



## Alicia's Story

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**Interviewer: Robby**

**Robby:** So, what initially drew you to Direct Payments and how did you hear of them?

**Alicia:** Years ago, I'd been offered help, when I first moved to the county, which was more than 10 years ago. I'd been offered help through Community Support but, as time went on, they couldn't find enough people to work with Sara, my daughter, her as they need two-to-one living and handling. They asked me whether I'd consider using Direct Payments, then I could fund part of it through Community Support.

**Robby:** How did you get in touch with Community Support originally?

**Alicia:** I must have got in touch with Social Services and asked if I could have some help at home. I had a young son at the time and I wanted to spend time helping him with his homework but because of the nature of Sara's diagnosis it was difficult to concentrate on his homework. She has to have everything done for her, so it was difficult.

I approached Social Services and they said that I could have help, something like two tea-times a week. Somebody who worked for Community Support and was also a TA at Sara's school came to our house and did tea-time sessions. Then as she got older and heavier and things became more complicated, more people came in. They also worked for Community Support but people move on to do different things, they have other things going on in life and so they couldn't find enough people.

My daughter was at a special school that happened to be at the bottom of my road. As you go into school you get to know the TAs and the teachers. They liked working with Sara at school, so people started asking if they could work with Sara but they didn't want to go through Community Support. The application was so long-winded and it meant that they had to have quite a lot of training before they could get anything done. They didn't hear back quickly enough, so they didn't know whether they'd got the job or not and it took such a long time. Whereas they could ring me up, come in, I would interview them very quickly and they came recommended by other people that I already knew. There was a continuous supply so over the years as people left other people said, "Oh, well can I come and work with her?"

**Robby:** That's part of the point of Direct Payments, being able to employ people that you know, so that's perfect. So, was it the Community Support worker who told you about Direct Payments?

**Alicia:** I think it must have been the social worker who told me about it.

**Robby:** Okay. And, how did you find applying for Direct Payments and the process of actually getting them?

**Alicia:** I think the social worker arranged it. I think all I had to do was open an account and in fact looking back I'm not sure that I even needed to do that. It was very straightforward but I think I found it straightforward because in my job at the time, I worked in finance with budgets. So, anything to do with payroll and spreadsheets was just second nature and I found it very straightforward.

**Robby:** How old is Sara?

**Alicia:** She's 18 now.

**Robby:** So, she's transitioning?

**Alicia:** Yes.

**Robby:** How is that going?

**Alicia:** Well she's moved into supported living, so I've only just stopped doing Direct Payments. For me it was all very straightforward because once she'd become 18 the system would have changed slightly. I would also have had to started paying pensions which would have been fine, me actually paying pensions, but I would have had to have started setting up and doing everything that went with it. Because of timings I was legally obliged to start paying pensions and so I was able to say, "Well actually, I won't have anybody on the books by then." So, I didn't have to do it and I was just very lucky with the timing of everything.

**Robby:** So, she moved out of yours into supported living at 18. How is she finding it? How are you finding it?

**Alicia:** Well, it's very quiet at home but it's definitely the right thing for her to do I think. You know, I'm not getting any younger and I want to know that she's set up as independently as possible before I keel over. By doing it now, I can make sure that all the things she needs are in place and the people working with her now know her as a person. They know what they're supposed to be doing with her, what she likes doing, and anything that's not working properly I can get involved in it so that when I do keel over, whenever that is it, the people working with her will know her well enough and they can all work according to plan. That's the theory, we'll see.

**Robby:** Well, the health benefits of the modern age hopefully will keep us all kicking for a good few years longer.

**Alicia:** Hopefully.

**Robby:** Do, you feel like you had enough help and support through the Direct Payment process?

**Alicia:** I think that anything I wanted to know about Direct Payments or if I had a problem with it I would ring Maria, who was responsible for administrating Direct Payments for Children's Services. She was from the County Council and I'd ring her up.

I did Direct Payments the whole time through an organisation called Essex Pass who are now called Purple and it's now Purple who have the contract now, so if I wanted to I could ring them. I stayed with Essex Pass even when the County Council changed their preferred supplier. They were fine as long as you knew what you were doing. I found that because I had worked in finance anyway, if something looked wrong I would question because I would know that it looked wrong.

