



Lizzy's Story

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Interviewer: Robby

Robby: We'll start at the very beginning if that's alright. How did you hear about Direct Payments and what drew you to them?

Lizzy: My daughter was moving from Child Services to Adult Services and I had never heard of Direct Payments. However, two of the girls that were already doing her caring, who worked for the County Council, they also did some work through Direct Payments. They steered us in that direction because we wanted to keep them because Jen was really comfortable with those two particular girls.

Robby: Can I ask how you got in touch with those two girls to start with?

Lizzy: They were supplied by the County Council because Jen's only had carers since we moved into this house. Before that we've lived in council accommodation which was never adapted for us to be able to have carers. It was never safe enough for a carer to work because obviously they have to work to different guidelines with lifting and handling and that sort of thing. So, when we moved here she was awarded a certain amount of hours.

So, the two girls in question were working already for the County Council and they were assigned to us by the County Council. Then Jen had to swap from Child Services to Adult Services. The two girls that were with us only worked for Child Services through the County Council. However, they also did some work with other clients that worked through Direct Payments, so they steered us in that direction. So, we kept the girls and just paid them in a different way. One of the girls has moved on somewhere else but one of them is still here with Jen now.

Robby: That's good, that's exactly what you want to be using Direct Payments for. How did you find the transition from Child Services to Adult Services?

Lizzy: Difficult because we've never really had much to do with Social Services other than during our constant moving around the council house system. Jen's had a series of social workers assigned to her because of the fact that council wouldn't adapt the properties that we were in. Obviously, it became quite dangerous for Jen and for me. So, the occupational therapist decided to intervene and she got Social Services involved. However, when we moved in here obviously the problem was solved.

So, we didn't need a social worker and she hadn't got a social worker until she had to move from Child Services to Adult Services. They assigned her a really

nice lady to start with but Jen wasn't in need of that much help on a constant basis. I remember we were about seven or eight months in and I phoned up with a query only to be told that that lady had moved on and Jen hadn't been assigned to somebody else. I think I spoke to about four or five different people who all were happy to solve the problem but only if she was assigned to them but nobody ever seemed to know where she was supposed to be. So, that was difficult and very frustrating.

Robby: Did that hamper the Direct Payment process?

Lizzy: It didn't hamper the Direct Payment process because luckily the problem that we had wasn't anything to do directly with the Direct Payments. Actually, it was it was to do with the fact that we were using Penderel's at the time to distribute the Direct Payment and they were having a problem. They didn't seem to be spending all the money. They were paying the girls fine but the totals didn't seem to be going down. We worked a full 12 months and obviously there's a review after 12 months. When we did the review, they'd got quite a large amount of money left. I must admit because of my past career, I'd kept up to date books of everything so I knew exactly what we were spending. I'd literally almost spend every penny of the Direct Payment, only to be told at the end of the first 12 months that we'd got a huge amount left, which was ridiculous because I knew we hadn't. I don't quite know what Penderel's had done but it turned out that Jen had been awarded two weeks' worth of full respite care and they were expecting Jen to go in to some sort of respite home. However, we'd used it to pay our girls for odd mornings and afternoons rather than as a bulk item. The girls had been paid completely fine, it was worked out and the money went where it was supposed to go.

It was complicated. We had to have two meetings both with the social worker, Penderel's and myself. We had to go through the work and find out why I was saying that every penny had been spent and they were saying, "Well actually no you've got this huge amount you'll have to return to the County Council." It was resolved eventually.

Robby: Okay, so how did you find actually setting up the Direct Payments?

Lizzy: Originally that was easy. Somebody from Penderel's came out to us and Jen already had her assessment from Social Services. We got paperwork saying that she was entitled to adult Social Care. That was really easy. Social Services themselves came out twice, once when Jen was here and once when she wasn't. It was a couple of quite long, quite tedious interviews. But I mean, once they've got the information down, after that you don't have to repeat the same things every year. It's just more of a review and everything is fine. If you need something else they are possibly able to provide that something else for you, you don't have to go through all the medical history

and everything. So, like I said, setting up the Direct Payments wasn't too bad the first time. I mean, we've had massive problems with Penderel's!

