah, yeah, yeah. I mean last year when we did that, when [Name] had to go back in, I went with him and I blacked out and I got sent to the hospital. And [Name] saw it happen, bless him. I blacked out and I had a seizure and I got sent to the hospital. Then I had another one when I was there and the doctor said that they were psychogenic blackouts. So I was having like non-epileptic seizures. And I was so apologetic, because I was like ‘oh what’s happening, have I kind of….’. And he said ‘no you can’t help it, they are involuntary. You have blacked out, you were unconscious’ and he said ‘your oxygen levels are low, but it’s the trauma, the trauma of what’s happening to you has made you do that’. He was very kind. And I felt so awful because I wasn’t with him, my husband had gone with him and I was stuck there. And then they got somebody from mental health to come and see me and then I panicked. Because I thought oh no. Because I’ve been an outpatient before in the past and I thought oh, the first thing I said when they sent the person down was ‘you’re not putting me away, you’re not putting me as an inpatient’, that was the first thing I said.

Time 15:05

But I was really lucky that this chap was really good and said ‘no, no I’m not going to do that, I’m more interested in what’s happened to you and what’s wrong with you, which was the other way round to my previous experiences. So that was good because a lot comes through physically with me. Because I have alexithymia, because I’m diagnosed with alexithymia and autism so I can’t….

Q What’s alexithymia?

A I can’t identify my own feelings, which is very common in autism. So I struggle to identify, particularly positive emotion. So a lot of stress comes out physically hence the collapse??? I tend to disassociate. And so it comes out that way. So like I had pain in the chest, it tends to come out in a very physical way. I’m losing my train of thought now. So yeah so I think that’s how it affects me really.

Q So after you’d had that blackout and you’d been to hospital and you saw the doctor, what did they say? Like he said it’s a psycho….

A Yeah he said it’s trauma, it’s trauma. And the chap said it’s trauma, he said it’s ??? And I thought I’d got some PTSD symptoms as well, which I have been told that in the past. I know RESPOND were going to do some work with me and I said, you know our Blackman’s? team, and I said no I didn’t want to do it. Because to do it they had to go through my GP or something, I just thought ‘oh my, my I don’t want them knowing’. I think if you are autistic you’re really worried that if you go to the GP, the GP knows or it’s on your record. I feel that anyway. Certainly I’d be worried about going to my GP and saying ‘look I’m really struggling with something’, because you fear you’re going to be sent…. Because the last time I did that as the carer/user go and said ‘I’m really struggling’ they sent me straight to the hospital and it was an awful experience. So I would be really fearful of going, you know.

Q Was that your first experience of being mentally unwell was when [Name] was younger?

A Yeah. I was stuck in. He was 3. I wasn’t seeing anybody, I was completely isolated, all I was doing was changing nappy after nappy after nappy. We’d just moved house. My mum had cancer so she couldn’t help out. I’d lost my nan who I was very close to, my grandad had a stroke. There were lots of different things going on around me and I started to go a little bit manic in my behaviour and a bit depressed as well. So I went to see the GP and I said ‘look’, I went for a walk late at night and I thought about….I thought things. And he said what were they, I said well I thought about not being around any more. Right, next thing I know took me to hospital as an out-patient. But I was threatening of being an inpatient, and every chap I saw was a man in a white coat. I remember they had a fish tank and all the fish were dead in it and I was thinking well this is a ??? not to put me in this place. And all these fish died in this tank.

But every time I went I met somebody different, and they put me in this room and they’d go through the same questions. And they’d always put me in the room next to the inpatient room, almost like a way of saying ‘if you don’t behave you’re going to be in here’. And I wasn’t spoken with, I was spoken to. And about week 6 I said ‘look I’m getting a bit fed up with you asking me the same questions all the time’ and they wouldn’t answer you. And I was on like a foot stool, and I said ‘can I have a chair please’, and the bloke’s still writing away, and I said ‘can I have a chair please, I want to sit up like you, not like on a stool writing away’. And at the end of it he said that they’d got some notes he wanted to share with me, and one of them was that they believe I had an issue with authority and I had anger issues. I had nothing….I thought they have not diagnosed these have they, you don’t have….

And I got scared then and I said ‘can I discharge myself?’ And he said ‘well at this present time you may’. And I said ‘well consider myself discharged’. ‘But I don’t recommend it’. But I said ‘no, no, consider myself discharged’. And I started walking out and walking down a corridor. He was chasing after me. ‘I really don’t recommend it and we’ll be writing to your GP’ and that. And I just said ‘I am discharged’. And I threw all my tablets away and I started a dance class the next week, and I’ve been dancing ever since. So I danced myself out of that.

