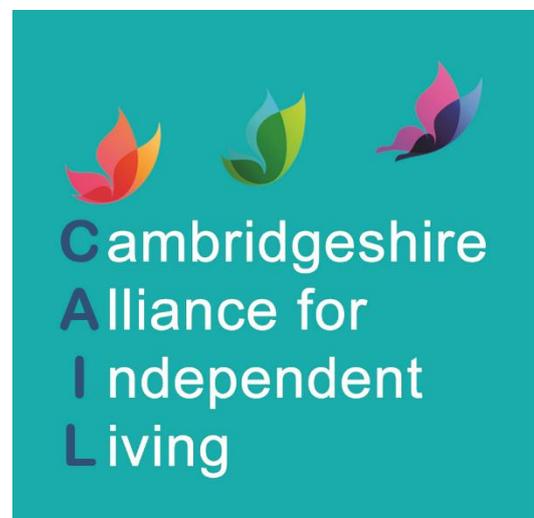


## Rachel's Story

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## Rachel's Story

**Interviewer: Addison**

**Addison:** So, can we start at the beginning and could I ask how you found out about Direct Payments and how you got into them?

**Rachel:** Well we've had Direct Payments in some sort of a form when I was ill and Jacob was in his teens. It wasn't Direct Payments then. The Children's Team handled it then. He's an adult now and he's had Direct Payments for a few years.

**Addison:** What was it like working with the Children's team?

**Rachel:** Well with the children's team it was very difficult. It took almost 3 years to get a full assessment done for Jacob They did an initial assessment in which there were mistakes and every time I contacted them they kept on saying, "Oh well, an assessment has been done." I knew they didn't have a full assessment of him because a full assessment hadn't been done. I needed one not because I needed services from them but because I needed someone to have a full record for him in case something happened to me.

Then something did happen to me, I had a serious illness. I was going into surgery with no care in place for my son. No Direct Payments at all. So, the way we got around that was that my surgeon called up Social Services and said, "I'm going to put him on the children in need register because he is a 12-year old being looked after by a 15-year-old and the mother has a long-term illness." So, they put in place four hours a week. That seemed to be a standard amount that some of his able-bodied friends were getting as well.

Nothing was offered, nothing was done. They denied that there was a Children's Care Centre somewhere where I knew there was one, with witnesses from other agencies there. So, basically they said there was nothing, no help they could give me or provide for me during this time. It would have been really helpful for 36 hours after my chemo, if my son had had somewhere to go as my daughter had to look after me. Anyway, so that was that. When he was in full-time education, there was nothing offered. I don't know what the criteria for eligibility was then when he transitioned.

When he was in his early 20's I was thinking of going back to work. We had a review with Social Services, I was going to work two days a week and they gave us the equivalent of 14 hours. It was okay. Jacob became very ill within a year of getting that package, so we continued to use that package for his

care at home. The number of hours wasn't increased, there wasn't a review that he was acutely ill, bedridden and confined to the house, but we continued to use the same number of hours care.

So, overall there are several issues for me; the lack of information at that time, I think it's better now, and the criteria for eligibility. I'd like to know what help I can expect and to know that it will be there. Then I don't have to spend so much time asking for things that maybe they're not going to provide. Just a clear idea, "This is what we do, and this is how we do it, end of story". Otherwise you're just groping in the dark asking. You might get a "Yes," or a "No," and sometimes when you get a "No," you don't get a reason why.

**Addison:** Did you ask for reasons?

**Rachel:** Yes, they kind of sort of sidestep. I think the difference came about 2 years ago or 3, just after Jacob was ill. We got a new social worker who seemed to have empathy for him and who wrote the first fully-comprehensive report on him. It took nearly 10 years within the system. You know, people would pop in for the yearly review and say, "I'm not his social worker," and then I'd think, "Why are you here?" They wouldn't improve the report and they wouldn't put more detail in. It was like, "Okay we've been to his home, we've checked, we've left."

There are other things like when Jacob started he couldn't afford in his personal contributions. From what I read the council are meant to look at hardship to see if the personal contributions are affordable or not but they just had the same hard line, "He's meant to pay £40 a week towards his personal contributions." I said, "Look, the number of expenses he has and the amount of help he needs, this is not affordable." Eventually I found out a way to do it. They sent us to the council saying, "He can get housing from the council." I turned up to the council and they said, "No, he lives with a close relative; he does not get any housing help end of story." So, what I can do is charge him rent and that's allowed towards his expenses. Now he doesn't pay a personal contribution because his total expenses outweigh his income.