So, for example, they wouldn't necessarily tell you things that I think they should have told you as part of the process, like the requirement to pay holiday pay. When you first set it up it wasn't obvious, I didn't think about it as it was such a part-time job. I had lots of people working at home and some of the people only worked 2 hours a fortnight towards the end. What they were earning was not very much over a month but you still had to make sure they were paid the appropriate amount of holiday pay and that would change if they worked extra hours over the school holidays. I didn't think about holiday pay at all. At Essex Pass, they didn't look at it and they didn't question why no holiday pay was being paid. I think in a company that's there to do the admin and be the payroll processor they should've automatically looked in to why it wasn't being paid.

But in all the years I did it, in all that time I think that the wrong person was paid once because they both had the same first name and it was very easy to sort it out. The holiday pay was the only real thing.

**Robby:** How did that get resolved?

**Alicia:** I just rang them up and said, "Should I be paying holiday pay?" I didn't know whether you had to work a number of hours per month to qualify for it. They said, "Yes everybody should be." So, then I got on the internet and looked. I worked out what I had to pay and I did the calculations of how much should be paid and I would submit that amount to them every month. So, for

me it was easy, it was second nature because it was what my job was. If you weren't a finance person I would think it would be more difficult.

**Robby:** Well, with organisations like Purple that should be what they're there for.

**Alicia:** They should be. They should think outside the box and that's the problem with all these things. In theory these things are very straightforward but actually unless you spend all your time questioning it yourself then it can be tricky. An organisation like Purple should be looking at what comes in. Instead of just processing it, they should be processing it and looking at it and thinking does that look right and if it doesn't they should be ringing and saying this is not right. As an employer it was my legal obligation to pay holiday pay and it would have been me who got into trouble for not paying it. It wouldn't have been them.

**Robby:** I think Purple are a bit more on it when it comes to things like that. What about your social worker? Did you have a good relationship with your social worker? Did you feel able to go to them and ask questions?

**Alicia:** Yes. I've had numerous social workers over the years. I found the first one who I met was the only one I ever had a problem with. She was very young and didn't listen to what I was saying. She misinterpreted what I was saying and then when she wrote her report the picture she was giving to the panel when I was asking for two nights help with the tea-time shift, was completely different. I still remember the report as I was annoyed about it.

My father had just died and my mum was looking after a smallholding, so there was a lot she had to do. She worked already, she did voluntary work for the local museum, so she was a busy person. She was very good at coming to help me out but she couldn't help out all the time. On the report the social worker wrote Sara's grandmother is too busy to do anything." I can't remember exactly what the terminology was but the picture that she gave was that my mum spent all her time sitting about drinking gin and tonic with people and couldn't be bothered. Really though the picture was that her husband of 45 years had just died, she was trying to keep on top of her own stuff and keep her job because she didn't have any money and she was in no position to help. So, I was annoyed about the report.

**Robby:** How did you resolve the situation?

**Alicia:** I asked if they would let me have it. I edited it and highlighted the original wording which had been put in by this girl who was very young and thought she knew everything. Then I put the truth, you know, what the sentence should have said to give the right picture. I sent it back and they accepted it.

**Robby:** And did you get another social worker after that?

**Alicia:** I think she was just there over the holidays. This girl was trying to catch up because the team were behind with getting all these things done. I was given different people subsequently and I always have really good relationships with them.

I've found out that if you communicate with them and you just tell them how it is, what you're good at, what you're not good at, what you need help for, why you need it and how you know your child will benefit from it, then they listen to what you say. So, I've never had a problem.

**Robby:** That's good to hear. So, if you wanted to start up Direct Payments again for Sara as an adult or if you had any other problems do you feel happy that you'd know where to go to talk to the right people?

**Alicia:** Yes. I mean we've still got problems with the supported living unit. The first port of call will always be to get in touch with the social worker. And, I've done that in fact this time, we've got the Safeguarding Team in.

**Robby:** How are you finding the move from Children's Services and talking to Adult Services and the Safeguarding Team?

