



Michelle's Story

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Michelle's Story

Interviewer: Addison

Addison: How did you first find out about Direct Payments?

Michelle: I'd heard of Direct Payments through the media and obviously hearing about Direct Payments for people with disabilities but never really considered that we were eligible or that, you know, that we would get anywhere near it. When Amy was about four our health visitor referred us to the Disabled Children's team but at that point in time she was a bit young to access any of the respite projects or anything. It just fizzled out and nothing really came of it. Then because we'd recently been doing her EHCP, several people had asked has she got a social worker? And we thought, no. And we've been struggling with her as she's been getting older it's becoming more difficult.

Addison: Sorry, what does Amy have?

Michelle: She has a rare genetic condition. It hasn't got a name. I think as far as I understand it from Unique, Unique is the rare genetic charity that we have contact with; there are only seven children identified with this condition. So it's very rare and it affects her in lots of different ways but the big umbrella title is global developmental delay. I hate that term. It's just an awful term because it's not actually what it is, it's lots of different things.

So, she's more like a six-year-old in an eleven-year old's body. So mentally her development is behind, speech and language has always been very delayed, physical disabilities. She finds running and walking and things like that quite tricky. She didn't sit up until she was two. Lots of milestones were very delayed or have never been reached. All the standard norms of development just didn't really happen with Amy.

But, she's always been in mainstream school and that's always been our decision, 'cos she's a very sociable child. She's always had lots of friends of all abilities so it's been really nice to keep her in mainstream.

When we were doing the EHCP, we referred ourselves to Social Services to see if we could get some additional support for her now she's getting to the age where things like hormones are kicking in and there's the change to secondary school. Lots of different aspects helping Amy getting a little bit more independent. All of that we needed more help with.

They then did an assessment and assessed her on a level three but felt they didn't need to have any more input on a social working side but did refer her

back to the Disabled Children's team. That's where the Direct Payments have come through.

Addison: How did you find going through the Direct Payment process?

Michelle: The lady who came out was very helpful. She came and met Amy and her younger brother who was keen to be involved in the process. I'd been posted out a pack of information prior to her arrival and it was great that she then bought that pack of information again, because actually I hadn't really had time to look at it and digest it, but I knew I had it. So, although you kind of think, "Well is there any point in sending it out beforehand?" It was actually very helpful. I flicked through it, had an idea of what she was going to talk about. Then she bought it again and then we talked about it. So that was quite helpful. Took a little while for me to understand what is classified as respite.

Addison: Sure, well I mean I've been working with people that use them of a while and I'm not sure that I fully understand it either.

Michelle: There's another mum at school who's got two children with rare genetic conditions. They have a genetic condition but they also have autism so because there's more of an identifiable label... Labelling is horrible but actually it does give you something to understand. So this other mom's like, "Well you can do this and you can do that," and I'm like, "Oh right, okay!" So, by talking to people that are also in the process it's been very helpful.

But as I say, the social worker came out and she did give me lots of information. She said, "Right, we'd like to do a split of about two thirds to respite and then a third of your budget to other activities." But for me, her being involved in other activities is a respite because it's time when I'm not dealing immediately with her behaviour. I'm not having to manage the activity to make it suitable for her and in a way differentiate everything to make it appropriate or avoiding situations because they're not appropriate. So, I would say that the project stuff she's going to go and the Sports Works programme is more of a respite because I know I can take her there, she's fully looked after, all her needs are met and it's a specialist provision. I can relax.

Addison: That's paid for through Direct Payments?

Michelle: It's paid for through part of her Direct Payments, yeah. So, that to me is more of a respite but then the other two thirds obviously they want to allocate to a PA and I find that a lot more stressful, I have to say.

Addison: Yes, there's a lot of a lot of paperwork involved in hiring a PA and that's not even, counting actually finding a PA in the first place.

Michelle: Yeah. I mean the finding of the PA. I had got somebody in mind as soon as she said it. Amy goes to Brownies and one of the Brownie leaders is a young lady, she's in the sixth form, she's just finished her A-levels and I knew she was DBS cleared. I wondered if she would like a little bit of extra cash. Amy knows her, she sees her every week, so I thought maybe that would work.

Olivia's taken her out a couple of times and they've had a fantastic time and Olivia has been brilliant. But unfortunately, because she's a sixth former, she's now going on summer holidays and actually she's going to another country with the guides to build a school. So, she's out for an entire month over the summer, which is time when Amy could go out and do things.

