K I am recording, so thank you very much, bye bye.

Q See you [name]

A Yeah bye, bye.

Q Right ??? nice to meet you.

A Yes likewise, yes.

Q And thank you for doing this interview. Did you have any questions before we start?

A No I think it was quite self-explanatory when I read the flyer that I was sent by [organization] , it was quite…yeah. And then I read your information you then sent to me, so yeah it’s fine.

Q OK. So I’m going to send – or it won’t be me it will probably be someone called [name]will send you a questionnaire that will be just to ask you for demographic details, it’s quite an easy tick box thing. It will be anonymous but it’s just for collecting everybody who takes part, we want to collect the overall characteristics of the people who take part. So you’ll probably get that on Monday. And we will be transcribing, typing up everything that’s said in this interview and I will send you a copy, which is only to read because you might just think ‘oh I’ve done the interview and I’m not interested’ but it’s just in case you decide you wish you hadn’t said something or you want to remove anything. And then we will anonymise all the data so what you say won’t be attributed to you in any way. So that’s so far all for now. And if you want to withdraw at any point you can. If you want to stop the interview and carry on at another time you can, it’s entirely up to you. OK.

A I would like to just do it and then it’s out of the way, that’s how I kind of look at it.

Q I think that’s what most people are saying I think.

A OK.

Q So can you start by telling me what made you interested in taking part in this study?

A The first thing is is about the support that you are going, or planning to put in place you know after you have finished your research and got the findings and discovered what is needed and worked out how best you can support parents of special needs adults. And I can’t remember if you were also trying to work out how to put more support in general for the special needs person, I don’t recall whether it was just for the family carer.

Q Yeah, it’s mainly for the family carer and it’s producing resources, learning and teaching resources and digital films which I’ll talk to you about at the end that are aimed at just raising awareness of family carers’ mental health needs. But obviously you’ll be talking about your daughter, and other people have talked about the person they support as well so they will feature, but the actual resources that are aimed more at carers.

A OK well that’s great. So it was really about that because, yeah I think the more support available out there then the better for families really. And especially if it can be rolled out sort of nationally that would be ideal.

Q So what do you think of the current support?

A I think that from my particular experience that it’s not everybody that gets it and I think - meaning that receives the support – and I think that is where the system falls down. Because it shouldn’t be that, you know parents have to go through such hoops in order to get it. And also you’ve got to be quite strong to sort of fight for this and fight for that and just keep going and keep digging at things. And that is very wearing. So it’s not every family that is able to do that because of their circumstances, or even because of their particular personality. For some people, you know it’s quite overwhelming having to do that if you’ve already got a special needs person that you are dealing with, that is overwhelming already and then on top of that you’ve then got to try and fight for this and fight for that within the system. It’s just it can be a bit overloading for some families and then they just wouldn’t be able to do that. So I think it shouldn’t be that you’ve got to fight for this and fight for that and keep going and keep repeating yourself to so many different people.

Time 4:55

There should be a system out there which is there for people to access and it should be that you know the councils, the social services, are the ones that are telling you about it so that you know, you don’t have to go digging or finding out from different parents or whatever. It should be an automatic thing that, you know social services or the particular council contact you and say ‘well this is available, this is what we’ve got, this is how we can help’. You know it should be like that. So the current system I think is not….the sort of information isn’t out there that should be, which is kind of offering it to parents rather than parents having to sort of find out from other parents or from research or by accident, you know. So there’s something missing I think in the current system which needs to be in place.

Q OK. And can you tell me a bit about your experiences as a carer?

A Well fortunately I’m in a family, so it’s myself, my husband, and I’ve got 3 daughters including my special needs daughter. So for me, my particular circumstances have enabled me to cope because I am supported by my family first of all, so that’s been very valuable for me. And on top of that I was fortunate enough to be part of a parent/carers group from the time my daughter was about….I’m trying to think now….maybe when she was about 10. And that parent/carers group was very active, it was like a….yeah a group of parents who….it was a nation wide thing that was rolled out to different regions to support parents of special needs children to get help. So it was like you know we’d meet up with the council and the council would….yeah so I haven’t got any food at the moment, yeah, do you mean ‘toilet’, you can go if you need it. Sorry, just one second.

