Q OK. So did you want to start by telling me why you wanted to take part in the research [Name]?

A I know I briefly highlighted to you. We have had to fight for everything for [Name], absolutely everything from the moment he was born. He’s 22 now. Each time you go into a new transition they go ‘oh there’s nothing wrong, we’ll pull everything away’ and fight again, gets reinstated, a couple of years later you’re fighting again. The last 2 years we have been put through hell, we have really been pushed to the limits. And it’s not even legitimately done. We have had to face all sorts of lies, accusations, misrepresentations. And it’s ‘oh well we….’ yeah, the council, the social services ‘well we didn’t manage to get him off our books that way so we’ll get him off this way’ or ‘we’ll try the next route’. It’s almost as if they are systematically going through a list of how can we avoid our legal duty to help this family. And we’re literally up against it all the time. Health – fantastic, they’re absolutely brilliant. He needs, he gets. We assess him, and they literally throw it at us. ‘Yeah, he needs this, he’s complex, he has this, he has that’. ‘What’s happening to you [Name]?’ To which I usually break down crying and go ‘nothing’ you know. [LOCAL AUTHORITY]? do not acknowledge that we need help, they pull it away, they call me a liar, misrepresentation, misleading blah, blah, blah, when he’s got diagnoses as long as your arm, when he is seeing specialists at [Place Name] ? Centre. He needs 24/7 care and support, he can’t be left alone, he lacks capacity, he’s attached to me 99% of the time he’s attached to me. I always explain to people. He understands but at a very minimal level. It’s a bit like having a toddler round your ankles all the time, you know I have to do everything for him, I have to look out for him, I have to prepare him before we do anything.

And that is draining, that is so draining. He doesn’t sleep well. We’re at hospitals constantly. And yet the authorities are in denial that he needs support and I’m fabricating it. I’m a single parent. And it’s just all…. Education, once we got him in the right place, fantastic. They actually gave him two members of staff to one in a room on his own, purely because he couldn’t copy. So Education are saying he needed that intensity of support. Social Services, they’ve actually done a report, well they done a mental capacity assessment on him last year and deemed he had full capacity and didn’t need any support whatsoever. I went like ‘no, he’s never had capacity, he never will have capacity’. And it took us 9 months to overturn that decision. But that’s how it goes, every single step. He’s had enough, he’s gone. Are you going in the conservatory?

N Yeah.

A Not a problem at all darling, not a problem. Let me know if you need anything. [Name]….just one second….[Name], [Name]….open the back door, it will get very hot.

N Yeah.

A Sure?

N Yeah.

A Good boy, good boy. That’s it. He’s bored. He’s had enough. But yeah that is, as I say we are literally fighting ridiculous accusations from social services. I mean one of them declared he hasn’t got epilepsy because she had never seen a seizure - she had met him twice. And it’s sort of ‘oh I’m so sorry I’ll time it next time’ you know ‘you can come along, I will invite you’, you know. But she literally took away support because she said he hasn’t got epilepsy. He was diagnosed 20 years ago, you know, we’ve got brain scans, we’ve got genetic evidence you know. It’s beyond belief. Health are just hitting their heads against brick walls saying what are they doing. And I said they’re trying to avoid their legal duty. It’s as simple as that.

Time 5:05

[Name] will need support for the rest of his life. I’m not going to be here for ever. And yeah I have to admit on Friday I broke down, absolutely sobbing, despair, ‘what is his future, how can they do this to me’. I mean I’ve been speaking to the courts,I’ve been speaking to the Ombudsman, I’ve been speaking to Citizen’s Advice Bureau, to counsellors, MPs, and they seem to be allowed to get away with it. And the fighting is just absolutely beyond belief. And it’s not….like yeah it would be nice for me to have a life, to have some space, but for [Name], what’s going to happen to his future? And that’s what really, really upsets me. My daughter as I say she’s just sent a message, she’s working abroad at the moment. She’s [Name]’s legal deputy and she keeps on saying ‘I’m scared, I’m going to have to stop my life to look after him’. And that’s not right. You know she’s 26 years old and she’s already thinking she’s going to be a full time carer to her brother. And I think that’s not fair, he’s entitled to a life, he’s entitled to independence.

I know it’s the usual thing ‘don’t compare, don’t compare’ but I see other young people more able than him and they get everything thrown at them. And you think ‘so why him?’ Is it because he needs more care, he costs more, ‘we won’t put it in’. So yeah it’s a pretty grim place to be in at the moment. So yeah as I say when you put up your flyer and that it was just like we fit that criteria perfectly.

Q Why do you think the council are not giving you anything?

A They’re bankrupt – as simple as that, it’s money. Literally they just pulled the plug without any warning. I literally got a phone call from his taxi on a Monday morning and they said ‘[Name] I’m sorry we can’t turn up today, the council have stopped the contract’. No warning, nothing. So of course I start phoning, phoning, phoning, phoning – nobody would talk to me. They don’t talk to you. They refuse to talk to you. Because they know what they’ve done. I ended up standing in their office sobbing and crying demanding to speak to somebody, nobody would come and talk to me. I ended up phoning Directors and they went ‘oh well, well, yeah’ and of course as soon as I say ‘you have broken the law, this is illegal, you cannot do this’, ‘oh alright we’ll reinstate it, but we’ll do an assessment and we’ll make sure that we have a reason to take it away’. So we went through this fake assessment where they then said I’d invented everything….whoops you’re getting attacked.

Q No, go on.

