



## Heather's Story

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**Interviewer: Addison**

**Addison:** So, as it's all about Direct Payments can we go back to the very beginning and ask you how you first heard about Direct Payments?

**Heather:** My son Lewis was seeing the educational psychologist and they asked what sort of support we get because we're originally from another country. It's just my husband myself and my two children so we don't have a big support network over here. I'd said, "We don't get a lot. We don't get him out, he doesn't get an opportunity to be independent because he doesn't get to go and stay at his grandma's or his aunts or anything like that because Lewis's autistic and got ADHD. He doesn't socialise anyway. It's really hard." So, they made a referral to the Early Learning Team and the Early Learning Team came out and we went from there.

**Addison:** So, when you got in touch with the Early Learning Team were they quite helpful?

**Heather:** Yes, they phoned Sharron, who was our support officer I suppose, for want of a better word. She came out and she met us during the holidays and she was really accommodating because it was working around my other kids. I couldn't leave the house as I was looking after them by myself during the holidays. So, she was able to come out, she worked around everything especially my little girl. We had cups of tea with her and everything. She was really good. She went through the paperwork and took time to explain things and then kept in regular contact. When the paperwork came through she phoned to say had we received it and that we had to sign it. She then did a follow-up because they do that every six months anyway.

**Addison:** So, how did you find the whole process of getting onto Direct Payments?

**Heather:** I think at the beginning we talked about setting goals and having goals for your child. We talked about what I wanted to achieve for Lewis. So, I wanted him to be more independent, I wanted him to socialise and get out into the community and have those functional and life skills. I mean, we do a certain amount with him but children are more hesitant to do it with adults than with their parents. I said, "It's just not giving him as much independence as I want to if it's either his dad or myself because he can always fall back on to us. Whereas if he has to go out and he has to manage his money and he has to speak to people. With support, that helps him." So, they were my big goals. We talked about the goals first. Sharron was really good, she sort of just asked questions and explained what she was asking and why. Then I'd answer and we did each section of the paperwork as we went through it.

**Addison:** So, you had someone there to support you with the paperwork?

**Heather:** Yes, it was good. When we first started actually getting the Direct Payments we'd gone through the payslips and stuff and how the process worked. Of course, because we hadn't done it before I must admit we did find it a bit tricky. We were late getting the first payslip in because you've obviously got to get it in by a certain date. After we got our head around what we had to do, getting the paperwork filled in and getting it sent off and stuff, it was very straightforward.

It's even easier now that we've gone through Purple. Purple were very good and came over explained it. It's an even more forward process now. But, the initial sort of getting head around doing the pay forms and stuff and getting it in and stuff was a bit...

**Addison:** Getting it all up and running?

**Heather:** Yeah, it's just being organised really and making sure you get paperwork in on time, make sure you put the right form in and all that sort of stuff really. It's just that we haven't had anything to do with it before.

**Addison:** Did you feel like you'd had enough help and support through the process?

**Heather:** Yeah. It was explained when we went through it. It was explained to us what we had to do. It wasn't until we had to go and do the first payslip ourselves and then get it through that we were worried we hadn't...

**Addison:** And this was when you were with Penderels Trust?

**Heather:** Yes, I think we were sort of a bit slow in getting in.

**Addison:** Did you have a conversation with Penderels Trust about it?

**Heather:** No, I think we did a few emails because what with both my husband and I working full-time its sometimes tricky to get through during working hours. We had emails and they did support us. We did manage to get the payslip in and stick to the dates. You get a calendar and everything that shows you all the pay dates and so that's good in that respect.

Purple came out and had another meeting obviously when it transferred over. We had another meeting again and it seems kind of, I don't know... We've been doing it for a longer time now and we've kind of got used to it but it seemed more straightforward. It didn't really seem as if there was as much paperwork. I don't know whether that was because it had been partly transferred over.