To use the same formula for everyone isn't quite right. Jacob has higher care needs than most people and to get the same hourly rate isn't right. I have to employ fully-trained care workers that charge quite a lot an hour, I have no choice. I can't have students come in and I can't have neighbours or relatives look after him who don't have epilepsy training and sensory training. So, for 14 hours I can actually only buy 10 or 11. Whereas, my daughter works as a personal assistant for one of Jacob's colleagues. This young person doesn't have as high a care need, so my daughter can work for her and is paid just above minimum wage. The parent of that young person can buy more hours

than they are given, whereas I can only buy less hours than I am given and that doesn't seem to be weighted in.

**Addison:** Have you been back to Social Services and told them?

**Rachel:** No, I am waiting for a review. We have a review coming and I'll see what answer I get. Some of the other things is when definitions change. Because the definition of respite has changed. We need to be informed if that definition changed and why it's been changed. I've been categorically told, and I think it's even in Jacob's care plan from last year, that out of his Direct Payments Jacob's carers can't be paid transport. My daughter working as a personal assistant for this other young person and is paid travel expenses. It's done formally through Penderel's Trust, it's always on her statement.

**Addison:** Yes. I can see why that would be problematic and stressful if you're trying to chase people down for answers but not getting much back in return.

**Rachel:** Yeah, and sometime some people tell me they're afraid to ask in case they take something else away from you. There's that fear factor that comes from not having a clear idea of how things should be, what the definitions are, what the procedures are. I think they could make their lives easier too, almost as if they could show you a table or a chart, "Well look here, these are the things that are allowed and that's it." It'd be easier.

Now we're facing a new change as this is his last term in formal education, so it's going to be interesting to see what they will cover for the coming year or not. Jacob is capable of doing quite a lot but he needs one-on-one assistance. He's tried his hand at photography and he's quite good, he's now doing drama which is great, he'd like to continue with his one-to-one maths instruction. So, it's going to be interesting to know what it is they will provide and they won't provide.

**Addison:** So, I guess it's a lot of questions for the social worker when you have this review. It's good that you've got a date for it.

**Rachel:** Well, as they knew there was a big change coming, I've had to chase it up several times to said, "You know there is a big change coming and something needs to be done." They've assigned a social worker, so she is coming.

There are other things. I think one of the things we do have to look at is Jacob's health, to improve his immune system. I need to make sure he gets out in the pool two or three times a week. He can't coordinate to swim but he can move around in it, he does cartwheels, because at the moment his level

of activity is very low and since his last hospitalisation his mobility is even further reduced. It's going to be really important now to get him to do the things he's capable of doing and get him fitter so maybe he'll fight his illnesses better.

**Addison:** And, he'll need to be supported through Direct Payments for that?

**Rachel:** Yes. Either that or personal budget whichever way they pay it, it doesn't bother me. But, his needs must be met. Sometimes when they bring up issues I say, "Well you know, he is an adult and could be in supported living with you. Then the care laws will kick in and then he'll have to have a properly adapted house to live in and since he has epilepsy and its life-threatening you would have to pay for two carers to be on duty at any given time. Then all his activities will be covered, through experience I know some of his peers have moved out and live in supported living with a carer etc. so why are you fighting with me over little bits? Because I'm saving you maybe a quarter of a million a year." That's the figure I got from Sense website for 24-7 care. So, I'm hoping it's not going to be a fight, I'm hoping that he'll get adequate amounts of hours and care that he needs.

**Addison:** Do you feel like you know who to go to for advice and support if it does not turn out as you hope?

**Rachel:** I think Mencap because I think Sense has closed down their legal department and I think they are now coordinating with Mencap, perhaps for visibility. I find that often when you have advocates at meetings, that social workers, educators and teachers don't take them seriously at all. They just see them as some powerless person sitting there. I haven't found it made any difference having an advocate because the social workers actually have a power. I found social workers just generally disregarded them or disregarded their advice.

The other thing is we only see a social worker to do the budgeting. We see them once a year now he's older. However, when he was younger I could've done with having a proper social worker. When he was going through his terrible teens, it would have been helpful if someone actually came and did social work. Someone he could have turned to if he wasn't getting on with me and I think that's sad. It seems they are just working as administrators and not social workers.