**Alicia:** It's fine. I think you just have to find out how it all works. The people I've had to deal with are all fine. What I find difficult is finding out how all the different teams fit together because they've all got different titles. Also, they're constantly restructuring or it seems to me that they're constantly restructuring, so they're always now known as something else. You're trying to work out what that team is and who they're responsible for and then they change it.

**Robby:** Do they keep you updated with changes?

**Alicia:** I just find ways. As long as you know the name of one key person, you can ring up and say, "This is the problem, how do I sort it out?" It's the same with anything to do with health.

**Robby:** And I suppose your key person was the person within Children's Social Services?

**Alicia:** Yes. I would have various key people. So, a social worker but also quite a few people in health and then in school, and then it just evolves over time. You just have to try and remember who they are. If you can't remember but you recognise them you just have to ask them and tell them you've forgotten what their name is. I'm useless with names; I'm amazed I've remembered yours actually.

**Robby:** I'm also pretty terrible with names, ha-ha. Okay, so what sort of problems have you found using Direct Payments, and, if you did resolve them, how did you resolve them?

**Alicia:** I didn't find it difficult really. The money that came from the County Council went straight to an account controlled by Essex Pass as it was called at the time or UCPD. And so, I had nothing to do with it. All I had to do was send in timesheets and I found that quite straightforward. I don't remember having any sort of a problem with it.

The only thing that could have become a problem was the holiday pay. In fact, I've just remembered that the way I found out about it was somebody who worked for me via Direct Payments was already working for somebody else, who received Direct Payments as well. She had been asked whether she wanted her holiday pay paid on a weekly, monthly or annual basis. When she came to me next time she said, "Do we get paid holiday pay?" And I said, "I'd never even thought about it." If she hadn't of said that I would never have thought about it myself because as a parent of a profoundly-disabled child one thing you're really short of is time. You tend to do things instantly and then you're moving on to the next thing because there's so much to be dealt with. I might never have thought about it.

That's why I think the onus is on the payroll provider to check up and make sure that all this is being done correctly. It shouldn't be up the employer because you're paying for a payroll service, they should be paying holiday pay as well. Also, they shouldn't just tell you your responsibilities at the beginning but make sure that every 3 months or 6 months or once you've set it up and it's been running for a month look at it and see what's missing from it. If your job is payroll you should know that holiday pay is one of those things you should be paying and it should be obvious to them if it is not appearing on the paperwork. Then all they need to do is ring you up and explain to you how you calculate it or say, "We'll calculate it." I didn't know why it was not calculated automatically in the same way as National Insurance. I mean it's the same.

**Robby:** I'm pretty sure Purple do calculate that for you now. All that kind of stuff, holiday pay, sick pay, pensions, can be quite daunting for people and put them off Direct Payments. If someone is thinking, "My goodness I have to work out all of this for myself," then it's important to have an organisation like Purple out there to help with that.

Okay, well that all sounds good. So, how easy did you find it to do the things you wanted to do using Direct Payments? Things like hiring people?

**Alicia:** I found the hiring of people very straightforward because there was always a supply of people from the school. If somebody new joined as a TA

and liked working with Sara and needed a job, or wanted a second job, one of the existing people would say there's somebody who's looking for a couple of hours of support a week. As I had so many people working at any one time, there was always the odd back-up shift that somebody would have covered, except for if they were on holiday that week or they were on maternity leave or something. It was in the holidays that it was difficult to get people mostly because they wanted to have holidays themselves. So, I would say, "There isn't any regular work but there'll be the odd ad-hoc shift, are you interested in doing it?" And, they'd normally agree to it. Then I would say, "If an opportunity comes up I'll let you know." So, I always had somebody there ready in the background. It was never perfect but it was good enough, it worked fine.

**Robby:** Brilliant. So, what would be some of the benefits that you've found from using Direct Payments?

**Alicia:** The benefits were that I had less shifts not covered using Direct Payments than I would have done if I'd stuck with Community Support. I've just remembered, that when I first started using Direct Payments the arrangement was that 50% of the shifts would be covered by Direct Payments and 50% by Community Support. And, actually Community Support couldn't find enough people to cover 50% of the shifts. So, then the social worker got involved and agreed that some of the Community Support could be transferred over to the Direct Payments. If I had access to extra people and they didn't have anybody, I could use Direct Payments. Eventually they said, "Look you're much better at finding people than we are, especially as there's a shortage of people here."