Time 20:20

Q What sort of dancing?

A I do like Latin, and I do ballroom, I do a bit of showroom but I don’t like the showroom so much, I’m not really a jazz person. But that’s what I enjoy, so I do that.

Q So you’ve done that ??? years?

A Yeah. But it’s also part of my routine and I get very upset if I’m going to miss it. I dance in the same spot and woe betide anybody if they go in my spot. So I have a little ??? spot. But I just love my dance class and it’s really important to me. It’s my thing and if I can’t do it I do struggle. But that’s the one thing that’s helped me mentally.

Q So then fast forward to last year and you passed out in the hospital, did they want to have someone go engagement with you?

A Yeah.

Q Did they offer you medication? Did you just say ‘I’m not….’

A They did offer me it. I only took the little bit of Diazepam, I only took it one night and felt really, really well with it, and then didn’t do anything with the rest of it. But I also knew after the sectioning episode, because they asked me how I was…. they tried to find out how I was feeling, and I have to admit that I wasn’t in a good place, and I wasn’t in a good place then. I mean I had to open up and say that I had got tablets stored away for ending it. They wanted to know if I was going to do anything else to….you know. I said I wasn’t going to palm anybody else, I’d never do that, that’s well out of the question. But to myself I had. I think the scary part was when the chap said ‘had you thought about your family at the time’, and I said no I hadn’t. Because I was so low I didn’t want to get up the next day.

Q So was this the recent time or the….

A That was last year, yeah, that was how low it got, yeah. Because we were stuck at home and the threat of [Name] being taken away again was just so great, particularly if he was going to be taken into [country in the UK] or [country in the UK] I was so terrified I couldn’t bear to see it. And I literally did buy loads of sleeping tablets and I put them away and I thought…. But the thing is, once I had them I kind of felt like I could get through the next day and I could get through the next day, because I kind of thought they were there almost as a reserve, as a back-up. So once I had them it actually managed to keep me going for the next day and the next day and the next day and the next day. I had one lady from the health board ring up and threaten me and say ‘you know you can’t keep going, we can have him sectioned, we can have him sectioned tomorrow’. And it was that threat, that like ‘where’s this going to go, where are you going to put him’. And you know and I know some of the awful places that are around, and I was just thinking I don’t want him sent to St Andrews or something. I was absolutely terrified. Which is a really cowards way out because I need to be there for my son, but for some reason I just couldn’t. I was really frightened. It was a really dark time.

Q And have you sort of like climbed out of that dark time now?

A Yeah, and quite quickly. And that’s the amazing thing, I can climb out of that very, very quickly, very, very fast. Because we were coming out of hospital, [Name] went in, I climbed back up, went for the job at [workplace] and then a few weeks started working at [workplace]. And everybody said to me ‘how on earth are you doing that’ and ‘what are you doing’. And then I was like weeks later I was up and running at [workplace]. That’s kind of how I can go really. I’m somebody who can pull themselves up quite quickly, very, very fast. Because once that I’d gone and [Name] was in the place, you know it was like ‘OK I’ve got to get on with it now, the worst has happened actually, now I’ve got to kind of….’. And we were exhausted, I don’t think I have ever….we were so exhausted. It was really, really tough in the house, and I just didn’t know how we were going to get through each day.

Q So you were a year on now. How often do you get to see [Name] then and how far away is he?

A Once a week. Once a week, we’ve got three solicitors, human rights case on the go. And people do say, you know well some people say they think it’s a good thing, other people think ‘oh you’re doing it to yourself, creating all the work’. But I’m like there’s no way I’m not going to ??? a human rights case.

Time 25:10

Q Yeah.

A I’m like well I’m going to do it because I want to get to the end of my life and look back and think ‘well I did the best I could for him and for others like him’. And I wouldn’t forgive myself if I didn’t try. Because at the end of the day his human rights are violated. The ??? thinks that there’s a case here and that there are violations of three Acts, and I think we should try. So I’m going to try.

Q And in terms of your mental health now, how would you describe it now?

A Alright. It’s OK. Yeah. I mean I tend to always notice it if I’m mildly a little bit low, I tend to always pick that up. Mainly because other people pick it up, my husband picks it up, and it’s more of a physical thing as I said than a….so it’s more physical. So I might start to get some chest pain or start to feel a bit….and then I have to kind of check in with myself and do something myself about it, like make sure I’m doing my dancing, make sure I’m doing lots of walking. So I do a lot of things for myself like walking and dancing. And actually my work, doing work, it’s actually part of….because I know [name] laughs at me when I said it was my hobby, and he said you can’t have work as your hobby. But actually it is, particularly if you are autistic, if something is a passion and you love it then it gives you purpose and meaning and actually it’s very important. If you’d said to me ‘tomorrow you can’t do any research and you can’t do any work’ then my mental health would drop because I wouldn’t feel like I’m doing anything useful or anything…. So yeah.

