



## Nicole & Kevin's Story

“I think our biggest problem which we haven't really resolved is actually finding things to spend the money on. Knowing how to use a PA and when.”



## Nicole & Kevin's Story

**Interviewer: Robby**

**Robby:** Let's start at the very beginning. How did you first hear about Direct Payments and what about Direct Payments first drew you to them?

**Nicole:** Well the social worker told us about them. I don't remember actually directly choosing to have Direct Payments.

**Kevin:** We started off looking for respite care and it turned out that, searching the web, we needed to get some sort of family assessment done from the social work team.

**Nicole:** So, we asked the social worker to come.

**Kevin:** And the social worker recommended it. We would discuss the sorts of respite we needed.

**Nicole:** He assessed our son as qualifying under the definition of a child in need and so we got a budget. The things that we got were a fortnightly Saturday morning group and holidays, one for one week in the summer and two days at Easter. Basically what was left was given to us as a direct payment. However, I have to say I don't think we got a huge amount of guidance as to how to spend that. And we've done really badly at spending it!

**Kevin:** They did tell us about it, I think it was Penderels then...

**Nicole:** Yes, and it's now Purple.

**Kevin:** I felt there was lots of support there for the admin and bureaucracy side of it but at that point we didn't sit down and try and work out what we actually needed the respite for. It's mealtimes and overnights when we find it hardest.

**Nicole:** I'm on a Facebook group of parents and carers in Cambridgeshire. There are a lot of people who employ a Personal Assistant for their child. However, our son gets home from school at about 4 o'clock, so actually there isn't much time in the evening left. We tend to give him his tea at about half past 5 and then get him ready for bed about half 7. So, there isn't time for somebody to come and do PA work. Then at the weekends we've got Saturday mornings on alternate weeks where he goes to a club that the social worker sorted out for us. Then every Sunday he goes to the gym which is something that we pay for, it's a mainstream thing.

**Kevin:** He likes it because it is very small.

**Nicole:** Although we did have a break from that. We were looking at possibly using some of the Direct Payments so he could get one-on-one support so he could go back to the gym. We had four sessions of the one-to-one but then they decided actually he could manage okay without one-on-one support. So, actually he's back in the gym without one-to-one support. However, if he has a particularly difficult week they are prepared to put in the one-to-one support on an ad-hoc basis. So, there is the possibility that we will need to dip in but it's not much each time and so far we haven't needed it. That means we're back to the point of having all this money and don't really know what to spend it on.

We've had a new social worker since the assessment because the first social worker we had was from the wrong team. The social workers were so stretched at the time. We were really lucky in fact because we got a consultant social worker to work with us, so he was basically the boss of his team. He knew what was what but he was taking early retirement due to ill health so we then got transferred to the correct team. Now we've got a senior social worker and she's really good. She has suggested a music thing that happens during the holidays. I can't remember but it's quite a lot of money per session so we've used up some of the direct payment for that. It's quite difficult to know what counts as being something we can spend Direct Payments on.

We had been planning to go to the PPP parenting course. That is there for parents whose children have additional needs. We actually needed someone to come and take care of our son while we went because it was in the evening. So, the idea was that while we went to that then the Direct Payments could pay for somebody to come and look after him. However, we didn't get on with that course and we didn't carry on with it so we are really bad at spending other people's money.

**Robby:** That's tricky because if you don't spend the Direct Payments then Social Services will take the underspend back at the end of the year.

**Nicole:** I'm guessing that they'll not give us as much next year. I don't know as we've only sent one return in so far, we haven't had it for that long. I think it's quarterly returns and we've done one quarterly return. We've not spent much since then. So, as I say, not very good at spending the money. What I think would have been better is if we'd had more of an idea what we were going to spend the money on. It's all very well saying you know that'll pay for so many hours a week but when you look at it...

We have a volunteer who comes and takes our son to the park or wherever for two hours. Again, that's once a fortnight so we arrange that so it's the

other weekend from the social club. So, we've basically got something happening every weekend.