A Yeah they literally done an assessment and attacked me in it and said I’d invented everything. I’d misrepresented his needs, I’d fabricated his diagnosis, I was an incompetent mother, I was an incompetent carer, I was an incompetent deputy. It’s hideous. There was nothing in it about care, nothing to do with [Name]. Because I’m a legal deputy I sent it to the Court of Protection and even they were horrified. I said this is disgraceful, you know 22 years I’ve been an outstanding mother, an outstanding carer, and they produced a report where they just ripped it apart. Even though they’ve got reports that actually prove his diagnosis. They’ve got reports, apparently I’ve been withholding his medications. They’ve got reports that he’s got blood tests that prove he’s taken his medications. The lists went on and on and on. I mean in the end we ended up having to fight that and we had to have a multidisciplinary review where every single accusation was overturned. I had one of their representatives sit in my house and say ‘unless I agree to them cutting the package they would prosecute and they would take my son away’. And it’s just you are evil, nasty people.

Time 10:00

So yeah they’re literally trying to avoid their legal duty. They think it’s going to save money. Well unfortunately it’s going to cost them a lot of money to see us in court. Because what have I got to lose? It’s the rest of his life, you know I’m not going to be around for ever, they’ve got no choice but to look after him. Because we’ve got the deputyship the courts have been very, very good and very supportive and they have seen through it. They know what’s happening, they’ve been to the house, they’ve met him, they know he hasn’t got capacity. They know [LOCAL AUTHORITY]? should be doing their legal duty. But, yeah, nothing. And unfortunately everybody, counsellors, MPs and that, their hands are tied, they can see what’s happening and they know what’s happening – nothing they can do, absolutely nothing. I mean the frustration is incredible. You know you phone up someone and they go ‘oh that’s illegal’. I know it’s illegal, but what can I do about it? Very little. Very little. You know short of paying legal fees to get it into court….it’s just sort of ‘great, thanks [LOCAL AUTHORITY]’ you know that’s just what I want to hear.

I had a carer’s assessment a few months ago, and I’ve known the lady for a long time and she said ‘oh I can’t believe this is happening, this is disgusting, you’re always fighting, you’re always having to justify’. We done my carer’s assessment and I said ‘he is now home 24/7, I’m washing him, cleaning him, cooking, I’m having to protect his safety, everywhere I go he has to go I can’t leave him alone. And she said well you would be entitled to a lot of support as a carer but I’ll tell you, [LOCAL AUTHORITY] are refusing them, they are literally cutting the carer’s budgets because they haven’t got the money. It’s as simple as that. And she said we’re going to leave what you’ve got – I get 5 hours a week as a carer – and she said we’re just going to try and slip it under the radar just so you carry on with 5 hours. But I’ve got him 24/7, 5 hours ain’t going to do a lot when he only sleeps 3 or 4 hours a night, you know. And it’s like ‘OK’. And that’s what happened. Even she was shocked that we still got the 5 hours. And it was just but you should have probably tripled that. But that’s the situation we’re in.

Q It’s terrible.

A Mmm. And as I say money counts a lot, money. I know that is the bottom line, money. But the way they’ve gone about it is just evil. I mean if they’d come to us and just said ‘we need to trim it, everybody take a small cut’ I would have worked with them. But they way they’ve done it and then blame the parent and threaten, it’s just ‘oh lovely’, I’ve sobbed a lot, an awful lot. I’m very fortunate, we live in a very rural village, GPs and surgery know us quite well because they do all of [Name’s] tests, they’ve known him since a baby, we go in there and they always ask how my daughter is, what’s going on, so you know village community. Phoned up and I said ‘they accused me of this’ and they went through all of his medical notes and she said ‘no, everything is up to date, everything is on there, there is no reason why the social worker can’t access this, so she knows it’s there, everything is black and white’. And the GP said ‘I’ll be honest’, she said she herself has a disabled child and she said ‘I know where you’re coming from’. And it’s like ‘wow’. And she’s been very, very good, she does phone me up occasionally and say ‘how are you, what’s happening’. And you know it all comes out and it’s sort of ‘absolutely fine’. She said ‘are you alright, are you alright’. And it’s sort of I’m alright, caring for [Name] I do it with my eyes closed, it is a parents’ love, duty. But I’m dead on my knees.

Time 14:50

And it’s just sort of, you know I just need a break now and then, just get away. He’s lovely, he’s a good boy, but you know he’s in my bedroom at 2 o’clock in the morning, 4 o’clock in the morning, 6 o’clock in the morning, it’s just ‘go away’. ‘I want some space’, I can’t do my activities or…. I like to go out walking, he’s got a mobility problem, he can’t walk, he doesn’t like people, he doesn’t like….I can’t meet my friends, I can’t have people in the house because he gets distressed. So you think, yeah I haven’t got a life. And he hasn’t, he should be with his peer group, he should be building independence and be stimulated. So we’re in a really bad situation and until we get it to court we’re not going to get anywhere.

Q What’s the time frames for court?

A Unfortunately, you can imagine, [LOCAL AUTHORITY] aren’t submitting the paperwork. They should have started the process 2 months ago. And I phoned up on Friday and I spoke to the courts and I spoke to the Ombudsman, I spoke to the solicitors, and they said there is no timescale, they can take as long as they want. So it’s now…the advice I’ve been given is horseshit ‘tell the media, tell the press, pester the counsellors, make a nuisance of yourself’. So yesterday I was on the phone nearly all day doing emails, sending out ‘this is illegal, this is illegal, this is illegal’, what good it will do I don’t know, I don’t know. But that’s all I’ve got. Or I start paying to force them into court. Well, as we all know, carer, I ain’t got a lot of income coming in so that’s a bit beyond me. Because the solicitor can represent [Name], but to actually force the prosecution would have to come from the deputy, so I would have to pay for it. So we’re caught between the devil and the deep blue sea. And it’s just great! And [LOCAL AUTHORITY] know that, they very well know that and it’s just sort of ‘ooh what’s next’.

