Q So you should be able to see it says ‘recording’ at the top. So I’m [name] and I’m one of the researchers on the project, and I think maybe you know that I’m going to ask you a few questions. It’s very informal, it’s not like a job interview you know, and we just really want to understand your experiences. But I’ve got a few questions that I’ll go through. We interviewed somebody and he said to me at the end ‘did you ask me any questions?’, I said ‘yes’. Because I think the conversation was just a conversation, it was like ‘hmm, where were the questions?’ So sometimes it can go like that, sometimes it feels like there are questions. So my first question though is what made you interested in taking part in this study in the first place I suppose?

A OK. So I am…I mean I kind of sit with two hats. So I’m an academic, I’m a learning disability nurse and I work in a university. So I sit with my kind of, you know always interested in wanting to help people out with their research, and the more research about how we support people with learning disabilities and how we support those who care for people. And then my other hat is I’m a mum of a son with a learning disability. So I felt like I possibly have something to offer you in terms of my experiences.

Q I should have said actually, I am also an academic at a university and a mum of a son with disabilities.

A Yeah and probably you want to ???

Q Oh OK. And, because his support worker needs to leave early to go for an appointment he’s going to arrive, so I might have to just go for a minute, so I’m really sorry about that. I was thinking ‘oh God, it doesn’t look very professional’ and I thought oh surely whoever I interview will be like ‘whatever’.

A We understand though.

Q Certainly, exactly. So can you tell me a little bit more about your experiences as a carer really?

A So my son is 24….

Q Oh a little bit younger than mine, yeah.

A He lives at home with me and his step-dad and step-brother and cats, it’s a chaotic household. Yeah, I don’t know where to start.

Q I’m wondering about, because you’re working and I’m working and it kind of makes me think how do you manage that?

A He’s fairly able in a lot of ways. So he’s fairly independent in terms of getting himself up and ready and getting himself off to the various different things that he does. And he’s able to kind of make himself snacks and that side of things. And he travels independently, I mean that’s his big passion is buses and trains.

Q Oh fantastic.

A He’s out at the moment, in fact he probably won’t respond to my text message because he probably thinks I’m checking up on him. But he likes to go out and travel around on buses and things like that. So he’s quite independent in that way. He’s also quite vulnerable in lots of ways. He’s somebody who perhaps could come across as being a little bit more able than he actually is to some people, and also be potentially quite vulnerable in the community. I think I’ve always tried to bring him up to be as independent as possible, I’m not one of the…I was going to say something and it sounded quite mean then and I didn’t want it to sound like that, is sometimes parents will wrap their children in cotton wool – understandably, you know want to ensure that they’re safe and don’t want anything to happen to them. I think I’ve always been possibly a little bit of the opposite, is get out and do life and experience things and be independent. So I’ve tried to do that with him so I think that has helped. But I’ve always worked, I’ve worked since he was tiny. I mean I started my nursing when he was 11 months old and he had a wonderful childminder. So he had a childminder while I was at nursing school but once I started working he had a wonderful childminder who actually looked after him for well over a decade, was like a second mum to him essentially. You know she was always….yeah she looked after him really until he was like 16. I mean started being a little bit more independent from 14 onwards, but yeah until he was about 16/17 he used to go to hers after school and she really, as I say was very much a second mum to him, because I’ve always worked.

Time 5:33

Q Yeah. So what happened? Because you’re sort of in the end of technically transition aren’t you, so how has that been?

A Erm….challenging. And it probably would have been more challenging if I didn’t know how the system worked. Because I’m lucky because I bash people, not bash people but you know I know who to email, and I know who to email to get…. So literally we’ve got a social worker here on Tuesday but….

Q Have you got a social worker?

A Well we don’t have a consistently allocated social worker.

Q Oh OK, I was going to go ‘wow’.

A The only reason we do have things on Tuesday is because I emailed social services to remind them that he was due an annual review.

Q Yes so are we, I’m going to put it on my list, because we’ve just been putting it off.

A So I emailed them to remind them that he is due a review. Because actually when he became an adult he didn’t actually have his first adult social care assessment I think until he was 21. And he didn’t need it at the time because he was at college, so actually there was no other kind of provision needed.

Q So has he finished college?

A He’s finished college now. He finished college technically last year. So he stayed at school until he was 19. So he was in an SEN school and he went to their sixth form, and their sixth form was a three year sixth form so he finished school at 19. And then he went to…and it was lucky actually because for some reason he’d been missed off the list for the local college and it was only like when it was getting towards the end of that last term and his TA at school realised that he wasn’t on the list and was like….and I was like ‘no I just thought automatically that he’d been put on the list to go into the college provision’. And luckily she realised and we managed to get him into the college provision.

Q What did he do at college?

A He did a….they call it Personal Progression Pathway, so a bit of a random mix of…it wasn’t anything in particular. Travel training, drama, woodwork I think, random things. And he did that for 3 years. So they’re only supposed to spend 2 years on the Personal….no, hang on, what happened, did he go to the internship for 2 years? I can’t remember now. So he started that at 19, so 19 to 20, 20 to 21, 21 to 22…yeah he stayed on the Personal Progression Pathway, I’m sure he did 3 years because we had COVID and obviously during COVID he missed 6 months of college provision. So I think they let him go back and do that for an extra year because he missed out. So they let them do ??? that they could have an extra year on that. And then he did a one year supported internship.

Q Oh right, cool.

