



Heidi's Story

“Having been let down so badly by carers it’s hard to trust someone and find the right person for her really.”



Heidi's Story

Interviewer: Addison

Addison: This is all about Direct Payments, so can we go back to the beginning and ask how you find out about Direct Payments and what drew you to them?

Heidi: Well, in the beginning it was the fact that Daisy was going to respite and she was let down there. So, it was to give Daisy a break and for me to get support. I think the social worker mentioned it as the route to Direct Payments and that's when I took that step.

Addison: How did you get involved with Social Services to begin with?

Heidi: When we moved here, being a single parent, I just asked for support from Social Services. When we first moved here Daisy wasn't getting anything, so we were coming up against brick wall after brick wall and that's how we got involved with Social Services. We did a lot of complaining.

Addison: Once you got in with Social Services they were all right?

Heidi: They've had their ups and downs. Not always been as supportive as I'd have liked. But, it's been fine.

Addison: How was respite letting you down?

Heidi: Well, basically Daisy can't feed herself, so she wasn't being fed properly. Also, I was guaranteed that she would have her own room every time she went and stayed there but that wasn't the case. She wasn't being entertained or stimulated. They failed her because she wasn't getting all the care that she needed.

Addison: What did Social Services say when you brought this up?

Heidi: I was made aware of what was going on with Daisy at respite through transport. It started when they were sending Daisy out on the school transport with just a t-shirt on and on two particular occasions it was -5 and -6. The transport that we were using at this time were having to put blanket's on board for children being sent out without their coats or anything on. So, the outcome of it all was, lessons were learned and all staff were being retrained. That was the outcome.

Addison: Sounds like what you'd see on the BBC's Panorama.

Heidi: You'd be shocked. She went to two respite centers. She started off at one which was outstanding. Then the council shut that one and she got a place at a different one. The first few months were fine but then it went downhill. Once the changeover was done and the old staff had left them to get on with it, it wasn't a very good experience for Daisy at all.

Addison: So, when you found out you approached your social worker and they suggested Direct Payments?

Heidi: Yeah, she suggested it because I stopped Daisy going, which obviously you would. However, I still needed the support. I've got someone with a lot of care needs, who's nearly twenty, who still lives with me. So, that's how it came about, looking for this support but in Daisy's own home and in the local community, not being sent off. That's how we've built on it now, Daisy being cared for in her own home.

Addison: How did you find applying for Direct Payments, all the paperwork and everything?

Heidi: In the beginning it was quite easy because we had someone from Penderel's helping us and they were very supportive. The first year I had no problems. Going into the second year, Penderel's didn't let me know they didn't receive the fax timesheets so the carers didn't get paid. I got a couple of emails, one saying the fax was unreadable so I sent them another copy. On the last two occasions they emailed me after the deadline to say that couldn't issue payment. One time was because I had a margin missing, a tiny black line missing, so they didn't pay then. On those occasions my carers didn't get paid.

Then there was the change from Children's Services to Adult Services. Penderel's Trust emailed me to say the carers couldn't get paid because Daisy's an adult. So, I got onto payroll but they'd already processed the payment. Then payroll got someone to phone us who said they couldn't honor the payment. They said, "If there was a problem before the next payroll they would contact me if they couldn't pay." Well, payroll came, I sent the timesheets in perfectly, written in best handwriting all round. I got an email back after payroll closed saying they couldn't pay because they'd stopped the package.

That's when I was told we're being referred to Purple. At that time my carer was owed 64 hours. She's now been paid up to date and we're now with Purple and things are going alright. Quite smoothly. So, at the moment we've got no bad experience but we have had.

Addison: Caring is still a profession and people need to be paid for it. How did you end up paying for the carers? Was it out of your own pocket?

Heidi: I offered to pay them out of a bit of money I had at the time but they wouldn't do that. They refused because it wasn't my place or Daisy's place to pay them and it would have left us short. So, they waited. I've got good carers.

Addison: Have you had a lot of carers?

Heidi: You wouldn't believe the amount of carers we've had. I've got two good carers and I'm currently looking for another carer. Someone may be starting with Daisy soon. So yeah, two good carers out of, what, eight?

Addison: Can you tell me about the other carers you've had who have perhaps not been so good?

Heidi: Well Daisy doesn't communicate verbally. She knows what's going on, who you are, who the boiler man is but she's got the world around her. Three of the carers chose to keep Daisy in silence, not communicating, not feeling, just not getting Daisy, there wasn't a connection. Obviously the carers I've got now are there for Daisy and not for the money. It's good money to be carer but if you don't care it's not so good on the person you're caring for.