Q So your husband supports you, he points out when you’re possibly having a dip.

A Yeah.

Q And then you have a set of strategies to try to sort it out yourself?

A Yeah. And I’m quite proud of myself because I have pulled myself out and go out quite quickly. And as I said, one of the things I’m most proud of is that I’ve always managed to get myself out quite quickly.

Q And now you are fighting to get [Name] home, and then fighting the human rights case because his rights are violated and you don’t want that to happen to anyone else.

A No I don’t. And that’s the thing that drives me because I don’t want it to happen to anybody else, and I’m back at the [devolved] government again in October. So I suppose the difficult part is that people think you are not caring if you’ve got somebody, a loved one, who is not living at home with you but the caring continues. And the other week I added it up and it was 19 hours I was putting in on top of the stuff that I do at [work] and it’s stuff that people don’t realise you are doing. And you’re always doing it, whether it’s ??? you have the meetings every week with the ward rounds? You’ve got the MDT? one, then you meet with the RC and senior nurse, and then you’ve got all the solicitors back and forth with paperwork. And a lot of it I don’t understand, so having to try and ask and clarify, because I’m not the sharpest around legal speak. So there’s always so much going on. There’s his epilepsy appointments and this and that, and I take an active role in all of them. So I’m always right at the heart of it. So he might be there but I’m there too.

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

A Oh gosh, so much. I mean my GP has never spoken to me about being a carer, ever – ever!

Q He knows you’re a carer though?

A I don’t even know if they do. Well they must do, I mean they know about [Name], but they never ever mention it – ever. And they never even mention my autism, they never mention that. Isn’t it bizarre. You know 20 years of caring but then never mention that and what that might do. And I’ve never had a health check as a carer, or even as an autistic person. You’d think they’d do that wouldn’t you? And I’m going through the menopause, which really sucks because just at the time of my life when I’m thinking ‘oh I can get on and do research now’ I get a bit of brain fog and sweats at night and horrible stuff. And I’m thinking ‘oh great, now my body’s doing that’. So it really sucks. So I kind of resent my body that’s playing me up just as I’m trying to get on with my career. But they never ask any of that.

Time 30:17

And then you get your carer’s assessments, which are just absolutely ??? aren’t they? What did mine come back with? What was it? Oh we’ll take you to groups for cups of tea or something, and yeah some kind of group for a cup of tea. And I was like that’s my worst nightmare, I’m autistic, I don’t want to sit with people and have a knit and a natter or whatever else it is, that’s just a nightmare. So I do have one thing, they did take her away from me actually. She’s like an autistic sort of support worker but she comes in every now and again. But they did take her off me during COVID which really upset me.

Q What sort of things did she do?

A Well sometimes she would talk to people and say, you know ‘[Name] is struggle with this at the minute’ you know whatever, can you take that into account. She’s done a health profile for me. She’ll talk through things with me and say ‘well maybe we could do this, or do that’. It’s just having that extra bit of support there. It’s quite hard sometimes. But I think there’s the academic me which people see; and there’s the autistic part of me that….I try like with my team, this is difficult sometimes, you knew this because I ??? this, but I try very hard not to show the autistic part that struggles and it takes a lot of energy, a lot of time up. I’ve tried really hard for people just show the autistic part that’s the strength but there is another part of me that can struggle. So she helps with the bit that struggles. But when they took her off me during COVID it was a really big….big er….yeah. And she’s seen me have a meltdown, not many people have seen that. And ??? I had one in the unit where [Name] is when they put the big fences up. They put all this big anti-ligature fencing up and he couldn’t see out of it any more and he couldn’t see the sunset that he used to look at. And I was like that really freaked me out, it did, I lost it.

Q It’s really difficult. Do you think that you might get that support back?

A Well she comes in now and again, but I do miss it, yeah. But I think it’s interesting, because I’m on a different kind of carer.

Q A different kind of care what?

A I think it’s difficult because I’m a different kind of carer, I’ve got a disability kind of myself as well.

Q And not much, what’s the word, support for that?

A No, it focuses very much on [Name], and it has to focus on [Name]. But I think they sometimes forget that I am autistic. And when you go the mental health tribunals and all that and you’re sitting there and it’s a big table, everybody’s talking at once, and they talk about something very sensitively, they do forget. I mean the RC did say one meeting ‘are you alright’ when it became a bit heated and I was starting to get a bit stressed. But they do forget that.