A Through the college and through the local MENCAP, so that’s a partnership. And he tried various different things but he ended up…because a few things fell through, and again it was post COVID so it was like September 21, you know there were still some of the previous places that had offered internships weren’t offering. So he tried a number of different things but he ended up working in a local day service, so a day service for people with more profoundly severe learning disabilities. But they had this garden that had been kind of neglected during the pandemic so a couple of the kids on the internship went with their PAs and did like gardening and sorted out the garden and had little allotments and that sort of thing.

Q Yeah.

Time 10:00

A Which he did for like 8 months, 6 or 7 months, something like that. And then again that was a kind of a bit of a time of transition because once that finished that was kind of it in terms of college. There was nothing more they could offer him, he’d done the college provision, you know there really wasn’t anywhere else for…. because with the supported internship obviously their ideal aim is to get them into work, but actually he wasn’t ready for that. So they….what did we do? I did manage to get social services involved. I think again it was very much me….because I have been….I was ??? with their team manager because I used to work in an integrated learning disability service, so I got my friend who is a social worker in ??? to give me the contact details. But again if I didn’t know that what would I have done?

Q So has he got a Direct Payment package?

A He has Direct Payments. It’s good in some ways, it’s an absolute nightmare in others. I get random amounts go in, never know what amount is going on, what is actually accounts for. He has to pay the maximum contribution, but again we still get random amounts. It’s just the most random thing. And the lovely guy in the Direct Payments team who I adore and I’ve spoken to on multiple occasions, he doesn’t get….he’s lovely but I don’t think he really has a clue what he’s doing. I mean it has been good because what happened is, when he had his review last year, so when we were setting up the kind of package of activities for him, I mean really that was on me. Did have a social worker who came and did the review and obviously put the package in place, but actually finding the things to do was entirely down to me.

Q Yeah, so what does he do now?

A So 2 days a week the local MENCAP, they’ve got a service in a park and they run….it’s a building and they have like a bicycle….they hire bikes out and they do various things, but he does a horticulture programme there. So they’ve got like an allotment at the back and he does that 2 days a week. And then one morning a week he goes to a local day service and does a couple of activities there. And then on Mondays he was originally, last year, he was kind of carrying on with the….not the supported internship but he was carrying on the day centre. The supported internship team, they were….like we were paying for the PA still going to do that work. Unfortunately what happened is, his PA died very suddenly, had a heart attack and they didn’t feel like it was going to be feasible for [Name] to carry on with a new PA doing that. So he had a couple of months where he wasn’t doing anything on a Monday and Tuesday. Then I managed to speak to MENCAP and get a buddy for him through their short break service using his Direct Payments. I mean I told social services all of this but they never updated his support plan or anything like that. That’s why I’m using the money, I can account for the way I’ve used the money you know. But that hasn’t really worked out because the guy again who has been like occasionally going out with him, he’s a nice enough guy but he’s not consistent. So like some weeks he just randomly doesn’t turn up. Like [Name] has been sat there waiting for him and he’s not turned up.

Q That’s no good.

A And he’s autistic. You know how can you do that to an autistic person? If you say something is going to happen….

Q It has to happen.

A It should happen, yeah. So actually he hasn’t. Because they went out like the beginning of August and then I’d arrange like the week after, and then he couldn’t do it. And then [Name] went on holiday and then he hasn’t been in touch with me at all. So actually I’m waiting for the review next week with the social worker because I want to talk about him. He’s asked, [Name] himself has asked if he can go to the day centre on another day, so actually if that’s what he wants to do then we might as well use the money and pay for that instead. Not that I want him stuck in a day centre but….

Time 15:00

Q No but it’s ??? to the people isn’t it? [removed to preserve anonymity]

A It is really tricky. I mean I have to say, there’s this guy who has been supporting him, he is a nice enough guy and they seem to get on alright but he’s just not consistent, he just doesn’t have the consistency of it. And it’s no good for [Name], he needs to know what he’s doing. He’s really good with change, he’s really flexible, for somebody who is autistic he’s actually quite flexible. But you know if something’s been agreed it needs to….

Q Yeah.

A And my whole thing is, I don’t want him sitting at home. So at the moment, he’s just gone out, he’s probably just gone and got on a bus and gone somewhere because I don’t want him sitting in the house, especially when the weather is….I don’t know what it’s like where you are but it’s boiling hot here. You know I don’t want him just sat on his computer all day, which he would do. And you know he’s a 24 year old young man, he’s quite happy to sit on his bum and play computer games all day, but I don’t want him doing that, so he needs….. It’s always like when he was at college he was always in college 4 days a week and he had Tuesdays off. Tuesdays were his day off, Tuesday was the day that he did his laundry and you know had to chill out and could lie in bed until 11 o’clock if he wanted to, and that’s fine. But as long as he’s got something to do on the other days then, you know that would be the ideal. So yeah hopefully when the social worker comes and does the review on Tuesday we can look at the….although because like I say I had a conversation with the social worker and I’m not sure she actually has a clue what she’s doing, but we’ll see.

Q Yeah. So you’ve kind of done what we all do, you kind of describe it ‘so I just did this and I just did that’ and you make it sound easy-breezy, and I think well it probably wasn’t easy-breezy. And obviously our focus is on mental health and I wondered if you did want to talk a bit about the less easy-breezy bits?