**Addison:** Well that's what you want, its meant to be to make your lives easier.

**Heather:** Yeah. So, when we transferred over we did find it a lot easier. Again, the payslips are just sent to us electronically so we can just print them out,

scan them and send them back. All of that process is really good. We can mail them but we just tend to scan them and send them back. All of that makes it easier because you can just do it, get on with it and do it all from home basically and that's much better for us.

**Addison:** If there's problems in other areas with the Direct Payments, do you feel you know where to go for help and support now?

**Heather:** Yes, we've got the contact phone numbers and if I've had an issue we either send an email or we phone.

**Addison:** Is that with the Early Learning Team again?

**Heather:** Yeah, we do phone the Early Learning Team, they're very good. But Purple are also very good. They've done a number of follow-up phone calls and again they're very really accommodating. We work during the week and trying to organise an appointment, well we often don't get home until six o'clock of an evening. Purple were really good and really flexible and would come out later in the evenings to accommodate our needs and just go through it all. They would not cause a fuss, would work around the kids and worker around the fact I had kids climbing over me.

**Addison:** Fantastic. What have been some of the problems you've found with Direct Payments and how would you say you've resolved them if you've resolved them?

**Heather:** The whole process was fine. I think the main issue for us was finding a carer, especially as it's such limited hours, Lewis has very limited hours. Getting somebody to work those really casual, really limited hours is the main issue.

**Addison:** How many hours does he have if you don't mind me asking?

**Heather:** Well it works out he gets about four hours a fortnight. So, it's not a lot. However, the flexibility is that you can use them how you need them. So, if we need to take him out for a day, if he wanted to go out for a day, we can accumulate them so we don't have to just use the four hours at once. It's really good for us as we can save them up and get him out for a day which has worked really well.

Finding a carer was quite difficult, obviously with all the correct checks and everything. But, because I work in additional needs I managed to find a carer through where I work. He does care for other people as well that have Direct Payments. So, if you can find somebody who cares for a few people then they can just schedule you in to different times then it works. But, that's been our main issue was just getting a carer and having the carer being able to work when we need him to work.

**Addison:** Has that been the same carer since you've been doing it?

**Heather:** Well the first one we had initially signed up, due to family commitments, he wasn't able to do it, as the hours tend to be on weekends or of an evening or in the holiday. So yeah, I think the carers is the issue, and speaking to other people that is an issue that people have, it's really hard to find the carers.

**Addison:** I hear a lot of problems with villages if they're more rural it makes carers very difficult to get to. But, then I was speaking to someone the other day in the city centre and they were saying it's just as difficult to get there as people don't like to travel in the centre of the towns.

**Heather:** I don't think our village is a great distance from anywhere and the carer we've got doesn't mind travelling. However, when you've got limited funds that does present a bit of a problem as well because you've got to pay your hourly rate and then you have to pay a travel rate as well because of the amount of petrol that they're using to get somewhere. That gets a bit tricky. I mean, we have to be very careful with how we use our funds.

Also, we've changed our plan a couple of times. Initially Lewis did have a portion towards a carer but then he wanted to do horse riding and that was about getting him active and keeping him energetic because obviously we struggle to keep him active as well. He likes to just isolate himself in his room and sit there and play games as teenagers do. So, it was trying to get him out and get him more active as well.

That was good, in that as long as you contact the team you can change planes. We changed it from horse riding because he got sick of that. He doesn't stick at anything for any one time. So, he did horse riding for a few months and he didn't want to do that anymore.

**Addison:** How easy did you find it to change?

**Heather:** It was okay. We just contact the Early Learning Team and then Sharron came out again and we explained to her that he doesn't want to do horse riding anymore. The problem with Lewis is he does swop and change so quickly it really is hard. That is why it's really difficult and I can't access really mainstream clubs because he just doesn't stick at it. We've tried scout groups and stuff and he's alright for a bit but then, and this is especially true if it changes to wintertime, its noisy in the halls he can't cope. So, we don't have a lot of options for things that he can access. However, he's just started doing jump club. So, we've changed the portion that we originally had for horse riding into jump club and that works really well. He really enjoys that because he enjoys trampolining.