I mean the social worker we’ve got, literally she started in March, she met me for one hour and she left here, emailed [Name]’s medical team – he’s got a lot of medical team around him – and literally started the slander against me saying ‘this mother’s lying, this mother’s fabricating this’. They’ve been working with [Name] for years, physios see him on a weekly basis, and he’s phoning me up going ‘what’s this, I don’t understand it’. And I’m going ‘I don’t know, I don’t know what’s happening’. And they eventually copied me into what she was saying and the emails. Well you can imagine, red mist came over, I’m like ‘no I’m not going to attack her, I’m not going to verbally lose it’ you know. But Health literally started fighting my corner and they say ‘[LOCAL AUTHORITY] you are bang out of order, you’ve got this wrong, there’s no way, this is a severe complex case’ blah, blah. Wouldn’t have it, wouldn’t have it, wouldn’t have it. And so we had to force them into a meeting to show them every single piece of evidence. And I’m going ‘but you’ve got access to this, you know it, she’s got the reports sitting….they’ve been emailed to her, I’ve been copied in, I know you’ve got the reports but you chose to start sending accusations out’.

So if I say my son has epilepsy, he’s had such severe seizures he’s stopped breathing 3 times. So we’ve had the crash teams in hospital, we’ve had paramedics trying to resuscitate, all sorts. And when I say to her ‘he’s got severe epilepsy, he has an genetic disorder which is epilepsy based, it will never go away, this is for life, he is at high risk’, I’m a liar, he hasn’t got epilepsy. It’s like you can’t deny the evidence – it’s there. So yeah it’s….

Q So in terms of…. Sorry, what were you going to say?

A I was just going to say it’s hitting your head against a brick wall, they don’t want to believe us.

Q So in terms of your mental health, because obviously you are talking about having breakdowns and crying, what are you doing about that or could you tell me a bit about that?

Time 20:00

A It’s very difficult. I must admit today is quite unusual, [Name] would normally sit next to me through a zoom, all the way through. I can’t get out to carer support groups because I’ve got [Name]. I don’t like talking in front of him. You know it’s not fair, it’s not his fault, none of it’s his fault. We’ve got carer support zooms that go on, again he’s usually by my side. Uncomfortable, awkward, don’t like to do it, they’re only once a month, it’s not a great support, it’s not great. I have got a lot of my friends that I message and they’ll phone me and talk and chat, if I say they’ve got their own problems but it is a comfort, at least they believe me, that’s a huge hurdle. The GP is, if I say very concerned, she has offered me medications but I can’t, [Name] has night time epilepsy, he is up every single night, it is 24/7 you’ve got to be alert. So if I start taking medications I might have a reaction, I might start falling asleep and he gets injured and whatever.

I would class myself as an extremely strong character. Yeah, since he was born I’ve had to fight all the way through. And I’m pretty good at fighting but I know when I’m in a bad place. As I say, Friday night I was in a really bad place, I had had lots and lots of negative situations coming up and it was just like ‘Christ, I can’t see a future here. Do I go to the doctor and say I’m in a really bad place’. Then you’d speak to a few people and they’d bring me back up and I think ‘OK, OK, I can do this, I can fight this, I can keep going’. But I do worry. I do worry that I’m going to go too low one day. It’s not a good place.

And [Name] can sense when I’m in a bad place and he says ‘mummy not well’. And it’s sort of ‘mummy’s fine, mummy’s fine’ but mummy’s been crying for the last 2 hours, you know. And it’s just sort of ‘we’re fine, we’re fine we can do this’, you know. And if I say I’m not happy any more, there is no…I can’t go out and have a social life, I can’t plan ahead. If we go away it’s just caring in a different situation, although it’s nice to go into a hotel and someone else cook for you and clean for you, that’s nice and then I escape all of the emails and phone calls and paperwork. A bit short lived and you think ‘back to reality with a clonk, OK how many more emails have I got to write, how many more phone calls, how much more rejection, how much more lies, how much more fighting’. And the frustration. So it’s not a good place.

And it’s difficult when you’ve got somebody at home 24/7 listening in. As I say [Name] is understanding, he’s got some understanding, he’s got some empathy but he doesn’t understand what’s happened. He was at a day centre, he was building up his confidence, his independence, I was planning with them eventually he’d move on to sheltered accommodation, he would have support. The actual day centre, they were brilliant, they were giving him bespoke package, he had one-to-one support there, they loved him, he loved them. And it’s gone, just overnight, he doesn’t understand. And for me, you know I said to social ‘how do I explain to him that you’ve taken it away’. And she said ‘well that’s your problem’.

Q How long ago was it that the day centre closed?

Time 24:30

A They took that away in May. If I say, bless his little heart, the timing was atrocious. He couldn’t attend school when he was 18 because of COVID, the school said it was too dangerous for him to be in school because of his vulnerability, his violence etc etc etc. So if I say they refused to have him in school. It was safer to have him out of school. And it was sort of yeah I understand that. So he came out in March 20 when we all went into lockdown. He was 18. The authority saw it as an easy option to say ‘well he’s not in education, he’s now of an age, we could stop EHCP?, we’re stopping his education’. And I couldn’t fight it because of course everybody was in lockdown and there was no-one to do it, so he lost his EHCP. OK we go into social care support – there wasn’t any because of COVID. So he sat at home 24/7. And January 22 we finally got him into a day centre. So he started in the day centre, we started building it up and building it up, and then as I say May this year they pulled the plug. ???

Q ??? around keeping it open or not?