A It’s not easy sometimes it really isn’t. It feels like it’s like a constant stress. And I think we do it, and it’s not….so I’m thinking about like when I was his age. I mean when I was [Name]’s age I had him. When I was [Name]’s age he was already 2 years old, you know I was a mum and I was doing. And he’s always going to need somebody to support him. You know as independent as he is he’s never going to be able to live completely….not that any of….but he’s never going to be able to live completely independently, it’s just never….that’s never going to happen. You know I know that, I’m quite….he’s always going to need some support. And the responsibility for that support is ultimately always going to come down to me. So his dad and I are divorced when he was 11. And his dad’s great, you know I would never kind of diss him as a parent. You know [Name] sees his dad regularly, he spends a lot of time with him. When he was younger he used to go and stay, he doesn’t stay with him so much now but when he was younger he used to stay with him every other weekend. And you know his dad’s always been the one who has taken him out and done stuff with him. So his dad was the fun parent, dad was the one who did all the museums or went on the long train journeys, and mum was the one who laid down the law. But mum was also the one who did all of the invisible work. And that’s ultimately always going to come, you know always going to be my responsibility to do that.

Time 19:34

And yeah that’s the kind of bit that’s….yeah, the not so easy part sometimes. It’s just a little bit wearing. And I adore him, I love him to pieces obviously, you know he’s my child and my only child and I wouldn’t change him for the world. But he’s not always the easiest person, you know his behaviour sometimes isn’t always the easiest to deal with. And again, it’s back to I think well I’m a learning disability nurse, I know how to adapt my communication and I know how to work with people who these behaviours might be ways, you know they might express things through different behaviours etc, I know that because professionally that’s my….you know I’ve done this job for over 20 years you know, I’ve got that experience. But it’s not the same when it comes to your own child. And it’s sometimes dealing with some of those not easy aspects. And people see the happy, smiley, friendly [Name]-y, because he is. And everybody, you know nobody in our local area really knows my name, I’m ‘[Name]’s mum’ because everybody knows him, everybody knows him. And everybody will say ‘oh you’re [Name]’s mum, oh hi [Name]’s mum’. But they generally see the kind of not stressed [Name], and I see the other side of that because obviously home is a safe space where you can let all that out.

Q Yeah. And I think I feel that pressure of we have to be the same, you know just the same it doesn’t matter what’s going on. You just have got to be the same. It’s like service has to be the same as usual, and if it’s not for any reason that’s not acceptable from us.

A Yeah ‘how dare you’.

Q Yeah exactly it is how dare you isn’t it? And that’s really hard when other things are going on and you’re just trying to….you’ve just got to be the same. Even like we went to the [place name] on Saturday, and I was excited. That’s not appropriate.

A Yeah, I’m not allowed to sing in the house. I’m allowed to sing in the car because we decided that the car is different, the car’s not the house. But if I’m singing in the house I get told off for doing that.

Q So do you feel like there’s been an impact on your mental health, has anything ever sort of come to a head I suppose?

A I don’t think it’s helped. I mean I don’t think….I’m a….now I was going to use a word there that I hate and I was reading a paper about it yesterday. I was going to use the word ‘resilient’. I read a really interesting paper yesterday about resilience as a ??? concept, but you know I don’t like that word ‘resilience’. But I’m a fairly tough person and I get on with things. I have had times where my mental health has been low. I mean when I divorced that was obviously not an easy period of life. And I think that having that additional responsibility of actually not only going through a break up of a marriage but then having to deal with the impact of that on an autistic child as well, that wasn’t an easy period. And he’s adapted surprisingly well to it on the surface but, you know it wasn’t, there were challenges around that. And I think that, yeah I think at times when other things impact and then you’ve got that additional kind of impact as well, you’ve got that additional stuff as well.

Q Yeah. And what’s helped you do you think, what’s supported you?

Time 24:20

A I do think my professional knowledge helps, and I say that….you know I always reflect on that a lot. And I think it helps in terms of navigating services and it also helps in terms of understanding the….you know I’ve worked with carers, I’ve worked with a lot of carers, I do think knowing that I’m not unique in this at all – I mean everybody’s experience is unique but actually there’s lot of similarities in kind of caring for… And again, and I don’t mean this in a kind of derogatory way, I never became one of those….I’m not one of the special needs mums. And I think that’s kind of two-fold is that I was never the one at school because I always worked full time so I never got involved in any of the…not….but I never got involved in any of the sort of school stuff and the mum stuff and I wasn’t one of the mums who stayed, you know I can’t possibly work I have to stay at home and look after my disabled child. And I’m not….you know people make those choices and people do those things because they have to when they’ve got no other choice to do that. But I didn’t have that experience. And I think actually in some ways that helps because I don’t think I ever kind of drowned myself in that experience of that is my entire identity, that’s not my entire identity. And again I don’t know if I’m sounding really mean and I don’t mean that in a derogative way or towards any of those other mothers, 99.9% of the mothers ???

Q Yeah. I mean we’ve had….so people talking about it being really important to them to be part of those groups you know, and over time losing those groups and things like that. But also we’ve had people talking about….because they are just full of people like every other walk of life aren’t they and just because they have a disabled child they’re not necessarily going to be your cup of tea or your best friend, or they’re not necessarily going to be a support to you. I mean some people are, some people aren’t, it’s not like you can know that is it before….

A No. My support network is, you know I’ve got a good long standing group of close friends that I’ve known for many years. And I don’t necessarily talk to them about the kind of learning disability, autism, you know that’s not….we do other stuff. But they are my support network, you know. And I have a long term partner, and again he finds [Name] challenging at times and they don’t necessarily have the best of relationships so that then impacts on me because I have to sort of mediate between the two of them. But he is in other ways a big support you know, a fairly big support to me. And work, you know work is very important to me and having that kind of work that I do and that I think I make a difference in and contribute to with something that actually then helps with my mental health because I am able to channel my energy into hopefully making sure that people with learning disability are better supported.