**Addison:** That's good that you can change your plan. I have heard from other people that changing is not always the easiest thing to do.

**Heather:** Well, I just contacted the Early Learning Team and explained why I'm eager to change it. Originally, when I was setting up Lewis's plan, I did say to them at the beginning that he doesn't stick things for very long and I did ask

the question what would happen if I needed to change it, if I could change it or alter it at any time. They said yes it could be but I'd have to notify them of the change before a change can occur.

**Addison:** Any other problems that you've found particularly other than the carers? What if the carer's off on holiday or sick?

**Heather:** Yes, that is a tricky thing. That's the bit we have struggled with a little bit. because obviously I have Lewis who's in his teens and I have Lisa who's a toddler, so there's a big difference. She's quite active and trying to juggle the two becomes a bit knacker at times. If I've organised something for the carer to take him to, which you pre-warn him about, if the carer can't do it then I have to try and reschedule it or try and get somebody to look after Lisa so that I can then step in and take Lewis so he doesn't always have to miss out.

That's the difficult thing with only having a carer you know. By utilising a carer that cares for other people as well, that carer then has to fit you in. If they've got somebody else booked in or scheduled and you try to reschedule, which is what's happened this week, you know the carer was unavailable to do it because he'd already had another person booked in, which is fine. It does however, mean things are a bit tricky. This week I had to try and organise care for my daughter so that then I could step in and take Lewis

So, it kind of works. There are hiccups and then it's a matter of trying to juggle things to get around it. One issue we've found was initially doing the paperwork, making sure we keep on top of it and keeping a record of it. Because it is Direct Payments you've got your bank statements so it's easy in that respect. But, our biggest thing has been the carers and trying to get them in for the hours they have to work as well.

**Addison:** It's been solidly this one person most of the time?

**Heather:** Yes, it's just been one carer. We don't have a bucket of carers, so we literally just have this one person and it was a struggle to find this one person. I'm trying to find a youngish male. The carer he's got is early 20's so he can kind of relate to Lewis and they can go out as a mate session. He can encourage him to be sociable, encourage him to join in, encourage him to be more independent rather than his dad or I being the adult who's overseeing him and having to cue him constantly. It's about him trying to take some independent steps himself. He still needs support of course but at least he can be a bit more independent so and he enjoys it!

We access a charity group as well called Little Miracles in the local area, so they organise different activities and obviously I can't always take him to those. So, sometimes we get the carer to take him to those activities, things like sailing. He and the carer went there and at first, I weren't sure how long he'd stay because it's four hours. I didn't know whether he'd enjoy it or not but he came back and I asked him how it was and he told me it was "Epic!" So, he obviously enjoyed it.

But yeah, it was a good match. We got the carer to come around and do a little introductory thing. He came round and had a pizza night with us. We introduced it on a casual basis so that he could chat to Lewis and Lewis could meet him and that was really good. We've found it really important he does a pre-meet and he gets to meet the person. You know that if he doesn't talk to them much then you know it isn't going to work, which then presents another problem of trying to find somebody else.

**Addison:** If you had to find another carer do you think you'd struggle with that?

**Heather:** Yes, definitely because it is really difficult to find a carer with the limited hours you do get access to and with all the correct checks and things as well. I mean you can't just go and pull any body off the street because obviously you're entrusting your kids into their care so you need to make sure they've got the right paperwork and checks.

**Addison:** I think like Purple can help out with stuff like that and that should actually be built in to the Direct Payments.

**Heather:** Yes, they did mention that and at the time I said, "I did have a couple of people in mind as our original carer then fell through because of his family commitments." Then it was trying to find somebody else so we did struggle a bit. They did mention that they do have a bank of people that they can help sometimes. But again, I was trying to find Lewis a youngish male, so they could help Lewis with what he needs to do.