I've found that the part of the process of having to organise the time and then the payment part, filling out the time form and sending it in, that's not too stressful. It's been a little bit stressful getting the funds through, all this Direct Debit mandates and getting all that paid from the county.

Addison: Has there been a delay in getting them?

Michelle: We're three months in and we only received the first payment last week. So it's been really delayed.

Addison: How have you been paying Olivia's wages then?

Michelle: I've just been sending the time forms in and Purple have been holding the time forms. I say, "Can you just pay her as soon as the money comes in please? 'Cos obviously it's not fair, she's done the work, you know?"

Addison: So she wasn't getting paid then?

Michelle: I don't think she's still been paid because of the mix up with the Direct Debit mandate. That is something on my to-do list today, to phone Purple and see where that's got to.

Addison: How is she feeling about that?

Michelle: Well, she's a lovely girl but I think she was really hoping for the money to come through before she went abroad because obviously she's going with the guides. She had to raise, I don't know, I think it was about £3,500 to go. So this whatever amount that I'm gonna pay her is part of that. She wanted a little bit of money to go with. I almost feel if I knew the amount I would just pay her and then take it back out again. But, I don't actually know what the amount is because Purple is doing all the bits they have to take off, things like the workplace pension and all of that.

Addison: There is a lot to that. In fact that's what puts people off Direct Payments sometimes, the thought of being an employer. You have to have sick pay, you've got to have holiday pay, pensions and quite a bit of other stuff.

Michelle: Yeah. Well, when they gave me the three options of me work everything out myself, I was like "No!" Basically because I work, I haven't got time to do that and that's just another thing for me to do. I approached Disabled Children's team for help and support and a little bit of time back, not extra work to do. So, that was a definite no.

Then obviously with doing the other option, the second option, which is that I do part of it and I feel that bit's manageable. The initial set up has been quite manic because obviously I've had to contact the insurers and get the insurance policy sorted. We had a meeting with Purple and got all the paperwork done.

Addison: So quite a lengthy process.

Michelle: You have to have time in your day to do these things and I've found that I'm using my day off to do these things. So, it's been quite time demanding but sort of manageable at the beginning, as long as it doesn't carry on like that. I'm thinking it's just the whole setup, getting it set up. I hadn't maybe realised quite how much to do in that initial set-up.

Addison: Yeah, there's a lot to it and it's a big process.

Michelle: Yeah. And, then obviously there's the other option, which is that they do everything. But, I think that is if you're using more PAs from agencies.

Addison: That's the flipside to it, you can get the council to do everything, but then you don't get as much control.

Michelle: No and Amy doesn't necessarily know the PA. For me I think it was quite important that the PA was somebody that was accessible. Maybe somebody who's in the village or very local so they know where she knows. Not just somebody who's coming in from wherever.

Addison: And, with the County Council you're not guaranteed to have one person consistently either.

Michelle: No. And, because it's not taking her for a particular thing, for example they're not picking her up, taking her trampolining and then bringing her back, that wouldn't necessarily work. I don't know how much the PA can be involved or should be involved in organising the activity. I would assume that they don't do any of it and it's down to me to organise it all.

Addison: Well I think it's however much you want them to be involved, that's the point. You can actually have more of a conversation with your PA than someone from an agency. You can work collaboratively to come up with some sort of arrangement.

Michelle: Yeah. That has been nice with Olivia because obviously she knows Amy lives in the village. She's said, "Oh, look it's the first school fate, would Amy like to go to the fate? I'll take her down there and then if she wants to go swimming, we can get the bus and go swimming."

Again, it's not as easy as it could have been because we live in a village and there are literally about three buses on a Saturday. So, they were able to get the bus there but then they weren't able to get the bus back. I had to go and get them, so, we just had to work out timings and things. If I know I've got to do it it's fine, but it's just again another thing. Which is why, as I was saying, to take her to a club or something is more of a respite.

Addison: For adults you can use Direct Payments to pay for transport but with children that's seen as a parental responsibility so it's not something that it covers.

Michelle: That was the other thing that was confusing me. Okay the parental responsibility means I'm paying for the bus fare for Amy but it isn't my responsibility to pay for the PA, or is it? That was a bit confusing.

Addison: I must confess I am somewhat confused on that as well because I've spoken to people who do pay for their PA's transport and do pay for their miles if they drive and that does come off the Direct Payment but on the flipside, I've spoken to people don't.