Q And when you work with families, because you know you’ve got other experience too I suppose, what do you think helps there, what support is there available to them?

A I mean like I say there’s a lot of groups and things, and it’s good for those families that perhaps don’t necessarily have anything else to support them. It always makes me laugh, like when [Name] was younger I would get…you know the social workers would be like ‘we’ll refer you to the carer centre’. ‘Well what can the carer centre offer me?’ ‘Oh you can have a massage at 2 o’clock on a Wednesday afternoon’. Well as much as a free massage would be lovely I’m working at 2 o’clock on a Wednesday afternoon, you know. And I’ve worked in areas where there’s been those kind of really good support networks for certain individuals. So I worked in [place name] for a few years and you know a big Bengali population, and there’s actually a big Bengali carers kind of network and there’s services that people can be signposted to. And you know I think all that is great but none of it’s particular coordinated, these things kind of spring up informally and maybe then kind of take on a life of their own and become really good support services, but they are very much led by the people themselves that’s not kind of any kind of necessarily pro-active service.

Q And what about professionals in families’ lives. Because one of the things it’s not really clear is about who people get support from. So we know they get support from their peers, some people have talked about their GP.

Time 30:00

A I think when there is people like learning disability nurses involved I think families do…and you know my experience and obviously I’ve got a slight amount of bias there, but my experience that I’ve had is that families do value that input. And you know I’ve certainly had conversations with carers about the challenges that they have with caring for their loved ones. But that’s by necessity very often quite short term interventions because there aren’t enough learning disability nurses and there aren’t enough…you know the services are set up to do quite short term….

Q Yeah, and I think I feel like I need every nurse to be a learning disability nurse in a way because you know we had really excellent support for … really good. But when [name] cut his finger and we go to the cottage in our local town, that nurse, you know she needs to be able….and she was really good actually, but you know I think everybody needs to care don’t they, everybody needs to take some sort of interest.

A Everybody needs to care and have the interest. And I think often times for us as carers it’s just knowing that it’s not that everybody’s necessarily got that high level of skill, you know that’s not the way, it’s just being human and just, you know showing an element of interest in people and not just being ‘oh actually this is just….’ And not accepting that things should be worse just because somebody’s got a learning disability, you know not accepting our shocking mortality statistics and not accepting that that is acceptable. But also I think having more…and again a bit of advice, but having more learning disability nurses and more learning disability professionals available because actually you know not that everybody with a learning disability needs to have a learning disability nurse nursing them but actually every nurse needs access to a learning disability nurse to be able to provide that advice and support that they might need in terms of making those reasonable adjustments.

Q Yeah I think that’s a really good point.

A And as I say, I do think carers value that. Like every conversation, not every but the vast majority of conversations I have with people and with families and carers, they will say ‘X, Y, Z was happening until the local learning disability nurse came along and sorted everything out’. And it’s like well actually I know some not lovely learning disability nurses. But actually you know that shouldn’t be the way of things, it should be yes the system needs to change.

Q So the system needs change so that everybody, all the professionals have access to learning disability nursing. So like our GP, I’d be really glad if our GP – if we ever saw the same one twice – had access to that. You know because I feel like I’m doing that.

A Well like where I used to work we had….so each of the nurses in the community team had a group of GP practices. So obviously all the GP practices in the borough were kind of clusters, they were in like 8 clusters, so there would be like 4 of our GP practices that worked quite closely together, you know that were in kind of one little kind of network. And each of the community nurses had a network that they were allocated to. And the idea was that those GP practices had access to…and yes it’s only Monday to Friday 9 to 5 and it’s not….but we would go along to their network meetings, we could go in. You know if they had somebody who…if they looked at their register and found that somebody hadn’t been for their annual health check for 3 years because they were too petrified to go to the GP then we could proactively follow that up. So they had access to that. And I think that helps. But again I don’t know if carers then necessarily….they probably did feel the benefit in terms of actually they could ??? them and supporting got better access to services. But again I think it….how do we provide that consistent level of support everywhere?

Q Yeah. And one of the things that people have been telling us is that they feel like the usual things that you do for mental health don’t work. So things like…well I don’t know if this probably works for anyone but maybe like have a Yoga class. Well yes fine, whatever. But things like being referred to IAPTs you know or….yeah exactly.

Time 35:16

A It’s not about the….it’s almost like analogous to like chronic illness isn’t it. So it’s almost like you live with a certain amount of pressure. So somebody who is chronically unwell lives with a certain amount of pain and then the doctor goes to them ‘well how much pain are you….’ you know where is your level of pain on a 1 to 10, and they say ‘well it’s an 8’ but it’s always an 8, it’s never not that and you just kind of get used to it. And it’s almost like what you carry is always there. So you kind of don’t see it as a problem until something tips it over the edge. So you carry this with you until something happens that actually tips that balance of being able to cope with it.

Q Yeah. And I think what people are saying is that then you get referred to…well you get medication or you get referred to IAPTS and that there’s no understanding that you were at an 8 and you’ve always been at an 8.