Q When were you diagnosed?

A I was diagnosed a few years back. Before then I think people didn’t know what name to give it, a title. At one point they thought I had bipolar, but it wasn’t bipolar, you know that’s a typical pattern for girls. Because I was born in ’76 so people didn’t know what it was then. But I did struggle. I mean I was in a special needs class for a year when I was about 7 to 8. And at other times I’ve been a really high flyer. So it’s been a very kind of up and down kind of path. But I’ve always struggled with really high levels of anxiety, extremely high levels.

Q So I mean struggling with seriously high levels of anxiety and then going through what you’ve gone through since you were 16 is extraordinarily tough isn’t it?

Time 35:00

A Yeah. I mean the Restraint part has been hard as well. I do quite a bit of work with [organization that advocates against restraint] because he’s been….that’s lessening off now but there have been times when he’s been restrained so much, when I’ve seen him being restrained. And I don’t think people understand what it’s like as a family member seeing your loved one being restrained. Nobody provided me support for that. You know I’ve seen him naked and being restrained, do you know what I mean? Just….horrible. And then there’s the report from the place where he was abused, where he got injuries from ??? restrain. And they hid it, you know it wasn’t even reported and you’re trying to fight that. But those kind of things are….they are huge things. And there’s no support for any of that, you’re just having to kind of deal with it on your own.

But I’m not the only one, lots of families are having to do that. But there doesn’t seem to be anything out there. There’s not actually even an emotional support line that you can ring up and talk to anybody for ??? and carers. I also think I belong to quite an exclusive group. You’ve got groups of carers haven’t you and there aren’t many of us who have got loved ones who are inpatients. And I think we kind of…dare I say it….we kind of scare other families because we are the group that they don’t want to be. You don’t want to be that group, you are hoping that will never happen to you so you don’t want to kind of talk to them. There are groups within groups aren’t there and some groups people don’t want to be part of and hope they’ll never be part of, you know just disenfranchised ones. Because I know people who have got loved ones with learning disabilities who don’t talk to us so much because we are what they fear.

Q What do you think….what would it mean to include carers’ views into mental health practices? It’s quite a tricky question.

A Could you just say that again please?

Q I read it out and I sort of think ‘what does this mean?’ There’s a probe here. Are there helpful supports or approaches already out there that you are aware of around including family carers’ views into mental health practices? So what helps? We know dancing helps you.

A Dancing helps, yeah.

Q Is there any other sort of supports out there, whether it’s….

A Dancing helps, but not the social side of it because they get on my nerves a bit – no offence – but people…. They’re all talking about their grandchildren and ‘has Johnny got his A levels and that’ and I’m just like that’s really kind of nothing compared to what I’m going through with mine, do you know what I mean? So it’s kind of….I go just to dance really. What would help me more than anything is the system doing its job, that’s what would help me more than anything, the system doing what it should actually be doing and it’s not. I wished I didn’t have to get up and think the system is this great big….I’ll always think like this, do you know Pullman, the Pullman books?

Q Yeah.

A Have you read any?

Q No I haven’t read them but I know them.

A I always feel like if I can compare it to that. That’s like the day [Name] was taken is almost like the day that me and my demon got spiked, you know got split apart. So I’m not the same person, I don’t feel the same person any more, it’s kind of like that was the day that it happened. But I also feel like the system is like the Majesterial, it’s kind of what I’m fighting against. And it is. It’s this awful thing that you just feel like is so big and so huge that you can’t….but it’s just….we always say ‘the system’, ‘the system’ but what is it you know? And it’s this huge thing. But what would help my mental health is how do you get justice. And I think there are so many families that are on Twitter and they’re just shouting out, but does anybody hear them? They’re just shouting out to an empty void isn’t it? And that gets me down, you know people who are just shouting out and shouting out and saying how awful it is when there’s nobody….just being….not being ignored by the likes of you or me but by the people who matter who should be listening because they could actually change something. That bothers me.