A Well it’s open, it’s just his placement they are not funding. And their reasoning is they’ve done this care assessment, which as in their eyes I’ve fabricated everything, when we’ve actually said to them his actual diagnosis and condition is worsening. Last…probably 2 years ago during COVID etc, [Name]’s got a leg deformity and he keeps breaking it, so he’s broken his leg 4 times in 3 years. It’s getting worse so we started pushing orthotics, you know ‘we need this looked at, we need this looked at’. They had a look at it and said ‘this is severe deformity’. He’s already had surgery on it once and it’s sort of now we need to push him for more surgery. They started looking at it and said ‘not sure if it’s kinder to amputate the leg’. For a mother to hear that, it’s….. And they said ‘what do you want us to do’ and I said ‘don’t ask me to make that decision. I am not knowledgeable, I don’t understand’. And he said ‘well we need a best interest meeting’. Yeah I agree. I have got so many questions, you know I need to know what is happening.

We didn’t have a best interest meeting but at the time, this is when he’d just started his day centre, I’m being told they may be amputating his leg. My mind’s going ping, you know it’s questions, questions, questions. The surgeon then 6 months later said ‘I’m refusing to operate’ his reasons being [Name] might not survive surgery, it is such a complex surgery, he would need 6 months non-weight bearing at home, just mum. Social Services had already started this, you know doing the mental capacity. ‘He’s got full capacity, he doesn’t need help, he doesn’t need this’, they were pulling it away, he said ‘I don’t think you are going to get support from social services, I can’t put that on you’. So he sent me to another surgeon for a second opinion, 3 months later that surgeon then says ‘I’m not operating. He may lose his leg, he will carry on breaking his leg, he will end up in a wheelchair’. He said ‘that’s what’s going to happen, but at least we’re not going to kill him through surgery’. And it’s like OK I can accept he’s going to get worse, he is going to end up in a wheelchair, OK I know, I understand.

But we’ve seen now 4 surgeons literally tick-boxing, having tried every option, all these surgeons, every single one said the same. According to social services I’ve invented this. There’s all the letters from the surgeons, the physio’s been with me to most of these meetings, we’ve had learning disability nurses attend, and she’s ‘no it doesn’t happen’. And I’m saying ‘he’s actually getting worse, his support would be higher’. And yet they turn round and say no. How can you see….future wise I can accept him in a wheelchair, you know practicality as you weigh up, you know do I force them to try and do surgery and he may die in the operating theatre or he may lose his leg; or we make do with what we’ve got, 5 or 10 years he might still be mobile, and then he goes in a wheelchair. Well being in a wheelchair is not the end of the world you know, we can cope with that.

Time 30:18

And I mentally adjusted to that and accepted that. But now I get this rubbish from social services and I just think wow, talk about kicking you while you are down you know. Instead of actually saying ‘well that’s a big decision [Name], you’re going to need support even whilst you’re going through this process’, I’ve literally been called a liar. And it’s sort of ‘really?’

Q Sorry I was going to ask, you said you’ve always been pretty good at fighting, is that before you had [Name]?

A No, no. Because I’ve got an older daughter as I say, [Name], stereotypical, absolutely bright fantastic little girl – she’s still my little girl. She’s been absolute special, she is outstanding, very bright, very intelligent, she is 3 years older than [Name]. She’s grown up extremely independent because I’ve had to spend so much time focusing on [Name]. We’ve been a single parent for 12 years now, so yeah it has been mum raising both of them. [Name] stepped up to the mark, she’s been the big sister, she’s been supportive, this that and the other. But literally, bless his little heart, when [Name] was born we knew straightaway things were wrong. He had epilepsy from the word go. He was jaundiced, he had infections. He only had 20% hearing. It just snowballed and snowballed and snowballed, so you know by the age of 3 he had diagnoses coming out of his ears. And it was sort of like ‘OK’ you know.

That was fine, you know we had great support. Then we tried to get him into school and nobody would accept him so we ended up, you know [LOCAL AUTHORITY] ‘there’s nowhere to send him’, where do we go, what do we do? Went to one school, no that’s a mainstream school, they wouldn’t accept him. Help. Get him into a specialist school. We actually….[Name] was in a specialist school, the headmistress was amazing, she said she wanted him in there full time and I said well I can’t because I can’t drive. I’ve got problems myself, twice a week I could manage but 5 times a week my back wouldn’t do it, I just couldn’t do it. And she said ‘no problem, I’ll get the transport, put the transport in place’. I think great, fantastic. She then sorted out what was DLA, then PIP, and she said ‘you need this, you need to get this in place’. And she said ‘and now we’ll look at getting him statemented’. And you go EHCP. And she organized all of that. So you know [Name] was in a specialist school, he had the transport, he got the EHCP. Then we got the diagnosis. And it was just sort of we’ve done this the wrong way round, you know. But it was so obvious, so blatantly obvious, we had a great teacher there.

Then he had to move on to another school. Again, no schools would help so we end up where do we go, what do we do, de-de-de-de…. Got him into another school – they failed him, he was in the wrong school, they couldn’t cope with him, they described [Name] as an animal, uneducationable. He was being put in an isolation room every single day. And it was ‘this isn’t education, this is just locking him up’ you know. So we ended up huge fights then, he was 10 years old by then, and I said enough is enough, pulled him out. Health confirmed he needed a specialist, specialist school, not just a bog-standard babysitting school, he needed help. Took us about a year, he was at home. Found another private independent school and [LOCAL AUTHORITY] said ‘OK go for it because we’ve got nothing else to offer you’. Got him in there – fantastic school, absolutely fantastic. They bought in OT, Physios, Change of Behaviours, all the stuff that he needed they just bought it in. And it’s sort of ‘brilliant, fantastic’. He started to talk when he was 13, very poor speech but something. You know at 13 you sort of think ‘my God he’s suddenly saying words’ and signing and PECS? and all of this and you think ‘brilliant, they’ve finally started to make progress’.