A And they don’t understand that. And also it’s not about me saying it. I mean you know I’ve done courses in CBT you know and I think it can work and help for some people, some things. But the kind of things that carers are dealing with is not about reframing, it’s not about…you know I know my A, B, Cs, I know that, but it’s not that, it’s the actual….reframing it doesn’t change what’s actually happening. So if your child has non-support service and you are worried about how you’re going to juggle X, Y, Z and you need to do this but you’re…. So it’s like years ago, I mean this was when I was still with [Name]’s dad. I had a day where I had a really important meeting at work. It was a CPA meeting, it was somebody who there had been a lot of difficulties with, I’d finally managed to get everybody who needed to be at this meeting to agree to be in the same place at the same time, and there was about 20 people in the network including the GP you know, and you never get the GP you know. And so I finally managed to get the GP and the Psychiatrist and the social worker and everybody to agree ‘yeah we’ll be in….’ you know so really vital that this meeting went ahead. And [Name] was ill and his dad was basically like ‘well I can’t take the time off work to look after him’. And I was like ‘but I have to go to work’. And he said ‘no you….’ And I’m like ‘but I have to’. And do you know what I did, I walked out the door. I walked out and went to work and left him and then he had no choice but to stop at home and look after him. But you know it’s almost like what’s CBT going to do about that, you know?

Q We’re still in that, we’re still in a permanent state of doing that. Whose day is more important.

A Whose day is more important, yeah. And it was, I mean it’s not so bad now as I said because it’s OK, he can be left on his own you know, he can be at home. I mean generally he’s not at home on his own because my step-son also lives here and he’s not working at the moment so generally he’s floating around so… But he can be at home on his own and that’s….so luckily because he’s that little bit older I’m not so much in that position. But until he was like 14/15 I would never have dreamt of leaving him at home on his own.

Q No. So if you’d got all the amount of money in the world, all the resources in the world, what would you imagine – so for the families that you support or for yourself – what sort of support would you have if you could have anything?

Time 39:30

A It’s that practical stuff. And I think particularly for younger children or adults who can’t be left on their own. But it’s the access to like some….so like say that day that, you know could have rung somebody up and somebody could come round and….almost like a sitter you know, somebody could come round and be with that child when they were unwell. Or things like….I don’t know….what makes my health generally and my mental health certainly better is when I know [Name] is well supported, it’s when I know that he’s got the things to do that interest him, that make him happy. If I know that he’s active and kind of doing stuff, that actually makes me feel happy. I don’t want to be a ??? you know I’d quite like in, I mean I’ve always said I’m not going to be the mum whose 30 odd year old kid with learning disabilities is still living at home and I’m in my 50s/60s and….you know. I want him to move out – not that he wants – yeah he would say differently because obviously it’s nice and easy living at home with mum who does everything for you. But I’d quite like him to move out. But also then I worry about that because I worry about….you know. And I know not all services are like that but….

Q I’ll just be one minute, hang on.

A OK.

Q Sorry about that.

A It’s alright.

Q And the handover. I’m sorry I’ve lost myself now.

A No I think like your services, I’ve worked with some wonderful supportive services but I’ve worked with some absolutely crap ones as well. And I’ve seen things that, you know are not acceptable. And I want to be assured that he can live somewhere and get on with his life. Because he’s a young man, you know I want to see him get on with his life but be supported to do that in a good service, but that are also….I mean he’s generally fairly fit and healthy, but who knows what could happen. And then you do, you read, you know I’ve seen enough stories. And I know, I’ve seen what’s happened to people’s children, you know. I’ve seen what happened to [name]? And I don’t want….I know that like the absolutely chance of that, you know like 99% of the time things are pretty….you know I’ve worked with really good services when people are really well supported. But also, you know it does worry me that what if he goes and lives somewhere and….sorry I’m starting to upset myself.

Q No I know. And I think you’re not the only person that’s worrying about the future. And the thing is, that worry about the future affects the now doesn’t it. That’s a very difficult thing to manage. Yeah.

A I think, knowing that there are better services out there would be one thing that would be…so if I had an unlimited amount of money, that money needs to go to make sure that there’s good support for people. Because actually as carers that takes the burden off you.

Q And I think, you know why do people end up in units where they pay the money for the unit – do you know what I mean? There’s sort of an inevitability that they need to fill those spaces, and then you see people living really well when they are in good supported living.

Time 44:35

A I think there is, I think there is that. I think it is….again you know I’ve been on that side, you know I’ve been in that commissioning side, I’ve been in that kind of side of….and I know it’s not easy, it is complicated. And the NHS and social care is such a complicated beast and I don’t doubt that the vast majority of people working in those services are doing it for the right reasons, they’re doing it for the right reasons. You know I don’t doubt that the vast majority of nurses and psychiatrists and support workers, you know they want to help people. You know people don’t go into work necessarily to set out to do damage. But the system does damage. And people are human and they work within a system that actually isn’t working, and we know it’s not working, it’s not been working…. I’ve been a learning disability nurse for over 20 years and what we are seeing now in terms of health inequality it was exactly the same then, it’s not new. You know this isn’t new.

It almost feels like….you know I get de….I always feel sometimes like I get desensitized to it, I’m like ‘oh if you’re somebody with a learning disability you’re going to die 23 years earlier than somebody without’, oh, you know. And I can just rattle off those….you know I’m teaching nursing associates tomorrow and I’ll be rattling off those statistics to them. And then, you know a little bit of luck there with how we find spaces and then actually what happens further down the line, you know they work in systems that perpetuate this inequality and perpetuate this difference.