Q Ah, sorry Pal.

A Yeah so through that I was able to….sorry, it’s just happened with my daughter as I said. So through that I was able to find out a lot of what was going on within my particular region and also help to inform the council through this group, the parent/carers group, of what the needs of parent/carers were. Because you had a database of about say 400 or so families and, you know we would always like send out information to them about what their needs are and then the feedback we got from that we’d sort of present that to the council and try and get them to….well first of all so that they would know what parents and families are going through, and secondly so that they could try to provide the help that was needed. So that was my experience. I was kind of like quite fortunate I was in that group for quite some time, I think 7 years or something, until my daughter was about 17 and about to go into adult services and therefore I left the group because adult services is kind of very different from child services.

Q So you developed another group of adults rather than children?

A No not really. I mean that group that I was part of, they can help parents of special needs children up to the age of 25 so I could have remained in the group. It’s just that because the responsibilities kind of changed where she was moving over to adult services I just wanted to sort of focus on how that experience? would function and what I would need to do in order to help her make a good transition into adult services. And I felt it would be difficult for me to stay in the parent/carer group, going to meetings and things like that and also trying to navigate my way around adult services. So I just kind of focused on the one thing really.

Time 10:24

Q And how have you found adult services?

A Again I felt that the transition period wasn’t….they didn’t put things in place soon enough and they didn’t inform me soon enough about what was going to happen. Because it was only in the August, as my daughter was 17 at the time and her birthday’s in the December so she was due to turn 18 in the December and it was only in the August that I was contacted by adult services to say that things needed to change. You know we were trying to do the transition from childhood services to adult services and I felt….and it was a very different service and I felt that they should have contacted me a lot sooner so that I would be aware of what the changes were and I would be able to prepare for them and that it wouldn’t be such a sudden thing. So how have I found them? Well very different and also not….I’m trying to think of the word now….yeah just not enough information at the right time, that’s what I’ll say, yeah.

Q And what sort of support….

A Just one second. ??? can you try and be quiet because I can’t hear. Can you be quiet please? Sorry what was it you were about to say?

Q What sort of support do they give you?

A Well I was supposed to….my daughter was supposed to have a social worker actually assigned to her since she was, you know in child services actually and she’s been on the list since she’s been in child services for a social worker. But that never materialized and so I found that whenever I did need help I had to contact the duty social worker, so whoever was on duty at the time, and then they take up the case and then deal with whatever it is needed dealt with and then they would, you know….basically they weren’t a permanent social worker so you couldn’t have the consistency of that one social worker and knowing you as a family, knowing your child. So it was different people taking on different things over the years as they arose. And even now in adult services it’s the same, she still hasn’t got a social worker assigned to her specifically, and then when I need something I usually phone up the Preparing for Adult Team, and again it’s whoever is on duty at the time you know is the one that takes up your case, they might deal with it themselves or pass it on to somebody else who will deal with it for you. It just means that the process is a bit slower I think than it would probably be if she had a social worker assigned to her who sort of knew her. But I mean it still gets done, it just doesn’t get done quickly that’s all.

Q How old is your daughter now?

A She’s 23.

Q And do you think that being a family carer has impacted on your well-being at any points in the last 23 years?

Time 14:42

A Well it definitely has because obviously the responsibility of caring for someone with special needs is a lot greater than your typical children, because at some point your neurotypical child will become independent, do for themselves and you can just step away and you don’t have that physical responsibility for them, you don’t have that….I mean you’ll still be guiding them and talking to them about different things at different stages, but the physical responsibility you can step away from, they can do things for themselves, they’re more physically able to do….you know go out into the world and do what they need to do for themselves and they can do things for themselves in the home. Whereas with a child with special needs, they depend on you in a greater way, because even though you might be able to step away a little, you still have to do a lot for them that they’re not able to do for themselves and it’s only if they sort of make improvements over the years, which obviously doesn’t kind of happen, then certain things they can take on board and do for themselves and other things, you know you’ll have to be doing. So did you ask me how do I find it?