The pressure points for us really are the holiday because as lovely as he is, he's got loads of energy, far more than we have. He doesn't seem to need as much sleep as we would like him to and we're basically running on empty by the end of the summer holidays.

**Kevin:** Or halfway through!

**Nicole:** Well yeah. So, the week of the holiday club is a little oasis really and he gets to have fun and work off some of his energy without flattening us.

**Robby:** So, the summer holidays have just gone haven't they? So did you have Direct Payments then and were you using them then?

**Nicole:** No, the holiday club is paid for directly so we don't pay for that. The Direct Payments that we get are what's left in the budget after what the social worker has arranged to have paid for.

**Robby:** Okay, so do you feel comfortable going back to social services and talking to them about this and saying, "These are our issues can you come and help us?"

**Nicole:** We had a meeting and that was when we said "We're not very good at spending this money." That was when she suggested the music thing. Anyway she made some enquiries.

**Robby:** Okay, so you've already answered this question a bit but what would be some of the problems you've found with Direct Payments and how did you resolve them?

**Nicole:** I think the main one is knowing what's allowable for what and what we can spend it on.

**Kevin:** We did use it a bit when you had to go away to look after family and I was on my own.

**Nicole:** Yeah. Last year two close family members ended up in intensive care separately for different reasons. So, I was away in connection with both of those. My parents live quite a long way away, so when my mum was in hospital I went up to see her. We got somebody to come and help A. with looking after our son so that he wasn't overwhelmed by having to be a single-parent. So, that was useful and we used the Direct Payments for that.

**Robby:** How easy did you find it to find people to come in?

**Nicole:** Well I used an agency. Somebody I know that I met is actually one of the people who runs an agency. They do babysitting, among other things. I asked that person and so that's how we found someone. That's probably easier than finding a PA because with a PA you've then got to get a DBS check. Whereas, if you go through an agency then they've already had a DBS check and also you pay by invoice.

**Kevin:** So you don't have to worry about payroll and holidays.

**Nicole:** Although, actually I used to work in accounts and I can do a payroll. Penderels are now Purple that's what they help with and that's the bit I don't need help with. I can take off tax and national insurance and keep records no problem but that's what they do so... I think our biggest problem which we haven't really resolved is actually finding things to spend the money on.

**Kevin:** Knowing how to use a PA and when. If you needed full-time support you'd really have to find somebody and bring them in but it's really just when you need them for a few hours that would help us as well as our son.

**Nicole:** It's not just about having a babysitter, although that would be respite for us so I'm not quite sure why that's not allowed.

**Kevin:** One of them said that some of that was okay but we need things for him.

**Robby:** It's about phrasing, for example ordinarily you're not allowed to get someone in to do the cleaning but you may be able to get support for help with light household duties. That's basically the same thing but it's about how you phrase it.

**Kevin:** I can't clean the house because he can't play outside on his own. So, if we get somebody in to play with him outside and then I can do the cleaning.

**Nicole:** Right, that'll be the day, ha-ha! We've got something else that we could potentially do. I think when we first got the Direct Payments we saw a list of the potential ways you can spend it and it had different groups on there. One of the things we saw at that point he wasn't old enough and so I promptly forgot it because you know, I've got too many things in my head to remember that aren't relevant. However, it is relevant now he's old enough, so we need to look into that.

However, there are all sorts of other things happening in our life that is complicating our ability to actually get down and focus on how we spend the Direct Payments. Hopefully, fingers crossed the other things will be resolved this week or next.

**Robby:** Fingers crossed. So, do you sort of feel optimistic about the future with this?

**Kevin:** I think we're going in the right direction.

**Nicole:** Yeah, I'm slightly minded to ask whether we should drop the Direct Payments and go for a full care package, so that we don't have to actually think about how we spend the money. Basically, if we have things put in place and then that would actually be easier. I know Direct Payments are supposed to be flexible but actually I'm not sure that flexibility is working all that well for us. The things that work best as far as I'm concerned are the social club and the holiday clubs and that's nothing to do with Direct Payments.

**Kevin:** They are being flexible, the music is the other side so we don't have to take it out of Direct Payments and put it back into the other side of the pot to do that.