But as I say, you know those figures, I know them, they’re not any different to what they were 20 odd years ago really. Minimal, a little bit, tiny tiny little incremental changes you know. Are services worse? It’s a little bit….you know it is too simplistic to say it’s all about money because it’s not, but money does impact, and you know a shitshow of a government that doesn’t give a flying one about….certainly you know doesn’t care about people with a learning disability.

Q Yeah. I can remember when [name] was little reading somewhere that it cost the state £2m or something to raise a child like [name]. And I thought ‘just give me the £2m now and I’ll never bother you again’.

A ???

Q He’ll have like the best life you know, just give it to me.

A I mean sometimes you see those parents don’t you, there’s examples of it, those parents who set up a service. But you shouldn’t have to do that. You shouldn’t have to set up a service specifically like around your child. And actually sometimes that’s not a helpful thing, you know some of them work well but some of them don’t work. You know I’ve seen times when that hasn’t worked well at all.

Q I think it’s that fear about permanence isn’t it, because if you own that building that’s…

A You own that building and that’s….yeah. And that’s always been my, I’ve had dreams about this. I’m like there’s some lovely big houses down the road from me and I’m thinking ‘if I win the Lottery or my premium bonds come in, I could move out of [City]’ because that’s what I’d like to do, you know I’d like to go and live down by the sea. Me and my partner down by the seaside, couple of dogs, not a care in the world. But I could buy a house, because I’d like [Name] to stay in [City] because everyone he knows is here. So his dad lives in North [City] and he knows how to get from home. But he’s lived, he’s lived within…so he’s lived in this house for the vast majority of his life, he’s lived in this house for 22 years, you know this is his home. And this local area, you know he was born here, he’s a [City]er through and through, he was born in [city suburb, he’s lived in South [City] his whole life. So I’d like him to stay in [City].

So my dream of like when I win the Lottery is, I’ll buy one of those nice big houses and I’ll set up a service. You know I’ll give the house to a support organisation and pay them to run it but I’ll be involved, I’ll be on the Board of Directors or whatever, and at least then I’d have some idea that it was a service that….and it be for young men like [Name], you know your quirky autistic young men who love buses and trains.

Q Yeah. I always think that if I win the Lottery I’d employ PAs on like £100,000 a year, do you know what I mean, make it like a really, really amazingly well paid job.

A Yeah. And I would make sure that the staff got appropriately paid and that they got all of the training and support that….yeah. And it’s not just about training, I mean you can give people all the training in the world, but it’s about that ongoing support and that kind of psychological safety net within services and that, you know ???

Time 50:00

Q I don’t know what banks do, you know like big banks, but you know you could have bonuses.

A Yeah you could have….but also just like, you know [name] always says it’s just like being human with people, it’s not… Yeah you need to make sure that staff are paid, you know staff need to be paid, of course they do. You know people say nurses are angels – no we are not angels we’re professionals, we do a job and we deserve to be paid, I mean you may say appropriately for doing that job. And support workers, you know have families and you know they deserve… But do you know what I mean, people who are just good people.

Q Yeah, and valued for the complex job that they have. Because it’s really complicated what they’re asked to do.

A It is. But that’s what I mean about that support. You know I do think even, you know it was that move away from….you know, and I’m not saying that the way services were in the past were better, but at least you had NHS led kind of residential type services, of which there are still some, but they were managed by nurses. And actually learning disability nurses have that whole model and ethos to support the staff as well as the people that they work with, and to make sure that people’s health needs are met but you make sure people’s social needs are met. And so yeah I’d love to buy a big house and employ a learning disability nurse to be the manager, you know get a properly good service in place. But then, like I say, it’s like parents shouldn’t have to do that, you know we should have services that are there and like that.

Q Yeah. So one of the things that we are doing, and you’ll have seen the information sheet and stuff, is making these little films. So I can talk a bit more about that in a minute. But one of the things that we were thinking about is whether there is any story that really stands out for you when you are thinking about being a parent and bringing up your son. Sometimes people have something where they think that is a story that stands out, or a story they would like to tell or a message they would like to give.

A No I was thinking about this. I don’t think….yeah I don’t think there’s anything kind of particular. Again, and you said it earlier, it’s like you say these things like they’re normal and I think sometimes you do normalize this.

Q Yeah, and that’s a good thing and not a good thing at the same time I think.

A I think you have to do it because you have to just get on with it. But I think that’s my kind of message is, yeah, that actually this stuff becomes normalized. It’s like the mortality statistics become normalized, it becomes normal to say that this is massive inequality, it becomes normal as a carer to say ‘oh yeah I do X, Y, Z’. And then you think actually does another mother of a 24 year old do…. I mean they probably do certain… I mean I’ve always had that, like you’re never completely independent from your parents. I mean my mum is still the first person I’ll go running to if I need advice or support about anything, but you know not to the extent that [Name] would need that care and support, you know. So somebody else who has a 24 year old who doesn’t have a learning disability, what amount of input do they have into their day to day life?

Q This sounds a bit weird but I think sometimes I can get a bit surprised and a bit upset when I notice it’s not all, do you know what I mean? You have that moment and go ‘oh, other people aren’t doing….’

A Other people aren’t doing that, yeah.

Q You know.

A Yeah there are times when you just think ‘actually…’ Yeah, when [Name] is having a meltdown in the middle of the street and I was stood there. You know he’s bigger than me. He’s not tall, tall for a man but he’s bigger than me and he’s quite strong, and you know I’m trying to bear hug a strapping 24 year old man, you know.

Q In the street.

Time 55:00

A Yeah. It’s like most parents of 24 year olds are not doing that unless they are falling over drunk somewhere and you….