Robby: Have you thought about moving on to Purple?

Lizzy: Yeah. Today I've actually spent the last time sheets to Penderel's so from next month we moved to Purple.

Robby: So, you're not actually with Purple yet?

Lizzy: No, I've had all the emails and everything. It's all pending so hopefully next month the process will be a lot easier.

Robby: Fingers crossed! Do you feel like you've had enough help and support through the process?

Lizzy: Social Services are always on the end of the phone if you've got a problem that's never been an issue. My issues have always been with Penderel's themselves. They are really hopeless at keeping you in touch with what's going on. We originally had one lady who came out who sorted everything out and was really good. I phoned up a couple of months later only to find out she'd been moved on but again, nobody really knew who our new contact was. I think the first three times I phoned over the course of a week, I asked the same question to three different people in the office and all three of them gave you completely different answers. That doesn't help.

From then on, I never got the same person on the end of the line twice, there's always different people in the office. Obviously, people move on but you never got told. They couldn't phone up and say, "Hi, can I please speak to so-and-so?". You'd phone up and you'd say who you were and say, "Can I speak to whoever?" They'd say, "What's your problem," and you'd explain a problem and they'd say, "Right you need to speak to so-and-so." So, you then get transferred and you talk to them with whatever the query was again. "Oh, I'm sorry you need to speak to somebody else." You'd perhaps find yourself saying the same things four or five times before you actually got to somebody that can actually answer the question.

So, my frustrations have always been with Penderel's. The Direct Payment side of it with Social Services has been completely fantastic, that's worked really well.

Robby: If you feel like you need to raise a query now or if problems do come up, do you feel comfortable going back to Social Services?

Lizzy: Yeah, I haven't a problem at all with Social Services. Once Jen was assigned to somebody else after the original person left and we got a proper permanent person, then everything was fine.

Robby: And, now that you're moving from Penderel's to Purple hopefully if you've a problem or a query you'll be able to give them a call.

Lizzy: That's right, exactly. Whilst I've been with Penderel's, we've had problems with tax owing and all sorts of things that the tax office has come to me for rather than going to Penderel's. When you get a letter from the tax office saying there's an outstanding tax bill, you think "Hold on a minute, why are they coming to me for this?" Now you have to make umpteen phone calls to Penderel's to get it sorted and never really get a straight answer. Then you get a phone call five days later saying, "Actually it's been sorted." But, you never find out why it wasn't sorted in the first place.

I mean, when Penderel's moved their Cambridge office they were supposed to write to everybody to tell them. I didn't get a letter to say that it had been moved or that it had been closed down. One of the girls that works for us uses Penderel's, her daughter has a disability and she gets some hours and she's another person who didn't get a letter saying that their office had closed. So, there is a complete lack of communication from Penderel's side of things. They're trusted by the council so you know you would expect them work with your best interests.

Robby: Do you feel like you have enough help and support now?

Lizzy: Well, we haven't made the transition to Purple yet so I can't judge Purple at all. I mean the guy that came out to fill the paperwork was very, very knowledgeable. He was brilliant and I've had contact with him via email since then. I've asked questions and he's been fantastic. He's answered everything, sent everything that I need so as soon as the transition is made we can crack on and get sorted.

Robby: What would you say were some of the problems you've found with Direct Payments?

Lizzy: Lack of communication more than anything. That's the main thing, the lack of communication between Penderel's and myself.

Robby: How about finding carers? You said one of the girls who was originally doing it had moved on?

Lizzy: We've been really lucky because we kept two of the girls that were working with Jen when she was in Child Services. Then one of their friends came on board too. Although at the time she was working as a teacher in a

prison she had worked with Sense in the past and just wanted to keep in touch and do a little bit of the caring side of things. One of the girls moved on moved on and again another friend of theirs said, "I'm quite happy to come in and do an evening or a morning in the holidays." Then the last lady that we employed was working with Jen in college and decided that she wanted to move into the caring side of things. We contacted loads of people that Jen had dealt with in the past through college and we picked her up through there. So yes, we've been really lucky.