Q Yeah, how do you find it impacts on your mental health and well-being?

A I see, yes. It’s very much more intensive and all consuming than dealing with a neurotypical child. So in that sense the freedom to, I guess be spontaneous and do things that you’d like to do for yourself on any given day isn’t there really because you always have to factor in that you are dealing with them and you have to work around them. So they are always central to whatever it is you need to do for yourself. And that can be difficult, but over time you just get used to it. So you know you can’t just say ‘oh I’d like to…’ like for example you know you might want to have a day off or something, have a day off, and you know if you haven’t got the things in place for you to have that then you can’t. So it can be difficult, but at the same time I think the key is to sort of having little breaks within each day for yourself rather than perhaps doing it in a way that you might ideally like to do it, like a day off and just do whatever you wanted to do whether it would be a day at the seaside or catching up with friends or whatever. But you just have to take little breaks in little ways throughout each day and that’s how I find I keep well, put it that way, because otherwise if you didn’t do that it would be just full on, full on, full on all the time and you’re not having any time for yourself, which is not the right balance.

Q So could you describe some of those little breaks, what do you do and who looks after your daughter in those times?

A Well for example fortunately she’s got two support workers, and it’s summer time now because she used to be at college 3 days a week supported by a support worker and then one day out in the community. So let’s say 4 days out of 5 she would be out, so 3 days at college, one day at the community supported by a support worker. So during those times I would plan how I could spend each day while she is out because that would be my opportunity. So apart from the sort of, you know routine stuff that has to be done, you know housework, laundry, shopping, catching up with paperwork, emails and all that, which isn’t a break. But the little breaks that I take within each day is something like deciding ‘right, I’ll take an hour, I’ll sit down, I’ll have a cup of tea, I will scroll through my phone looking at messages, catching up on messages, texting people. Or I could decide right I’m going to watch a bit of TV for that time while I’m having my tea, eating my food, you know just sort of killing two birds with one stone.

Time 20:15

And it’s just kind of taking those simple little time-outs when at least I’m not thinking about my caring role, I’m just doing something really simple, something that I can enjoy before getting back to my routine day which is, you know the routine things that I talked about while she’s out. If I’ve got time I’ll go to the gym because that’s very important for me because it helps with my physical and mental well-being. So I usually try and do that twice a week if I can, sometimes I only manage once a week. But these are the things, the breaks I’m talking about that I will take when she is out. And then I’ve got to time myself on each so I can get back home in time before she comes home. So I’m always kind of on a….I’m always on a schedule in that sense, because I think ‘right, she’s going to get home at 3 o’clock’ for example, and so whatever I have to do I’ve got to make sure I can do it within that time before she gets home. Some times even I’ll you know have a coffee with another carer, I’m in touch with quite a few carers so I might go. Again that’s not as often as I’d like to, it could be once every 6 weeks or something like that I’ll, you know have a coffee for a couple of hours with another carer so we’ll just kind of have that time together while she’s out. So that’s my little breaks that I’m talking about.

Q So it sounds like….

A It helps.

Q It helps you.

A Definitely.

Q How did you reach the point of knowing that that would help, was it like a gradual process or….I’m quite interested because it sounds like you’re very well organized on this so I just wondered how you….

A Well it is all the time because obviously it’s not something that….when she was a lot younger – but you want to focus really on adult don’t you?

Q Well no, say when she was younger.

A OK. So when she was a lot younger her two sisters were also a lot younger so it just meant that if I wanted to go out, you know and her dad was off and available, whether it would be going out let’s say in the evening then or something or a weekend. If I wanted to go out socializing on a weekend or a weekend when she was a lot younger, because she wasn’t on her own, you know or her dad was there or her two sisters were there, it was easier for me to do that so I could just kind of do that as long as I plan it in advance. ‘Oh I’ve got this to do’, ‘I’d like to do that’ or whatever, then you know her sister’s about two and a half years older than her anyway and she’s quite responsible her older sister, so she’d be there to sort of take over and do things that [name] would do, and then what she couldn’t do then her dad would do. So when she was younger I didn’t really, you know have that much….I was a bit freer I would say, I was a bit freer – not when she was really, really young but just kind of maybe primary school/secondary school that sort of thing. I was a bit freer because I had family who would take over so I could do a lot more. It’s only since she’s come into adult services and then of course her sisters are older – [name] she’s got a younger sister and an older sister but what I’m saying is that obviously they themselves are older, and because they are independent which is what I was talking about earlier, they’ve got their own lives now so they’re not always in and that sort of thing.