**Nicole:** You know I can't help but think that we use the Direct Payments so infrequently that it would be better just to say, "Okay the budget is going to cover this, this, this and this. Then we don't get Direct Payments and if we want a babysitter then we pay for a babysitter." Then we don't have to worry about whether our son's getting any direct benefit from it or whether it's just because we want to go to the theatre or something.

**Robby:** Yes, you can choose either Direct Payments where you spend it yourself or you can say to the County Council right you sort it out.

**Nicole:** I think that would be easier quite frankly.

**Robby:** You can do that but the County Council are very keen on pushing Direct Payments because they've got limited resources so they want other people to do the work.

**Kevin:** I think they increased the budgets because there was going to be Direct Payments and Penderels or Purple would have to be factored in.

**Nicole:** I don't think Direct Payments works particularly well for us but people who are organised and have a PA that's if their needs are full-time. Even then it's still not going to cover that, it's one evening a week and some hours at the weekend. Also if you're employing somebody to do that, then you want them at a particular time. We're just not very organised really, that's the problem.

**Robby:** Okay. So, have there been any benefits that you've found with Direct Payments?

**Kevin:** I don't think we'd have been able to use the agency people under the Council scheme.

**Nicole:** They wouldn't pay for it, no. So, it was useful when my family were ill. However, I'm hopeful that I'm not gonna have any more family members nearly die because you know, that's not great. That's kind of extreme and it's not every day but if we had to sort out those events then it would be useful. If we'd carried on doing the parenting course then that would have been useful for that but we didn't. It's horses for courses, isn't it? I don't think it's been a massive benefit and we've still got most of the money sitting in the account.

That's another thing as well. You've got to open a new bank account and, according to the rules, it's got to have the child's name on it to actually signify that it is the direct payment money for the child. However, you can't actually open a bank account with the child's name on it, at least not the banks we tried. So, what we ended up doing was we had a joint account at our existing bank. Then via web access, because you can use internet banking, I've labelled it as our direct payment account. That is apparently okay but if we had a cheque book it wouldn't have his name on it. It doesn't have it on the debit card, so I've actually put a sticker on the debit card.

**Kevin:** So, we know which is which.

**Nicole:** So, we know that it's his account so that I don't accidentally buy my groceries with it, although I don't actually tend to carry it round with me.

**Robby:** They are bringing in a pre-payment card soon with your Direct Payment preloaded onto it. That will mean that you don't have to open a separate bank account. Hopefully that will be useful for some people. I can imagine setting up a whole new separate bank account can be tricky.

**Kevin:** I'm surprised you couldn't put a label on a bank account, I'm sure I've seen bank accounts with labels on.

**Nicole:** Yeah, business accounts you can but obviously not personal ones. But anyway, they seem to be reasonably happy with it and obviously they've put the money in it. I don't even know how much we've got in there but it's most of the money they gave us. Which is ridiculous really because we've had it for more than a year.

**Robby:** I think any underspend does go back to the Council at the end of the year.

**Nicole:** Which is fine, I don't want to spend money just for the sake of spending it. However, I also feel that we could possibly be getting more help than we are getting. As I say, the holidays are our pressure points and I think that if we

can sort out this music thing then you know that will help but we don't need Direct Payments for that. That's something the social worker could organise out of our budget without us having anything to do with it.

**Robby:** Okay. What advice would you have for any other people who are thinking about using Direct Payments?

**Nicole:** Have an idea of what you want to spend it on before you sign up to it. Discuss that with your social worker and find out if what you're thinking about is actually allowed under the scheme. If you don't have a clear idea of how you're going to spend it then it's just money sitting in an account and you might as well not have it. I think we didn't really know what we were going to do and we sort of had this idea that we'd have somebody in but you know...

**Kevin:** Until we actually sat down and worked out how and when we didn't realise how difficult it would be to make it work.

**Nicole:** Exactly. We didn't know how difficult it would be to work out when we would get somebody to come in because you have other things going on. I'll say talk to people who it's working for and find out what they're doing because we haven't really done that.