Q No, they’re all out for brunch!

A Yeah!

Q So the storytelling workshops, you don’t need to be a filmmaker, you don’t need to be good with tech, you don’t even need an idea of what you’re going to do. So when I went to one of the workshops I had no idea of what film I was going to make, and it was through the….there’s a meeting where we just talked it through. And so there would be a lot of support around that. And we can do it however it would work for you if you are interested in becoming part of the digital storytelling. So there are some meetings in October but we recognise that everybody won’t be able to go to those so there would be support outside of those meeting times as well. But the first meeting is where you would meet other people and that’s where people generate the story ideas, but we could do that individually if you preferred it. So I wondered if you were interested in thinking about doing the next bit?

A Yeah I’d be interested. I don’t have any particular kind of ideas.

Q It really doesn’t….

A I never see myself as the most creative person.

Q I can send you some examples of the stories.

A Yeah. The lady that initially emailed me, she sent me a couple of the ???

Q Yeah. Have you seen the films?

A Yeah I had a brief look at them.

Q So I think some people arrive and they go ‘this is the story I want to tell, this is how I want to tell it’. And then other people like me go ‘well I have no idea’. But it could be a film about ‘normal’, because normal was quite strong, you know what ‘normal’ means and those moments of the bubble being burst and…you know. Through the conversations such things happen. And I was thinking about, I was talking to somebody last week about mental health and I was saying that it’s like….somebody said to me ‘it’s like carrying books’ and they put a book on, and they put a book on, and they put a book on, and they put a book on and then the books….

A And then you put the last book on and everything topples down.

Q Yeah. And I was thinking I wonder what my books would be. I was trying to think what would be the titles of the books. And I was like ‘No Social Worker’, I don’t know. Do you know I was trying to think.

A Yeah, ‘How to Navigate Social Services’, ‘How to deal with a meltdown in the middle of St George’s’. Obviously he was tiny then, he was only about 2. But I had to go to St George’s Hospital for an appointment and he had a meltdown in the middle of the corridor and I had to….he just sat down on the floor and refused to move. And I wasn’t well and I couldn’t pick him up and I had to kind of grab hold of him by the back of his coat and was dragging him along. And that, you know that would be a normal kind of 2 year old behaviour. But then when that’s happening when they’re 9/10/11/12.

Q Yeah. And I was also thinking about people who took the books off, like friends, like when they take one of those books off you. But in the end….in the end I got too many. And then in the end it was too much. And I didn’t even notice, I didn’t notice I was carrying it I guess. So there might be ways of thinking about….

A Like ???

Q Yeah, and anything in conversation that will come out really well. So is there anything else that maybe…did you think I might ask you about something in particular and you were like ‘oh I want to tell her about….’?

A No. I mean my understanding was that it was just about sort of….yeah those experiences. I suppose I always…it’s difficult and I think that’s what’s come out of this conversation isn’t it, that I don’t ever think like….sometimes I go through life thinking ‘oh well maybe it hasn’t really had that much impact on me’ and then sometimes I start to talk about it and think ‘well actually it does but I just don’t think about it’.

Q Yeah, that makes total sense to me.

A Yeah, because it’s easier not to, it’s a lot easier not to think about it. You know I think about all of that stuff on a professional basis every single day, but thinking about it on a personal basis ??? makes it difficult sometimes.

Q Yeah, yeah, I understand that. So was there anything else that you wanted to ask me?

Time 1:00:04

A So with this, so I’ve been involved in it, I’ve been involved and like been interviewed for a couple of stuff before and then never really got anything back. You know I know all these things, I mean we are just writing up. So we did some quantitative interviews during last year and we’re literally just writing up our results you know. But in terms of like where this goes.

Q I can tell you all of that. So the first thing that will happen is that when we’ve got your transcript you will get that back and you can comment on it. And I will have anonymised it but if you want you might want to anonymise it further, you know there might be things that you think ‘oh….’. Or you might just think ‘I don’t want that in the world, I just want to take that out’ and that’s absolutely fine. So that’s the first thing that will happen. So we’re going to do….so if I tell you about how the project works. So we’ve got a literature review that will be published soonish we hope and then the next phase of the research was to co-design a survey about mental health with carers. And what happened at the survey workshops was that the carers said ‘we don’t want a survey because tickboxes….??? what were you thinking?’ We’re like ‘oh, oh yeah’. What we would like is an online exhibition which will have pictures and drawings and songs and sounds that say something about mental health. So we’ll be doing that and then you can upload that if you want to.

Then we’ve been interviewing people and then we’ll have these storytelling workshops and we’ll produce….so everyone will have a film that will be their film and then it’s up to you to decide what you do with it. So you can decide that you made that film just for you. Or you can agree that we can share the film. And we’ve been very careful, so if someone’s identifiable in the film we would also need to get permission from them for you to share it. But you could do a film that was totally unidentifiable you know, and it’s important that we get that bit right.

And then the last bit of the project is, so running all the way through this we’ve got a group of carers and people with learning disabilities who are guiding us and we will get all of the information together and we will start to build some resources. We’re not exactly sure who those resources are for because we are not exactly sure….some of them….well they’re definitely for families and friends of people; we think they’re probably maybe for GPs; they might be for learning disability nurses. And so we’ll work to sort of include the films and the images from the survey that’s now an exhibition and all that kind of stuff, we use those to develop the resources. And then we’ll be really trying to push them out.