Time 24:33

So that’s when it became more difficult for me because I would rely on them before but obviously they’ve got their own lives now so they’re out a lot, and obviously her dad, you know he’s busy as well, so it’s only kind of really hit me I would say since she’s become an adult because I’m seeing that the family support I used to have more frequently isn’t there as frequently. And so then it became quite intense for me to look after her in that way and then I realised that I can’t carry on like that, you know without having the little breaks that I need. Because she always had the support workers but obviously sometimes you want to go out in the evening or weekends and they only work sort of in the day some days. So then I realised that I need to work in breaks for myself otherwise it’s going to be too unbalanced and it will affect my caring role if I don’t take time out for myself. And so yes it’s definitely been something that I’ve learned over the years rather than I just knew. Yeah. Because obviously you get tired and over stressed and things like that, and that’s not ideal for caring for a vulnerable person. So you need to sort of balance things out and do things that will help you to feel less stressed and less tired and just take some time for you. And that feels nicer, then when you feel better you can jump back into your caring role with more efficiency I would say.

Q And have you talked to people about this, about this balance and trying to….have you talked to anyone like your GP or your partner, or friends or….

A Definitely family because they’re aware because obviously they live in the same house so they know the difficulty. So I’ve talked to family. I’ve talked to other carers because, you know we as carers are aware of what it’s like. Because everyone’s got their own family circumstance but you know at the end of the day they understand because they themselves are in their own situation. And even friends that aren’t carers, you know I’ve explained my circumstances to them, they know I’ve got a special needs daughter and they’ve seen me with her and how her needs are, so they understand too. And I also try with them to meet up with them and get breaks and stuff like that by meeting with them because that helps me because I’m kind of socializing then. It’s just that I don’t do it as often as I’d like, that’s the only thing, I’d like to do it a lot more often but because I’ve got other things to do on top of my caring role, which is the paperwork that you need to do, because there’s a lot of stuff involved around dealing with my daughter, it’s not just the physically dealing with her it’s all the other admin stuff that comes with it too and you’ve got to keep on top of that. So because I’ve got that to do as well it’s not possible at the moment for me to do the socializing bit as much as I would like to, which is why I have to take my little breaks in the way that I explained to you earlier, rather than do it more frequently with socializing.

Q What do you think needs to change to help carers of adults to feel better supported?

A Well it’s just getting the support. So for instance it’s about social services, the council, listening to families and seeing what they need individually, because each family can tell you what they need because every family circumstance is different. So it’s about the council and social services listening to families about what they need individually and putting that support in place. So for example, again fortunately we do get Direct Payments and through that I am able to enlist the help of a carer on top of the support workers that she gets, but just a carer which is very useful. But that’s only like for 2 or 3 hours in the evening. That’s only a recent thing that started in terms of me enlisting the help of a carer, but even that has been very useful.

Time 30:19

Yeah so what needs to change is just that the council needs to listen to families, find out what they want and try and give that. And I know it’s easier said than done because it’s always about resources and, you know because we are in difficult times at the moment with cuts and things like that, although that is the solution it may not always be possible because of the cuts because the funds aren’t always there, available.

Q And with your carer friends, do you talk about your mental health between you, or does it come up in conversations?

A Not in that way, you know you don’t mention it in that way. But you talk about your circumstances and your situation and then you try to help each other through that. So it’s about giving advice and information about what you have found out along the way in terms of support for your special needs person. Because people are at different stages, you’ve got parent/carers who have got children of different ages. So for example my daughter is now 23 so obviously I’ve travelled quite a long road for 23 years, somebody else might have a teenager, somebody else might have a primary school aged child. So it’s about when they talk to you about their circumstances, because you’ve already been down that road you can then say to them, ‘oh well when she was in primary I did this, I did that and I found out about this, that, that’, so it’s about sharing information from what you already know and vice versa. Because parents sort of pick up different things along the way, and what the council and social services don’t tell you very often you find out from other parent/carers.