Addison: How have you found looking for and finding carers?

Heidi: Well after the respite experience a little bit harsh because the trust goes. It's a big trust thing to leave the most precious thing in your life to someone else. It's a big trust for you to go and let someone into your life and it's not so much I'm being let down, it's Daisy's being let down. It's not like Daisy can sit down and say, "Look Mum, I've had a really rubbish day." She can't say that. I'd only know that over a matter of time. It was a shock to come from somewhere where we'd had nearly 10 years of excellent care and excellent support to here. The respite care here was quite a shock. It was like going back to the stone age. It got better.

Addison: Was that since you transitioned from Child Services to Adult Services?

Heidi: Well we've only been with Purple for a little while so I can't give you a view on Adult Services. So, I couldn't give you an opinion on Purple's Adult Services really.

Addison: How was the transition with Social Services?

Heidi: Awful. Daisy was left for 8 weeks at home because her care plan didn't come right or didn't go to panel. I couldn't get carers in because the carers were still waiting on their payments to be paid. So again, for Daisy, the transitioning was really awful. We had meetings after meetings and those meetings must have been a waste of my time and everybody else's time

because what was agreed at those meetings has only just started happening. The meetings started in February and we're now in mid-May. I don't expect any service for us to come through immediately but I would have thought after months of meetings everything was set in place. Daisy was only supposed to be home a week and then start off on her adventure. I would have thought they would have got that bit right but obviously it overran. It's not like they didn't know where she was going to, where she was now or what we were going to do or anything like that. We've discussed it for six months.

Addison: Have you had a lot of different social workers?

Heidi: Phil is a very good social worker, we've had him for 4 years. Before him we had quite a few. We had four before we settled on him. Now we've got the Adult's Services social worker. And, again we only met her a few weeks so I couldn't give an opinion on how well she's going to be.

Addison: Before did you think you could approach Social Services if you had a problem?

Heidi: Oh yeah. If I had a problem even now I could still probably phone Phil. He was very committed.

Addison: What about the new social worker, do you feel she is approachable?

Heidi: So, far so good. I'm going to meet up with her next week. But again, I've not had enough contact with her to judge her, to give an opinion on really.

Addison: What would be the problems you've found with Direct Payments and how have you resolved them, if you resolved them?

Heidi: Only the payment things with Penderel's. Lucky my carers waited for the month of their wages. It was only when my carers were owed 64 hours wages and she had a landlord that we tried to chase it up. Then Children's Services and Adult Services sort of worked together to get all that solved. Which like I said, has been paid up to date and is now solved.

Addison: Frustrating at the time I imagine. Are you worried that it might happen again?

Heidi: Well no, the way Purple do it you've got a deadline but if you miss that deadline they can pay you quicker than waiting the full month. At the moment I've only submitted what we were owed from Penderel's, so I've not submitted any timesheets yet and I don't know.

Addison: Okay. How easy do you find it to do the things you want to do you on Direct Payments? Do find it easy or hard to find carers?

Heidi: Yeah, finding carers is hard. Having been let down so badly by carers it's hard to trust someone and find the right person for her really. They've got to understand the whole eye communication, her eating habits, everything. It's a lot to understand and as good as some carers are, it can still be hard getting that concept across. They just don't understand the concept of someone understanding but not communicating.

Addison: Do you do interviews with the carers?

Heidi: I've mostly stuck to people that I know. So, Daisy has her elder sister care for her on Fridays. We keep it quiet, especially because of past experiences, we do try and keep it around the family rather than rely on strangers.

Addison: What about other things? Is there anything else you use Direct Payments for? What are the benefits of Direct Payments for you?

Heidi: It gets Daisy out without me. I do get the benefit of her care in the mornings, that's beneficial. It's mostly for Daisy's benefit, to live an independent life, that's my goal for her. Even if it's a silent world or whatever the future holds for her, to live as independently as any other adult would do.

Addison: Yeah that's part of point of Direct Payments, to live independently. Well, finally what advice would you have for other people getting into Direct Payments?

Heidi: Look into it quite well first and make sure you know the people that you're employing. That's the only advice I can give. Make sure you check people out and keep checking them out while they've got your valuables really. Just keep on top of it. Make sure they're doing things correctly and do not just presume that they are.