Time 35:15

Then he had major surgery, couldn’t get him to school, [LOCAL AUTHORITY] couldn’t help him, couldn’t get any taxi to provide safe transport. All this sort of thing went on so we were arguing again. One day before he turned 18, literally one day before his birthday, that’s when the social worker said ‘he hasn’t got epilepsy, we are pulling away all his support’ so he had no respite. And it was sort of you’re joking, one day before he turns 18. Yeah. He goes into adults, pull it all away. So it took us another 6 months, all the courts? all of the Ombudsmen overturned it, get him back into respite. And of course we had it then taken away. It’s just been constant. And it’s just sort of ‘right, the next transition, what are they going to pull away next, get ready for that fight’.

Q Have you got the 5 hours a week at the moment?

A Yes, and all that is for is for laundry and housework.

Q What, for you to do it or for them to do it?

A For me to pay for someone to do it.

Q Oh so you don’t get a break away from….

A No, no, that’s all they would do for laundry. And then it’s just sort of ‘wow’. Yes it helps, it is nice to be able to say to my young lady, you know ‘there’s the pile of washing’ it does about 50% of my washing. But….yeah. As far as employing somebody to say ‘I’m going out of the house’, no they won’t do that.

Q And has your….you said that you didn’t want to take medication, has your GP suggested anything else that might support you?

A Only the telephone carers things and that. Something, MIND, there’s a local one which they support. I haven’t gone down that route, I haven’t. I find it very difficult to admit that I’ve got problems to people who don’t understand the system. As I say, my friends who are carers themselves, I know they’re going through the same sort of rubbish, none of them quite as severe as what we are going through at the moment, but at least they understand. Lots of them wrote letters of support to say to social services ‘you’ve got it wrong’, you know ‘we will prove to you, we know [Name]’, blah, blah, blah, at least supported me. Because you end up doubting yourself. I mean the social worker actually wrote a letter to my son – who can’t read, can’t write, so of course who is going to read it – I started reading it and I was, you know ‘Dear [Name], your mother has stated that you have anxiety and you have behavioural problems. This is untrue. And she has said that you have toileting issues. You have nothing wrong.’ You know and it’s sort of how dare you. You know all the evidence. And literally all my friends literally just swamped her email box with ‘oh yes he does, we can prove it and we’ve seen it, and we see it every single week’. You know he’s had carers in the past who literally went ‘we’ll tell her’ and literally bombared her Inbox with ‘we’ll give you a witness statement then’ you know. And it’s ‘now try and deny it’. But yeah she actually had the audacity to do that. And I’m thinking thank God my son can’t read it, you know, absolutely crazy. And then….

Q Sorry carry on.

Time 39:33

A I was going to say, I’ve sent it all into the courts. We’ve got a court handler, she’s been watching it all, and even she’s saying ‘this is absolutely unbelievable, it’s disgusting that you are actually being persecuted here and victimised’. And I said I know, there’s nothing I can do about it, it is an awful, nasty attack all the way through. And if they want to put down a carer and really try and break me they are doing a very good job of it, instead of supporting. And saying, 99% of people would turn round and say to me I’ve got a fantastic rapport with [Name], I promoted both my children to be independent within their own scope. My daughter’s currently working in Australia, she’s moving on to Hong Kong this week, she’ll be moving on to New Zealand after that, she knows eventually she may have to come home and look after her brother. So me, I’m saying ‘stay, keep going, live your life, do what you need to do’. And she’s going ‘but you need help, you need support, I’m worried about you’. No, no, I’m not her problem. You know I’m fine, I can do this, don’t worry.

She’s the legal deputy and I have to keep her informed. She loves her brother, she worries about her brother. So yeah, ‘what’s happening, how can I help, what can I do’? There’s nothing you can do, there’s nothing. So of course she’s been crying and sobbing. And it’s just sort of ‘no it’s not your problem [Name], it’s alright, I can fight this, I can do it, I’m tough, I’m macho’ – of course I’m not you know, but you have to put that persona on to protect her. And it’s just so ridiculous. I’m not asking for millions of pounds, I’m just saying….in a lot of ways it’s more be honest, acknowledge he has these problems, acknowledge we need support. You can’t afford it, OK you can’t afford it but at least tell me the truth, you don’t have to be nasty about it, you don’t have to make up reports and threaten me and slander me. Instead, acknowledge. You’ve made a huge mistake, you’ve misjudged this altogether. But they don’t, they’ve made a mistake and they are covering it up with more lies and more threats and more accusations. And I think that’s the worst part. I would rather someone was frank and honest. As I say, if they’d come to me in the first place and said ‘we haven’t got the money, can we cut this back’, I would have worked with them. I’m not a confrontational person but I certainly won’t let anybody walk all over my children, you know, they’ve picked the wrong person.

Q What would be the support that would be right for you?

A In an awful lot of ways it’s reassurance that [Name] will be in the right placement so that I’ve got that safety…. The day centre he was in and he had overnight respite, he had two nights a week…oh a year….oh what am I saying, 2 nights a month he had overnight respite. They were building up a fantastic support for him. I could talk to them like an extended family, you know ‘[Name] had a problem today, he’s soiled himself, he’s wet himself’, they would be ‘that’s fine, we’ll handle it, we’ll look after him, we’ll talk to him’, it was just part of the family, we got on brilliantly. [Name] doesn’t like to join in with their group activities, he’ll sit out, he’s very isolated, he’ll watch and all this sort of thing. And they said ‘we’re not having that, we’ll take him for a walk, we’ll do this with him, we’ll do that with him’. They looked after him. They cared. That’s the biggest thing and it’s just sort of ‘OK I now feel confident he’s in good hands, I’m in a better place, I get that space’. Eventually he may have moved into their sheltered accommodation, he would have had the same clients, the same staff he knows. It’s building up his future. I want him to be safe, I want him to be comfortable, I want him to have as much independence as he can then I am in a better place. I will have more space, confidence to be able to handle him.