And by doing that, that is the help that you give to each other without sort of saying it, labelling it ‘mental health’ or whatever, but you know you are giving advice, you are giving support, you are phoning up, you are texting them, and just helping them through their situation that they are going through at the moment. And you know that is where you can really life somebody up – because I’ve had that said to me that oh you know ‘you’ve been really helpful, they were ??? the help I’ve given them and told them about has really helped this and this’. And it’s about doing that for as long as you need to do that to get them through that particular circumstance because they don’t know certain information, but you’ve come across it, you know how things work so you just share that with them so that they’re able to take that on board and go down that route that you’ve already gone through. And that helps you because you think ‘oh that’s nice, I’ve helped that person, it’s great’. And you sort of feel better as well because you think ‘oh well at least they’ve been helped there so I’m glad I was able to do that for them’, because you don’t necessarily know that they’re going to take it in such a huge way, but I’ve had the experience that they have, you know taken it.

Q Do you sort of feel like that’s your role, or should there be somebody else doing that role that isn’t a family carer?

A Well yes there should be. It should be down to the council and social services, they should be doing that. But it’s not there. I mean I just don’t know why it’s not there. But it goes back to what I said in the beginning, it’s not everybody that gets the help, some people get it, others don’t for whatever reason. And you know where it’s lacking then you step in as a parent/carer and then you give it. And you give it happily because you know that you also got that help along the road. Because I did, I got lots of help from parent carers along the way, things I didn’t know and you know they shared with me and I was able to take that up and get help for my daughter. So yes somebody else should be doing it but if they’re not doing it then you do it. Because somebody has to do it and somebody has to help struggling parent carers to alleviate their stress, and in turn alleviate the stress of, you know ???

Time 35:40

Q One person we interviewed said that he felt very strongly that family members of adults with learning disabilities or special educational needs were ‘invisible and hidden’. Do you feel that?

A I think it just depends on circumstance, and it also depends on how that special needs person presents. Because some special needs people can be quite capable, even in their severity meaning if they are diagnosed as severe, some of them can be quite capable of certain things and be able to access certain things out and about in the community. Because where they might fall down in one area they might have a strength in another area, so they might be really good at something that they can then go out in the community and access and do and enjoy. And if the parent is in a position where they are able to support them in that, so for example you know if that person can drive them to here, there and enable them to access that; or if they can get a support worker to go with them and access that, then they can actually do things out in the community. So it just depends on circumstance and the behaviour of that special needs person.

I think that if a special needs person is severe and very behavioural, then yes I think that statement is true because you’ve got to be careful about taking them out and about if they are very severe and behavioural because then they could become very distressed out there because of all the sensory overload and you know it could mean that they then sort of have meltdowns while they’re out there and they could put themselves in danger according to how they present. So for example some of them might be runners because you know they’re fearful, they might just suddenly run, and obviously then don’t have the awareness of danger. So you have to be really careful about where you take them, knowing what their vulnerabilities are and how that might affect them and how they might behave.

So I just think it depends really. It depends on the special needs person, how they present. And also it depends on the parent, what they feel able to do. Because sometimes, you know as a parent you might not have the confidence to take your special needs person out if you feel that they will get very behavioural, and if it’s just you and them how are you going to deal with that, can you keep them safe out there. If they run can you run after them? And you know you have to think about all those things. And then if you think ‘actually no I won’t be able to manage that situation’ then it’s better to keep them in. And then if you keep them in, yeah I suppose they become invisible. But it’s trying to….yeah it’s a tricky one really because I don’t think it’s a blanket situation for everybody, there’s lots of things that depend on that, lots of things. And if you feel that your special needs person can cope out there and you’ve got the confidence to take them out and do things with them, then they’re not invisible, they’re being part of the community. You know if people stare and don’t understand and whatever, but again you’ve got the confidence to say well you don’t care if people are looking and don’t understand, whatever, you’re still going to make sure that your special needs child accesses what they enjoy, what you would like them to access, and you’re going to take them out regardless as long as you know you can keep them safe. Then they are not invisible because people are seeing them. So it just depends. It really depends on quite a number of things.