Because it’s been really interesting. This call was from NI? at ??? and it was around the mental health of older carers of older people really was what they were thinking about. And so you know there’s loads of information that comes with a call and there was nothing about carers of adults with learning disabilities. So you know carers of adults with learning disabilities are a marginalized group in research, whereas it’s normally focused on children really.

A Adults with…yeah. People with learning disabilities are marginalized, and carers of people with learning disabilities are marginalized.

Q Yeah. And I think the things where people feel that they are different and that they are being offered stuff that doesn’t meet their needs I think is really important. And the other thing I think that’s been really important to understand is that people have very different understandings of what mental health means to them. Like for some people they see themselves as mentally ill, I mean maybe they had a diagnosis before they had children; and then somebody might see themselves as mentally ill and say ‘this has aggravated my mental ill health’. Other people have said ‘I’m not mentally ill, this has been done to me by a system that I’m having to fight’. So you know it’s quite interesting how they understand it, so experiencing distress but ‘there’s nothing the matter with me, I’m not disordered in any way, I’ve just been fighting, fighting, fighting’. And I think that’s important. So if you’re supporting me I think it’s important for you to work out how I understand my mental health before you sweep in with ‘actually you’ve got depression’ or ‘here are some anti-depressants’ or ‘have you thought about CBT’ if you don’t understand how I’m understanding my own experience.

A How do I train? that experience? And it may be, you know some carers my have diagnosable mental illness, but for some people it is just that, yeah that every day kind of….that mental well-being rather than illness isn’t it 15and how we support that well-being.

Time 1:05:

Q We spoke to somebody and she started and said, and I thought good on you, she went ‘I just want to start by saying that you shouldn’t assume because I’m a carer of an adult with learning disabilities I am any more likely to have mental health issues than anyone else’. And I thought ‘yeah’.

A It’s true, yeah. It’s for me….yeah absolutely I would say that, yeah. I don’t think being a carer necessarily pre-disposes you to mental illness, but it’s more that well-being side of life.

Q Yeah. And I think that fighting a system pre-disposes you to mental stress.

A Yeah.

Q I think Joe Public probably looks at me and thinks ‘ah bless, it’s a bit sad isn’t it, she’s got him and he’s the problem’. And I think ‘he’s not the problem, there’s been problems because we live in a society that doesn’t welcome him, doesn’t support him’ you know. [removed for anonymity]

A Don’t be sorry for the fact that I’ve got a child ???

Q Yeah. I mean he’s still looking at me. And I thought ‘I’m not here for that, I’m not here, I’m not available to you to pity me”.

A Yeah exactly, I don’t need to be pitied. It is. You know I’m one of those people….I’m not one of those people that, you know if I could wave a magic wand and go back to before he was conceived and him not to have a learning disability and not to be autistic, I would probably do that, you know I don’t think anybody wants…like deliberately sets out to have a child with a learning disability. But you know that’s not real life, I can’t do that, he is who he is, why shouldn’t we live in a world where people are accepted. Yes he has particular challenges and yes he can be a dickhead sometimes, you know that’s just his personality, he can just be a dickhead. But you know so can many other people’s children.

Q Yeah exactly. And you’re allowed to say that. We are saying ‘selfish little shit’.

A I call [Name] a dickhead sometimes, when he’s done something where he’s….I call him a dickhead because he is sometimes. But I remember being on a bus with him and there were some kids and they were kind of giggling, you know I can’t remember what he was doing, he was stroking his hands and doing his kind of stimming stuff and they were kind of laughing at him. That’s him just messaging me – oh he’s in town. But you know they were laughing at him and they were like…. And I think I did turn round to them and I used that face, you know, ‘he was born like this, you’re just choosing to act like little shits basically’. You know he can’t do anything about the fact that he’s got a learning disability but you can do something about the fact that you’re being rude and horrible to him for something that he can’t help.

Q Yeah. And that’s just so upsetting isn’t it. You’re out having a nice time and somebody else just…

A I mean I’ve always taken it. He comes. He’s always come. You know I don’t isolate him, we do stuff. And sometimes he just has to put up….you know sometimes there are things I know he’s not going to be able to tolerate, and sometimes I’m just like ‘no, this is what we’re doing and you are part of the family and you’re doing what the family does’. But he’s always just come everywhere with me you know, always done, I’ve never isolated him from stuff.

Q No. And I’m quite good at just filtering out people staring.

A I ignore it. I remember when he was quite young, maybe 5 or 6 and we were in Spain on holiday. And basically I think there was another family came over because he was like running around and kind of laughing and stuff. And this mum came over and it turned out I think they had suspicions that their child was autistic and she was trying to kind of ask questions about kind of parenting. And I felt a bit like almost like she’d seen somebody that actually had that behaviour kind of ‘out in the wild’ you know. And it was like ‘oh maybe actually it’s not such a bad thing’.

Q Yeah. So I just wanted to check before we kind of wind up that you are OK, because I realise I’ve kind of stirred things up.

A No. I’m actually going after this, I’m going to see the ??? documentary and film tonight.

Q Oh that sounds good, that sounds good.

A Yeah. So I’m going to go and meet some friends in a bit. So that will be nice, something completely different, something still learning disability related but like completely different.

Q Yeah, and have a nice cup of tea while you can before your son gets back. And thank you so much for talking to me. And so we’ll be in touch about the transcript and the other stuff, but it’s been really lovely to meet you and thank you so much for spending that time with me.

A That’s alright. Nice to meet you.

Q Thanks so much, OK we’ll be in touch, bye bye.

A OK, bye.