**Addison:** Any other problem?

**Heather:** No, I think that everyone's been really good. They always phone us back, they've been really accommodating. Because of our hours to try and catch up with people is really tricky. So, they just try and accommodate us. Then emailing and sending through all the paperwork electronically has really helped because, obviously it easier to have it stored on the computer rather than have it sitting around on a bench, especially with my kids. So yes, that's been really good and if we have any questions or concerns then we email Purple or phone them.

**Addison:** And you're happy to approach the Early Learning Team as well?

**Heather:** Yes, I've got both their numbers and they've always contacted us back. It's sometime a bit of a juggle back and forth. They phone and leave a message and I phone them and leave a message and it goes like that sometimes but we do always eventually catch up and we do always sort it out.

**Addison:** Fantastic. So, how easy do you find it to do the things you want to be doing on Direct Payments?

**Heather:** Well, as I say it's about being organised. I think it's really good for Lewis. We just need to be mindful of what we can organise for him to do, because obviously, with Lewis it's about consistency. If we chew through a big

amount of hours, that'll meant that maybe he didn't have any hours for the next month. That would sometimes presents a problem because he's seeing a lot of somebody and having a really good time and then he doesn't get to see them for a while and then he gets to see them again.

In terms of organising activity my husband and I will sit down, and if it's something through his charity group, like the sailing is really good and we've organised for him to go bowling, then it's not too bad. It's just being mindful of where they're going and what they're doing, because if it's a distance to travel then that chews up your hours in travelling. Yes, there is the child but if they're traveling then they're not actually doing an activity with the child. We try and access as much as we can fairly locally so that he's getting maximum interactive time with the carer rather than the travel side of things.

In terms of organising stuff it's not too bad, although I do struggle for him to find free groups and things that are not a big cost for Lewis to be part of in this area rather than them being further out of town. It is a bit tricky sometimes though.

**Addison:** Do you manage to get into town at all?

**Heather:** Yeah, we do but again sometimes of an evening he gets home late and by the time he gets home from school he's not overly keen to go out of an evening. We did have a sports group mentioned to us but he didn't want to go. It was a multi-sports group for additional needs but he didn't want to do that. We were going to give him a taster session but it was quite hard actually catching up with the people who ran that session. It didn't come about very well and by that time he'd lost interest so that was unfortunate.

We tend to organise our own activities or activities that have been organised through the charity group because obviously if its organised through Little Miracles they fund it or at least part fund it and so then we're just paying the care fee and the carer takes them so it's better.

**Addison:** You said your son is a teenager. I suppose transitions is not far off. Is that something you're thinking about now?

**Heather:** Yes, we really don't know what the futures gonna hold. As I said, the reason I want to get him out and be independent and away from us is a little bit because he's very attached to us as a family unit. Which is good, you know. We're a very pro-family unit but it doesn't overly help him manage his independence and his social skills. I don't think he envisages himself living anywhere else but here with my husband and I and his sister. He can't foresee a long way in the future. It would be nice for him to get out and be a bit more independent but we'll just have to see.

**Addison:** I think when I was a teenager I certainly didn't envisage living elsewhere, although, I certainly couldn't envisage living with my parents now!

**Heather:** Ha-ha, yeah. I don't think he'll want to once he gets a fair age but definitely when he grows up. When he goes through that teenage stage we'll gripe onto each other a bit but it'll be good for him. He is in some respects a very smart child and he does well at school with support. He's in his top maths group and in a mainstream school. He's quite clever, he just struggles with the social aspects like understanding instructions, especially if you have to use different strategies to what he's used to.

I'll always try and get his friends over in the holidays as he doesn't like going to their place even though the parents are great. They know him but because they've got siblings as well he doesn't like going to their house, so they always come to our house. Which is okay but it's just extra work for me in the holidays. He'll say he doesn't have any friends and I'll say, "You do!" And, he'll say "I've only got like 3 friends." And I say, "Yes it's good to have three good friends."