I have been in touch with Penderel's with regard to advertising but before I could advertise somebody has come forward and said, "Actually we'd like to work with Jen" So, I can't say how easy or difficult it is to actually go out in the world and advertise because I genuinely don't know. It is something I will probably have to do because we've sometimes got quite big gaps in Jen's diary when people are on holiday. So, perhaps another girl on board would be handy. I'm probably going to have to advertise in the next few months.

Robby: How do you feel about the process of doing that? Do you know what you have to do?

Lizzy: No not really. I'm hoping that Purple will guide us in how we go about wording an advert.

Robby: Yes, I know that they do.

Lizzy: So yes, but other than that I know nothing.

Robby: There are quite a few ways of doing it. One person we've spoken to finds all her carers through Facebook. Purple are still setting up this matching service, where they pair individual PAs with people who need them. Did your interview any of the carers?

Lizzy: Yes, they all came in to see us. The original two girls were assigned by the County Council. Obviously, they weren't employed by us because the money that Jen was getting came through the County Council so they were employed by the County Council. However, they still came in and met with myself and with Jen to start getting to know her before they took over any of her personal care. One of the girls had already worked with Jen in the past, so that was quite an easy transaction. The other two ladies came in spent time with Jen here at home before venturing into actually doing any of her personal care. So yeah, the process was quite clear.

Robby: How easy you find it to do the things that you want to do using Direct Payments?

Lizzy: Quite easy because at the end of the day the council provide the money and stipulate how it should be spent. So long as you don't go over what she's allowed to spend then there isn't a problem. We sometimes find that one of the girls can't come in of a morning but they can cover an extra evening. Sometimes you find you've got a couple of evenings that haven't been used because nobody could cover them. However, the girls are willing to come in and do an extra session during a morning or a daytime.

Robby: How easy do you find it to cover sessions if somebody rings in and says they can't do it?

Lizzy: Usually I just text the other girls and see if any of them are available to come in and if not then I do it myself. I mean this last week one of the girls has been on holiday, so we've four if not five sessions that have been empty. One of the other girls picked up an extra one. However, it's one week so I've done most of the shifts myself.

Robby: How do you find doing it yourself?

Lizzy: It can be stressful. Jen has a tendency to be rather argumentative when it's me doing anything for her, whereas with the girls she's not. I mean, if I wash her hair all hell breaks loose. The water's too hot, I've got bubbles in her eyes, I've rubbed her hair too hard, I've not used the right shampoo. You name it. I've used the wrong comb but that's typical mother and daughter stuff. You know, the normal stress of being a mum.

Robby: Sure, I can understand that. Okay what would say are the benefits of using Direct Payments that you and Jen have found?

Lizzy: It's the control. You're in control of the sort of people that you employ. Whereas, if you're going through the council and they're providing the carers and you don't have much choice. It's a case of, "Well this person is available, they're coming in then, then and then." When you're employing people yourself and using Direct Payments you have more choice.

I'm not racist in any way shape or form but Jen finds it very, very difficult to work with people that don't have a good understanding of English because her own language and her own speech sometimes can be quite underdeveloped. She has a tendency to do a run of words. She can say a whole sentence together and it'll literally sounds like one whole big long word. Then sometimes she'll talk into her chest. She finds it very difficult to understand anybody with a foreign accent. So, you've got more choice if you're employing the people directly. I'm not saying I wouldn't employ somebody from a different country. I'm saying that I would prefer them to have a good understanding of English before they came to work with Jen.

Robby: That seems quite reasonable. So, finally what advice would you have for other people using Direct Payments?

Lizzy: To go for it. Yeah, I recommend it so long as you've got a social worker that is behind you to work out everything for you and is looking out for you to start with. You've got your set plan of what hours you've got. Like I said, I've got no experience with Purple, all my experience is with Penderel's and the process to start with Penderel's was nice and easy. So, we've been lucky with regard to carers because we've not really had to advertise ourselves.

Broadly speaking it has worked. It's spent a bigger chunk of time working than it has not working. I think the thing is, so long as you keep your own records rather than just relying on other people, so long as you've got a record every month of what you've used and what you've got left, then you'll be fine.