Time 44:32

To look after [Name], as I say it’s like a toddler, you know I have to get him out of bed, I have to help him get washed, get dressed, feed him, cook, he can’t be left alone, all of that. To have 4 or 5 hours break I can then get the house cleaned properly. I can go out and meet my friends. I can have small treats and do nice things, just for me, just for a few hours. Great, that’s all I’m asking for. But when you can’t do anything – you know. I have back problems, I have to go and see the chiropractor on a regular basis, he’s having to come with me, in the room, with me stripped down to have my back done. And I’m thinking ‘he’s 22 years old, I don’t want my 22 year old with me’. But that’s the situation we’re in now. Wherever I go he’s got to be there. He doesn’t like coming out, he’d rather sit at home all day long. He’s got a weight problem so trying to motivate him…. And I think he’s a heart attack on a plate. He doesn’t want to move. I’m trying to do the best I can for him and I’m not getting any help. And I think I’m not asking an awful lot, I’m just asking for him to have a quality of life, I can do my own thing then and I’m in a better place and I can cope better. But you just don’t even get that.

Q Is [Name]’s dad around, or not?

A He…if I say, when all this blew up social services pulled him back in. Before that he would only see [Name] 2 or 3 hours a month. Be on a Sunday he might see him and take him out. If I say ‘tick a box’ he’s done his duty. Saying that, I’m not saying he didn’t care. He works full time, he lives with his father and is sole carer for his father who is deteriorating rapidly, he’s spending more time in hospital than he is at home at the moment. He’s got kidney failure, he’s 89 years old, it’s a bad situation there. He’s an only child. So you know there’s part of me sort of thinking ‘OK you’ve got a bit of your own medicine now’. Because he wasn’t a good, if I say ‘good father’. He couldn’t cope, he couldn’t cope with [Name], he couldn’t cope with the autism. He is autistic himself so it’s a bad dynamics in the family and I literally in the end had to say to him, his violence was getting out of control, his gambling was getting out of control, there was abuse in the family. And it was just ‘go away, get out, we don’t need you, go away’. And he did. And it was the best thing for all of us. He’s in a better place. We carried on. For me it was easier because I actually had one less issue, problem, he wasn’t a help he was a problem, so we’ve removed that.

Since all this has blown up social services have said ‘oh the father’s got a right to be involved and be….’ you know. And I said ‘but actually he doesn’t do anything as a father, he actually doesn’t….’ He’s now feeling very important because social services have said ‘you are an important part of [Name]’s life and….’ ‘Oh yes well I’m insisting that he has his day centre, I’m insisting’. Yeah but you haven’t been there in the past. So he doesn’t help in that way. I mean OK he has the last 3 weekends he’s seen [Name] for about 3 or 4 hours on a Sunday, which is fantastic, but if I say he’s only doing that so he can get his gold star. Mmm, OK so you’re doing this out of duty ‘oh look at me aren’t I doing well’ you know. But I was thinking I’m not going to knock it, you’re seeing [Name], you can have [Name], you know. So it helps that way.

Q OK. So what would you do, if he’s with [Name] for 3 hours do you go out, or is there something you do for you?

A He went with his dad on Sunday. Honestly it is an amazing feeling where you just sort of go ‘oh finally I don’t have to stress’, I’m not watching and thinking and hearing and looking out for [Name] and running around. And I went out walking. I spent…well I done over 12 miles walking. He was just like ‘what are you doing’? I’m out. I ended up talking to myself halfway through, you know going over all the scenarios and what’s happening, how will it play out in court, what will the judge say, which court will I end up going to? All these scenarios and thoughts and ‘oh I have to remember to tell the counsellor about this’ and I have to…. So I play it all through.

Time 50:07

If I do get a break, you know I’ve got other friends who say, you know I’ll sit with them for a couple of hours. They’re nervy because they don’t know [Name] and, yeah he won’t interact with them, he’ll just sit himself out. I can hear him on his iPad in the conservatory, that’s what he’d do, if somebody came to the house to look after him he would put himself in another room ‘I’m not interacting with you, I’m not going to talk to you, I’ll sit here’. And it’s just sort of, yeah he’s uncomfortable, he doesn’t want anyone there. When I go and see him in a minute he might have wet himself, he might have soiled himself. He wouldn’t say anything, he’d just sit in it. So if I do say to a friend ‘I need to get out, I’m really in a bad place’, she’ll come and sit here. When I come in he’s wet and soiled and she goes ‘oh I’m so sorry’. I’m like ‘don’t worry about it, it’s what he does’, I expect him to do that, he’s stressed and anxious that somebody else is in the house. And I said ‘it’s fine’. But few and far between now, really few and far between.

And of course a lot of the time I’m sitting here at the moment doing paperwork and it’s phone calls and it’s running around for him, you know preparing the next hospital appointment for him. I do a lot of ferrying [Name] backwards and forwards to appointments and his clubs and his social side of things, so any spare time I have I have to get those things done which I don’t specifically want [Name] around for, although it is for [Name], you know. I don’t often get much time now to do anything for myself. And it’s just ‘OK I’ve got 2 hours I can do all this report now’, social services and medical reports and courts and everything else. So it’s not much of a life.

Q How did you find out about going to court and what the legal duties were?