He doesn't like going into shops, he gets very agitated and frustrated if he has to go into a shop and he doesn't cope at all with going into really busy environments. He does come out to some restaurants with us but generally they don't tend to be overly busy. Sometimes they are but generally when we go it's not at real busy times. Otherwise he very much likes to be housebound so that's why it's really important to try and get him out.

**Addison:** And that's something the Direct Payments helps with?

**Heather:** Yes, that was the point of trying to get the carer to get him doing some activity. Plus get him active because he's very reluctant to go out and do anything with us. I suppose being a teenager he just likes to play his games and that's it. You know we do have a trampoline and he has his bike and he has things to access but he's not overly motivated.

**Addison:** Are there any other benefits of Direct Payments for you that you can think of?

**Heather:** Well, I think it works both ways. It gives us a bit of time away from him and him time to develop his independence. So, I think it's really good in that respect because it opens up that opportunity for him. And, for us it's crucial because he doesn't have an extended family network support here, so he doesn't otherwise get out and do anything.

Also, the flexibility of being able to create different plans and different packages. We used it for horse riding and then we changed it to Jump Club. I think that's really important, being able to do that because with children like Lewis they don't stick at things and if you can't change it then you're going to end up just wasting a lot of money on stuff that they can't access in the end. So, for us that's really important. Also, being able to pay people directly is really important so that we don't have to be physically managing that money.

**Addison:** That's good. So, it's flexible to meet your needs. Okay, what advice would you have for other people using Direct Payments?

**Heather:** I think it's just making sure that you really understand what you need to do. I was unsure about what to do and what I needed for my son, for example, when I was saying, "Can you change a plan?" So, I asked. You need to make sure to always ask people if they take Direct Payments before you actually do the activity as well. Because we manage the care ourselves, with the horse riding we use to write out a check and we'd get reimbursed us afterwards. I think it's good you do have that flexibility, you just need to understand and make sure that you're doing the right thing. Also, you make sure that you just are keeping a record because you've got to keep a record of where the money is being used and how it's being used.

But, it is flexible, it is worth it, it is good. For my son it is worth it. We did struggle a bit at the beginning with all the paperwork, understanding it and what we had to do with it because we hadn't done anything like it before. But like I said, now it's working, flowing a lot easier and we are understanding it a lot better. It's been of benefit to Lewis It gets him out and he can go to some of the clubs.

He can go out and do some of the things independently with his carer and he really does enjoy it. Every time he comes back I say to him how was that and he says how he got on. I get feedback from the carer to say if there was a problem or if he's had a good time or if he's had to talk him through something, like if he hasn't had enough money for something.

So yes, it is worth it, just ask questions. My advice is just asking questions, if you're unsure of something ask. If you're not sure whether it will cover a certain activity or a certain thing that you're doing then just ask because that's what I did with Lewis, I just asked. I asked if I could get an element of a carer and what I planned with the carer and then I said, "Could I use it for horse riding, if that doesn't work can I change to something else, for example the Jump Club?" And, we've stuck to that at the moment, we've stuck to the Jump Club.

**Addison:** So, a lot of positive things then?

**Heather:** Yes, it is good, it is worth it and its really supportive for people like us that don't have a chance to get our son out otherwise.

**Addison:** Any other things about Direct Payments that you want to tell me or share with me today?

**Heather:** Well, like I said we've just found that the team at Purple have been amazing. Every time I've spoken to them on the phone they've been really supportive and told us everything. Purple has been amazing, been flexible to come out and accommodate our needs. I always explain to them our situation or I say, "We're working and we can't be home at this time but we'd really, really like to talk to somebody, need to talk to somebody." And, they always find someone to accommodate our needs. So, it's really good. Just it is really

beneficial and I'd say asking questions is crucial so that you do understand it and so that you do get what you need.