I agreed to do the whole thing because I had control of it, I think that was the important thing. With Community Support I didn't know whether or not there would be somebody in 2 months' time. Whereas with Direct Payments I could speak to the individual and say, "Have you booked your summer holiday yet, can you do these shifts over the summer?" So, I would have most of the summer holiday organised by Easter because I needed to have a plan. I wanted to do all sorts of things with my daughter and I needed a second person for the moving and handling. If I was going to the beach and took the mobile hoist with me I needed two people, I needed myself and somebody else.

I needed to have a plan to and to get people to put it in their diary because these people who take up working via Direct Payments will often have two other jobs. Some of the TAs would have another job. They'd work their main job and then in the holidays, evenings and weekends, they'd work not just for me but for other people with children with special needs as well. So, they were juggling all these different things and if you wanted them to come and work over the holiday you'd have to get the slot in their diary. It was easier to

do the whole thing at once, than to have half of it and then find out that actually you didn't have anybody.

I had a mega spreadsheet and I'd put everything on it, it was just like being at work. I think that's why I found it easy because it was a financial thing. You needed to know the hours you had and the hours were for specific things. You had to be very organised and know how much each hour was going to cost and all the rest of it. You had to make sure you had enough money to pay for it. It's not a walk in the park if you've not done it before, especially if you're trying to juggle ten different things. But, I found it straightforward because, you know, that had been my job before so I was very fortunate really.

**Robby:** That's good. So, what advice would you have for other people thinking about using Direct Payments?

**Alicia:** I would say give it a try because it's better controlling who comes in to your house. Under Community Support sometimes it would be a Community Support worker who was employed by the county council, sometimes it would be an agency worker. What I found was that, although you would meet these people, they never just turned up for a shift as a new person; you would meet them but you would have to train them and then they might decide they didn't want to do it, they were travelling too far.

**Robby:** What was the training like?

**Alicia:** Well, they would have been trained in health and safety from a moving and handling perspective but I had to train them in how to do it specifically with my daughter. I had to go through how she liked to be fed and go through all the routine with the tea, bath, bed and everything. I got fed up with continually having to train people. Whereas if I chose who was coming in and if they were coming from school then I knew the sort of person they would be, that they would already have worked with very similar people and I knew the type of training that they would have done. Also, there was a good chance they would last longer because they would have already met Sara. She'd have been in the hall having dinner at the same time as they were working with somebody else.

So, the downside of it is that you have to find your own people. It's not always easy. I was just fortunate to be living close to the school so they could come straight from school or if they found it easy to drive to school then it was not very far just to come up to my house. However, if you've got to look for people from scratch it's a different ball game altogether. I would say if you know anybody already who you think would be good at working with your child then Direct Payments in the way forward.

Also, you can think creatively about how to use it. So, for example, I had I always wanted to take my daughter on holiday and I used to take her down to stay with an old neighbour that I used to live near, years and years ago. It became more difficult when she had to be hoisted because you need to know what you're doing and the house I was staying in wasn't set up for hoisting particularly. I only had a two-hour tea-time tea, bath and bed shift, so rather than traveling down with somebody I employed somebody via Direct Payments who I'd known in that area before and she'd known my daughter since birth. Her own daughter had had seizures as mine had seizures. So, I knew that she was able to do the job. She wasn't local to me up here but when I went on holiday she was ideal. So, you know, you just have to think outside the box.

As Sara got older and this person decided it was becoming too difficult. I then asked the social worker if I could take one of my existing Direct Payments workers and pay an overnight rate. The answer that came back was, "Yes, you can but you need to do it out of the pot that you have already." That was fine and so that's what I did.

So, you just have to be always thinking, "Well if this doesn't work, can I do it another way?" Then change the direction you're going in slightly until you've found a solution. It gets a bit tiring but you get there in the end.