Time 40:30

Q And how do you feel about the term ‘family carer’, is that how you see yourself?

A I see myself as a parent carer because, you know I’m the parent of a daughter with special needs, so that’s how I kind of term myself as a parent carer. How do I feel about it? I don’t have a problem with it because that is what I do, that’s what I am and that’s what I do. Yeah.

Q Do you think that like GP services or mental health services should be more aware of the experiences of family or parent carers?

A Definitely. And I think that….ooh sorry, one second, one second, I just remembered….. yeah sorry about that, I had put the cake on and I was supposed to turn it off by a certain time and I’d forgotten completely about it. It’s a bit browner than I’d have it but never mind, it will be fine.

Q I hope it’s alright.

A Never mind. Sorry I’ve missed your question now.

Q It was about whether GPs and mental health services should be more aware about family carers’ experiences.

A Yes definitely. Because unless you register with your GP then they’re not going to be aware. But even sometimes when you register you still have to remind them because they don’t….I don’t know, it’s not flagged up necessarily when you contact your GP. Because the other day – well very recently, I think last week or the week before, I contacted my GP, obviously you speak to the receptionist, and I was talking to them about an issue, not to do with my daughter but with myself. And it was only when I said ‘well I’m a parent carer, my daughter’s got special needs and I’m her carer’, then they go ‘oh well, oh well we need to write that down, take that into consideration because that will make a difference’. Because I was trying to see a doctor basically, it’s very difficult seeing a doctor these days. But once I said that she said ‘oh I’ll put that in the notes and make sure that we’re aware of that’. And lo and behold I think the next week a doctor was able to ring me. But I was thinking if I hadn’t said it maybe I wouldn’t have got a doctors call because, you know they were saying that if the doctor deems that your issue is serious enough to warrant a call they’ll call you, otherwise they’ll tell you to manage it through the pharmacy or whatever it is. So I thought really they know I’m a parent carer because I did register but it obviously didn’t flag up when I was talking to the receptionist, it was only because I verbally mentioned it that she wrote it down in the notes before passing it on to try and get a doctor to ring me. So definitely there should be more awareness yes, because it makes a big difference to the type of care you need or your child needs.

Q And do you think there’s anything…I mean I don’t know if your daughter has annual health checks?

A She does yeah.

Q And do you have an equivalent assessment with the GP or an appointment?

A Sorry?

Q Do you have a health carer’s assessment with the GP in a similar way as your daughter?

Time 45:00

A Well not specifically a health carer’s assessment. But like every person who is like 40 to 74 or something is supposed to be able to have an annual health check. It doesn’t happen though because…well not with me anyway. I’ve had them but not annually – and this is even before COVID, not annually, they tend to happen every few years. And that was another point that I was raising with the nurse when I saw a nurse a couple of weeks ago. I said to her ‘I haven’t had an annual health check for a long time, it was before COVID’. And she looked it up on the record, she goes ‘oh the last one you had was 2018’. And so she kind of did one but not in a full way. I mean things change doesn’t it because we’ve had COVID now and whatever, the shortage of doctors and you know those sort of things. So before you could see….this is my particular practice, whether it is nationwide I don’t know, but before you could see a doctor for your annual health check and then the doctor could order whatever they felt was necessary, whether they felt ‘OK you should have a blood test’ so they could put that through, and then you know you’d come back later, another date, to have your blood taken by the nurses and that sort of thing.

But it’s kind of changed now, the nurses do it and they don’t have the authority to give you a general blood test, it’s only the doctors that can authorise it, and then you have to try and see a doctor. You know it’s all this very jumping through hoops now, but obviously things do change. So you have a health check but it’s not very full and it’s not because you’re a carer, it’s just you know the health check that you’re supposed to have but it’s not as regular as it should be. And then you know they might ask you a couple of questions about being a carer, but yeah. But I think you have to, again, be quite pushy to get what you want, otherwise they don’t kind of offer it to you unless you are like that. And even then she said ‘oh I’ll book you in for another one in 5 years time’. And I think well 5 years is a long time to what supposedly is an annual health check. So you know it’s not as it should be. And I won’t really be waiting 5 years, I’ll kind of contact them before then even if it’s not yearly, but maybe 3 years or something is better than 5 years, unless you know I have a particular health issue and then I can contact them a lot sooner – not that I’d want a particular health issue but I’m just saying.