Time 40:10

That would be like when I went to Parliament and I tried to speak to people who didn’t want to know, even the people who I thought might want to know because they’re on the Left, just didn’t want to know. That really gets me down. And then you feel like giving up, but you know you can’t give up, you’ve got to keep going. But if anything was to help my mental health it would just be like just don’t allow people like my son to not mean anything, to be ignored. I’m fighting the [name] Museum at the moment, the bloody [name] Museum I am fighting! Because their exhibition on mental health doesn’t include people with learning disabilities, it’s on autism. And they talk about mental health as if it belonged to the Victorian times. So I’ve taken them on and I’m writing to them again and again and again, and I’ve taken them on with other people and they don’t get it. And I think well I could just give up on this, but I don’t want to because I think thousands of people walk in there every day. And it’s bad enough that my son’s living a social death but it feels even worse that people are going in there and he doesn’t even exist as part of history, he’s just been wiped out. It’s just the sense that my son doesn’t matter that affects my mental health. People like him don’t matter, they don’t count. And not even in the [name] Museum, there’s no mention of ??? or autism in all the medical displays. Isn’t that wrong? So that’s what….

Q Yeah I completely agree with you.

A And I’m there in with this woman from the [name] Museum and she’s just…..oh! She thinks I’m going to give up, but I’m not. I’ve even threatened to go in there into the seclusion room and do a…. ??? Do you know what orange confetti is? But oh God I can’t…yeah it’s tiring. It’s tiring and it’s wearing on your mental health because you’re just fighting all the time.

Q Were you, sort of before you had [Name] were you quite a strong supporter of justice before, or ???

A Yeah, yeah, yeah. I did a strike when I was 7 and my mum got sent up to the school when I was 7 for holding a strike. And when I was young I used to be all about animal rights. Because mum had to go up to a shop because I was caught taking pictures of snake skins in a shop ??? So I was always doing….I was very….so I think maybe that comes from being autistic actually as well. And I’m also bisexual. So I think if you’re autistic and you’re bisexual then you’re not kind of….well you’re in one of the minority groups aren’t you? And also I think if you’re autistic you’ve not got a learning disability but you’ve not got a disability either. And if you are bisexual you are not gay but you’re not….you’re kind of walking in the middle aren’t you? And I think that….and also it took a long time for me to start to talk about my bisexuality because that was suppressed for so long. So I think that’s probably why I think. It’s just that I’ve always had that sense of looking out for injustice, and maybe it also comes from it also being within me.

Q OK. That’s pretty much all the questions that I’ve got written down, other than saying is there anything else that you wanted to say that we haven’t covered yet in this exploration of yourself.

A I don’t think so. I’ve covered a lot of stuff. But I think at the end of the day – and I’ll just say it again, I think if anything was to improve my life it would be just people doing something. And I go up to [devolved] government, I’m going up to [devolved] government again, I’m going to talk to them again about sectioning, inappropriate sectioning in [devolved], a section that could be avoided, a section that I think is probably illegal. But I’m fed up of going there and just talking, I want a bit of action and things to change. I want things to change in terms of people having decent homes and not being sectioned because there’s no appropriate provision. I think it’s the endless fight I think without getting anywhere that actually can get you down. That’s the thing that makes me end up in a heap sometimes and crying and they’d ??? and all together again. I do this thing where I crunch up a piece of paper and shove it down and go like ‘come on, carry on’. But that’s the thing that gets me down, not [Name], [Name]’s lovely, it’s the rest of it.

Time 45:00

Q Well thank you [Name]. That was amazing and I really appreciate you sharing all of that, which was great and very important for our project. So thank you.

A I hope you don’t think less of me, because obviously you may.

Q What was that?

[removed to prevent identification]

A Thank you.

Q And good for you for doing what you’re doing and getting through the unimaginable. So yeah don’t give that a second thought.

A What happens now then? Do you just type it all up?

Q Yeah. It will be sent off. We’ve got obviously transcribers who are signed to secrecy and all the rest of it and then they’ll probably type it up in the next couple of weeks, and I’ll send you a copy. Oh, things I didn’t mention, [name]will be in touch with a background demographic form, which is quite funny, you just literally tick all the boxes and it goes off anonymously into the pot of demographic background. And also she’ll sort out a voucher for you for taking part, for your time, so thank you. Oh and then the other thing which is the information sheet, is that we are doing the digital story telling. And part of the point of these interviews is partly to be analysed as a dataset but also some of the stories that have been told in the interviews you will be invited to take part in the digital story telling workshops that will be happening in October, not far. Martina will talk to you about that too. You can choose whether you want to or not and hear more about that later. And then we’ll just keep you informed about where the project’s at.

A OK, and you’ll be anonymising me for the….

Q Oh yeah, all of it will be anonymised.

A Yeah, yeah. I don’t want my…..

[removed to prevent identification]

A Thank you.

Q [removed to prevent identification].

A No, it feels tiring but I’m OK. Because I share my story that many times in different ways in terms of….well not my own personal but [Name]’s story I share quite a lot.

Q OK. Thank you. Well take care and I’ll be in touch.

A Right, and you, thank you. Bye.