A When [Name] was 17 he was under a pediatrician and his school and he had a good social worker, she had got to know him, she literally put herself out. She was, I would say in his 20 odd years of having social workers we’ve probably had 2 or 3 really good ones. And all 3 of them said to me ‘you have got to get the deputyship in place’. And I went ‘huh?’ you know, I’ve heard of Power of Attorney, I think everybody in this country knows Power of Attorney but what’s Deputyship? And they said, yeah, he lacks capacity, he never will have capacity, you have to go for deputyship. Oh right OK, I’ll be guided by you. All of them done mental capacity assessment, all of them agreed. All of them knew [Name] very well so they all done their reports and they reflected exactly what [Name] is, does, needs. The courts rubber stamped it in no time and said ‘yeah 100% he needs support for the rest of his life, he never will be able to cope’. So that is fantastic. And the court protection, they literally send somebody to your house, explain the whole process, what are you legal duties. In my eyes I’m his mother but I would like to think that everything I do is in his best interests. And if I am out of my depth I will seek professional help. And as I say, medical wise they’re outstanding, they have always looked after [Name], supported [Name], I have never had a problem getting the care and support he needs. It’s fantastic in our area, we’ve got a learning disabilities medical team.

Q Oh that’s good.

Time 54:30

A Yeah. At 17 and a half I said to the social….he’d moved into another department by then so we lost that brilliant social worker, I think we had about 3 by the time he was 17 and a half by that stage. They last about 6 to 9 months. And this particular one, 17 and a half I said ‘I understand he can be referred to the learning disabilities medical team’. And she went ‘never heard of them’. Well I have and I believe when he leaves school he needs this support, he will need OTs, he will need Physios, he will need Speech and Language, he will need….. And she went ‘never heard of them, never heard of them’. So I made enquiries, found out I can self-refer, fantastic. Done all of that. I think a year later the social worker actually done a referral herself to them and she actually got the wrong department and I ended up having another assessment from the wrong department. And I’m going ‘really?’ you know, I’ve already done it, I’ve already put it in place. So it was me that done that referral – one of the best referrals I’ve ever done because that’s the team that are around us all the time. He has Physio every single week, he has the OTs coming along, they’ve fully equipped the house to his needs. There was no question from them. They’ve come and assessed him, they’ve looked at him, they’ve….you know ‘yes he needs help, he needs support, we’re putting it in’. And it’s sort of wow, what a difference.

But as I say, the social worker. Social Services, when we got the deputyship, as I say they were fully supportive – this particular social worker, fully supportive, 100%. All the reports say he needs help for the rest of his life. They then go and do an assessment last year and say ‘[Name] was talking to them fluently’ – don’t think so. You know he can’t talk. ‘[Name] fully understood this, [Name]….’ – no he didn’t, no he doesn’t. Oh they’ve done the mental capacity assessment without my knowledge, I should have said that, made sure I wasn’t around. Not set up, you know nothing like that, not set up.

So of course I immediately throw back but your own social worker, this is her report from 4 years ago stating he will never have capacity. This has been rubber stamped by the courts. ‘Oh are you a legal deputy?’ Of course I’m a bloody legal deputy, you’ve got copies of it. ‘No we haven’t got copies of that’. Yes you have. So I send more copies. ‘Oh we didn’t know you were a deputy’. Yes you did, of course you did. Now we’ve had another social worker and she immediately turned round and said ‘we haven’t got any paperwork that you’re a deputy’. This is the third time I’ve sent it to you, you know, I’m a legal deputy. ‘Oh, right OK’. And the courts have been brilliant, they have been phoning up social services, they’ve been to the house and done assessments themselves, so they’re 100% convinced of the situation. So legally they are very, very good at supporting me, pushing social services. As they said, short of them prosecuting [LOCAL AUTHORITY] for failing in their duty of care, which they’re contemplating, they said at the moment they’re building the evidence, and building it and building it, I don’t know how long you’ve got to go on building evidence for. But they are very, very good and I’m so pleased I got the deputyship, so pleased.

I mean a lot of my friends say ‘oh there’s a lot of paperwork involved, it’s legal, it’s this, it’s that’. If I didn’t have it behind me now I think [LOCAL AUTHORITY] would have tried taking [Name] away. So you know there’s part of me….I didn’t know where to turn, I really didn’t, because I tried the Complaints Department, [LOCAL AUTHORITY] ignored my complaint. I tried the Ombudsman who said this isn’t an Ombudsman criteria – well where do I turn, what do I turn. Now I phoned up the courts and they went ‘it’s us’, this is his legal position, they have deputised and it’s all…. Wow, you know I’ve finally got somebody who can talk and fight my corner. So they have been absolutely brilliant. I’ve absolutely inundated them with all the rubbish, but you know they have been very good.

Q Oh that’s good. Can I check, you know you said about the zoom support meetings. Is that a support meeting with other family carers or is it like a therapy session?

A It’s family carers.

Q Right, OK. And have you been for any therapy?

Time 1:00:00

A Nobody’s done any therapy. I mean I know of mindfulness and I’ve done mindfulness for myself, I understand that. I don’t get any space or time to think about it with [Name] around, so I don’t know what other therapies would be suggested. To me, my favourite passion is walking. I live, as I say in a village, I go out, 100 yards down the road I’m in the fields and that’s it, I’m in my element you know. But I can’t do that. And I was joining walking groups when [Name] was at his day centre, you know I’m off, I’m walking, I’m with people, I can forget what I’m doing.

I did have a volunteer role, part of the {Place Name} Football for girls and ladies, I’ve been doing that for 13 years. And it was great because none of them knew what my family life was. They didn’t need to know. I was there to produce football for kids and join in and do the activities and organize and all of that. Loved it. But because of all this I couldn’t access that so I’ve actually resigned from that. And I think that was my outlet, that was me, that was…. As I said, I say I resigned, they haven’t accepted it yet, they keep on coming back to me. And I can do things at home and online for them, but I’m saying I can’t attend things now, I can’t get involved, I can’t get there. Two or three of them do know my personal situation because I’ve had to say, you know this isn’t anything against the role or the organisation, I just literally haven’t got the time, I’ve got [Name] in tow. And they fully understand but they just….you know that was me and that was for me and I can’t do it anymore.