Q And you’ve mentioned your small breaks and going to the gym and socializing with friends. Is there any other form of support that works for you, or any form of support that you think would be really helpful?

A Well for me, I would like to have regular sort of breaks away like for a weekend and things like that. But again it’s about having somebody there to look after my daughter. And it’s not always possible within the family because everybody’s got their own life as I said, they do their own thing so they can’t always be available the whole weekend to say they’re going to look after her. And I can get, and I have in the past got a carer in even for like 5 hours, but that’s not the whole weekend, you know it would be nice. And then there is something that you could do probably, to say put your daughter somewhere. But again, because she’s not used to doing that, she hasn’t really been put into respite all her 23 years so I would be reluctant to do that because she probably….well I don’t know how she would feel about that, sleeping somewhere for the weekend while being looked after by other people and….you know the other residents there, how will they be towards her and all that. So there’s….yeah. So I suppose the options are there but it’s whether you want to take them up or not in the way that they are there. Yeah.

Q And how do you see the future?

Time 49:52

A I would hope that more support through support workers is given, and carers, is given to my daughter so that she could be supported within the home. Because you know she’s part of the family, and being vulnerable I like to have her within the family rather than say put her into a home – meaning a care home, because I don’t really know how she would feel about that. You know obviously as a family you sort of treat your child a particular way, with love and all of that, and care, and you know them really well and you know what they like and don’t like. And even down to the food, you know she’s a big foodie, she loves to eat and you give her the foods that she likes and then you also try and keep her healthy by not feeding her certain things that might ??? And just trying to get her enough exercise, take her for walks. She goes to the gym with her support worker, she goes trampolining. So you know it’s trying to get her balanced as well in the things that she’s doing. And I don’t know if she was living in a care home how much of that she would maintain because sometimes, depending on the home, not much goes on. And you know she might be very bored then because she’s used to doing things, and not only bored but you know how you are healthy and things like that. So the future for me and ??? would be getting support within the home so that she can be looked after within the home whilst maintaining her lifestyle of doing the things that she likes to do.

Q Good. That’s nice. That’s all my questions. Is there anything you wanted to add that we haven’t talked about?

A Not that I can think of really, no.

Q Well thank you that was absolutely brilliant and it was lovely to see your daughter as well in the background. So the next part of the project….so we’ll send you the transcript like I said, but you don’t have to read it if you don’t want to, that’s fine, and then….

A I will read it.

Q And if you want to take anything out then just send it back, just highlight it and we’ll delete that, that’s not a problem at all. But then in October we are holding digital storytelling workshops, which is the next stage of the project. We have a connected academic called [name] Douglas who is really experienced at working with family carers of autistic people to created digital stories, which are about 2 or 3 minute stories from peoples’ lives. And so there will be a workshop. But it will be on a Saturday, I think they are two hour workshops, I’m not sure, I need to check that. But I will send you the information about the workshops in case you would like to take part, and they are part of the study as well.

A Yeah I will do because you know anything that will help is worth taking part in.

Q Well that’s brilliant, thank you. And if you’ve got any questions or you wanted to ask anything else just drop me an email whenever.

A OK, yeah.

Q And thank you again for what you’ve contributed, it was such an important interview.

A OK, well I’m glad to know that I was able to help in your research.

Q Really very much so. So I shall be in touch soon. And the transcript will probably take about two weeks to be typed up.

A That’s OK.

Q And [name] will be in touch to give you a voucher as well to say thank you for your time.

A Oh that’s fine yes. Thanks very much anyway.

Q OK, have a nice weekend.

A Yeah you too. Alright, bye bye.

*Interview ends at 54:00 mins.*