**Addison:** You want someone to be there for the support.

**Rachel:** Yeah, that's the whole point of training to be a social worker. That's why I hear people in other services saying, "I used to be a social worker but

I've left because I was just in an adversarial position with the parents and the families and not doing any social work." They need a more clear-cut system so all the financial bits are sorted quickly and it's done aside so it can leave them free to do some social work.

If they were honest with us and if Social Services or the head of Social Services said, "Look we are doing our best to provide this and even though legally we should be providing this, that and the other but we don't have the money, the money has been spent." Then parents can go up to the government or to the local MP and say, "Why is the funding not there when there is a bicycle park and a mess being created for 40 million or something through the city. Why is this not being covered?" Then we can be active in that process. They need to be honest and say, "Right this is the best we can do." Are people afraid for their jobs and they'll lose their jobs if we speak up? I don't know. So, in some ways its unfair on the social workers, they're caught in the middle.

**Addison:** Yeah, it's important that social workers are honest with you. How have you found things like hiring carers?

**Rachel:** Well for me it has been easy because I can normally go to Carer's Trust. They were the only ones who actually replied to me. All the other agencies when I told them it was 11-12 hours a week job, none of them called back. Carer's Trust were the only ones. If they didn't exist I guess I would have had to use, I don't know... I don't even know if Social Services have their own in-house carers any more. I don't know if they all went to Carer's Trust or Crossroads. If Carer's Trust didn't exist then I could have care in but then I would have to around in case he has a seizure. I could have someone in just to get help when he's ill, to get him washed, dressed, fed and things but I would still have to be around.

And, then you can't employ a near-relative. For example, in my case I could not get my daughter. My daughter goes out to work as a nanny and as a personal assistant. So, if there weren't these restrictions then she could be his personal assistant, I could pay her. I don't think she'd like to do 11 hours a week but for a couple of hours or so. At the moment if she goes out to work I have to make sure I'm around or there's a fully-trained carer here. But, yeah you can't employ a relative. It's a lot of juggling.

**Addison:** How about things like paperwork?

**Rachel:** Carer's Trust takes care of it all for me because they're employed and I'm on a contract with them so they take care of it, thank god.

**Addison:** Is it different people each time from Carer's Trust?

**Rachel:** No, we had regular members of staff.

**Addison:** Can you tell me some of the benefits of being on Direct Payments?

**Rachel:** I think the main benefit is that we can decide when and how we need the care. Because I know the amount of hours coming in and the money I have, I can talk straight to the Carer's Trust at the office. They have a "My Roster" scheme so I can look up and see who's coming and who's not. I can look directly and get things changed if I need to. There's no third-party to go through each time. I mean I have to make sure it's someone from the team who's trained with epilepsy. I think that's the only complication.

**Addison:** Okay. What would you say to someone who is thinking about going for Direct Payments themselves?

**Rachel:** I think it depends on their circumstances really. For me using Direct Payments works well because Jacob's complicated needs means I can only employ someone through an agency like Carer's Trust. That works well for me, I can talk to them and they take care of all the paperwork. If he didn't have epilepsy and high needs then I might pay other people. For example, the young person my daughter works for I think they use Penderel's Trust. The mother does her own hiring and arranges the hours but she's quite willing and able to do that. I think it depends on your individual circumstances which way you go. For me this is the best, there's no way I would be able to advertise for private carers of the calibre that I need. So, it's good to have that flexibility the way you want to manage it. Things have improved over the last few years. And now that he's getting older it's easier to talk to social workers.

**Addison:** A lot of people say that they have to chase social workers to get them to do their annual review at the moment.

**Rachel:** Yes, I had to chase them this year. Three or four years ago they would somebody out once a year but they didn't come prepared to do an in-depth review. It was just a quick meeting in and out.

The next review is going to be interesting because one of the many things we're asking is Arts groups that have various classes. The classes aren't that expensive but what Jacob needs one-to-one support, which is a big thing. We're also at a crucial point in his life that I don't want him to get used to just being at home. He needs to have access to the community, he needs to keep on doing things. Every time he has been on a particular course it has been a challenge but he has improved. So, it shows that he is capable of learning and

maturing at his own pace. He's only young so I don't want him to withdraw from society. I doubt he'd go with me but I could go with him to all these places. I'm just not sure that he would want to go to classes with mum. Then when he gets there, I don't know whether or not he would do his best because mum is sitting there like a nanny. It's that parent-child interaction. He does do better with other people and not with us. He is more mature, takes on more responsibility. So yes, we are at a crucial point.