If I say when [Name] was at his day centre I enjoyed my life, I was happy, I had my own social group, I was able to…you know if I wanted to go walking I’d go walking. I’d do his paperwork, I’d take him to the hospitals, I’d do ??? Because I was in a better place. I can’t even do that now, there’s no space for me.

Q I’m sorry, it’s awful, it really shouldn’t be like this. That’s all my questions and I just wonder if there’s anything else that I haven’t asked you that you wanted to add?

A I mean the only thing I can think of is I know I’m not alone. As I say I’ve got a lot of friends who are carers, Facebook groups dozens and dozens, and I hear other people. And I’m just thinking they’re doing it to everybody. Sometimes I used to join groups face to face and I’d actually stop going because it was so negative, and I know it’s negative and I know it’s a horrible situation, but sometimes you don’t want to hear other people’s. And some of them, I don’t want to trivialize it but you know some people ‘oh it’s because my son or daughter aren’t getting a specific pen or paper at school’ and I just think OK that’s inconvenient but actually it’s not the end of the world, you know you can do something about that, go and buy the paper at the end of the day. There are some things where I just sort of think OK it’s a big deal in your life but in the reality do I need to hear about somebody talking about that.

But then I hear, one of my friends bless her heart, she had been caring for her husband for the last 10 years, he passed away a few weeks ago, but she couldn’t get out of the house, ever, and nobody would put in support for her. And she would phone me at night sobbing and crying. And she said ‘I can only talk to you [Name] because you are in the same position, you can’t get out, you haven’t got a life, you understand’. And I’m going ‘yeah I get it’. My quality of life was better than hers because I can take [Name] out of the house, she couldn’t take….her husband was bedridden. So in some ways I’m sort of thinking ‘oh I’m in a better position than you’. But it’s wrong, it’s so wrong.

Time 1:05:00

And as I say her husband recently died. She’s still in carer mode. She feels guilty if she goes out and has a meal now because she thinks she’s got to get home and you know there’s going to be somebody waiting and she’s got…. And it’s sort of no it’s your time now, you deserve this time now, you cared for him constantly 24/7 foregoing everything for herself. I mean her health is absolutely rock bottom, even to the point she had heart problems and she couldn’t afford the time for her appointments to get to the hospital. And you just think that’s wrong, that’s so wrong.

So yeah, as I say I’ve got people who come and say ‘you do know you’re not the only one, you’re not the only person’, I know that, I understand that, I know others are in a far worse position. But it doesn’t make it right. It doesn’t make it right anywhere. And there are some people where I’d like to get them by the throat and say ‘fight, you’re entitled to a life’ ??? But how much fighting do we have to do? Friday I was ready to throw in the towel and just say ‘sod you’ you know I don’t need social services, go away, I will do this 24/7 on my own for the rest of my life until I’m dead. But I think that’s not fair on [Name]. So yeah, yeah I’ve got a new zest of life and I’m back fighting it again. But I just think I’m sick of fighting. Because I know even when we get into court I will get it all back because they have broken the law, the court handler isn’t allowed to say it but she has said to me, ‘it will take the judge 10 minutes, it’s not going to be a problem, they have broken the law’. And it’s just sort of I hope you’re right, I hope you’re right, you know and I believe in her confidence and everything else. But I know 2 or 3 years down the line we’ll be back there again. They’re try another angle. And I think well what other dirty underhanded scheme will they come up with next time?

[Name] goes….our area is 16 to 25 social services and then he moves on to the adult, adult section. He’s coming up to 23, not long until he goes into that next section and I think, yeah now we’ll start all over again. I know we’ll start again, I know it’s going to be hanging there. And I just think ‘right OK, do we carry on fighting’, do we just literally say sod it, you know, is it worth the fight? And financially the country’s stuffed, you know, there are no PAs out there, you can’t find anybody to help. I know the court’s turned round at me and said ‘well can you use [Name]’s money privately just to buy in help? I said well it will soon run out, you know he’s only getting benefits, it’s not going to last long. And she said yeah but it’s essential, it is essential.

So yeah, all I can say is I do appreciate there are thousands out there in a far worse situation. I am a pretty logical person, I know. Logical, the practical side of it I know I can fight it, I know how to fight it, I have the skills, I’m fortunate I’ve got the experiences as well to know where the laws are, who to turn to. I have got people behind me fighting our corner. But why, why do I have to keep fighting.

Q Mmm, it’s a good place to stop I think.

A Mmm, oh bless you.

Q Thanks [Name], I really appreciate you giving up the time to share your experiences and it’s going to be an amazing contribution.

A No problem.

Q And we are also going to be running digital workshops in October on Saturdays. Martina who is going to be in touch with you after this interview and arrange to send you your voucher and that sort of thing will ask you about whether you would like to take part in the digital stories. Because the people we are interviewing, and you are about number 6 I think so far, will be invited to see whether they want to produce a story from their experiences. And we have a colleague in Canada who is going to hold workshops on the four Saturdays in October, but we will arrange other times as well for people if they want to be involved in that part of the research to make sure that everybody who wants to take part can. So that’s something for you to think about as well, that you may produce a story of your experiences, because it’s a very powerful set of experiences you’ve been talking about. So I hope you are not going to feel upset after this.

A No, no problem, I will simply find out when this engineer’s coming or going, we want to be out. That’s my main thing, I have to keep busy otherwise my brain goes into overdrive.

Q Go out in that lovely weather. So it’s lovely to meet you and it’s lovely to meet [Name] as well and we will be in touch.

A Oh bless you. Thank you very much for all you are doing. Good luck. Take care. Bye bye.