Michelle: But, then if Olivia wasn't going somewhere, she's making that journey especially to take Amy on the bus, so I feel therefore I should be reimbursing her bus fare. I have to take the bus fare out of the Direct Payment but I'm obviously not taking Amy's out, just taking Olivia's out.

I've approached the pool and said, "I've got a PA bringing my daughter, do you have a special rate?" And they're like, "Yes that's fine." They just ask for a disabled plus carer. I've got a cinema card so that Amy can go in with adults for free. But, finding that information's hard enough you know. I went on a few blogs and things people had written and found out about the cinema card.

But I've tried ringing the bus company and they said, "No we don't do that, you'll have to ring the council. And I'm like, "Right okay fine." Just feels like you're going round in circles. There doesn't seem to be an easy point of information. If you've got a carer who's going to take your child on a bus, this

is what you need to do. You know, that would be very helpful, a one stop point of information. I suppose it continually changes, that's the only problem.

Addison: Do you feel you know where to go for help and information?

Michelle: Not really, not at the moment. Our social worker has unfortunately left the Disabled Children's Team so I emailed her replacement and said, "Look, I'm struggling with the PA and particularly over the summer, she's not here. And then she's going to university in September." So, I'm gonna have to find a new one. She thinks she's going to come back on weekends so it might be that we can still do it at the weekends, which is fine but I suspect that university life will take over within a short while. So, I'm thinking about October/November I'm going to be looking for a new PA. And then we start the process again and it's a bit like err, really?

Addison: Do you have anybody in mind?

Michelle: No. She was my one person. I mean, other people have said, "Oh, well what about such and such's daughter?" But they're not 18 or they're not DBS cleared. Okay, the DBS we can get over but we can't get over the 18 bit, you know.

Addison: The DBS checks should come out of Direct Payments.

Michelle: I'm happy to do that and take that out of the Direct Payment but obviously I don't want to keep doing it because that's taking money out of the Direct Payments.

Addison: You want like people who are already DBS checked really.

Michelle: Yeah. Trying to keep somebody you know. Ideally if somebody could come and take her to her swimming lesson and bring her back that would be nice. But, obviously you're dealing with a child so it wouldn't be a case of, just drop her at the door and let her go in on herself. It would have to be somebody who's happy to go in with her and make sure she gets herself dressed and things like that. So that would be more of a respite, more of a help. I'm feeling at the moment we're a long way from settled.

Addison: I think it's a continuous process as well. Things do come up even for people that have been on it for years and struggling to find PAs unfortunately is a big one that many people have mentioned to me.

Have you heard about Purple Match yet?

Michelle: No.

Addison: Purple Match is a sort of similar to a dating agency where PAs register and people looking for PAs register and they see if they're compatible for one another.

Michelle: Oh, I like that idea. Yeah I will speak to Purple later so maybe I'll mention Purple Match because I don't want to fob Olivia off yet because I've got to give her a chance. And she feels that she's going to be able to carry it on in September and we've just got to get through the summer but I'm thinking, you're not going to be coming home. She might initially but I'm thinking eventually she probably won't or not as much as she's hoping to anyway. And, when she does come home she'll want to spend time with her family and not be necessarily taking Amy out or working.

Addison: Sure. It's always very good to have a plan B in any case.

Michelle: Yeah, have a backup.

Addison: So do you feel comfortable going back to your social worker or Purple even and talking to them about advice and information? Talking to them about some of these issues you're telling me about?

Michelle: Yeah, I'm quite happy to do it. Having the time to do it is more of an issue. But, I am happy to make the phone calls and to chat about it but I think it's more the time to do it. When I did email my social worker she did mention that the allocation would have to go back to panel to be looked at if I decided to change the amounts of things I was using the Direct Payments for. So, that was just seemed like quite a lot of effort.

Addison: You can ask to have a review at any time if your needs change but then having been through the process already, then it's still quite a long process.

Michelle: Yeah exactly and if it's then going to take another three months to sort it out it just feels like is it worth it at this stage? Or do we try and persevere with it as it is for another three months and then if it's still not working in three months let's decide on something else.

Addison: Yeah, trial and error.

Michelle: Yeah.

Addison: I do know that the council are pushing for Direct Payments at the moment. You said that's the third option, the council sorts everything out. They don't want to do that. They'd much rather give the money to you and let you and Purple sort it out.

Michelle: But, you see I'm happy if they make the Direct Payment to me and I can book her on specialist sports clubs or things, then I'm happy to do that but does the money specifically have to be used for a PA?

Addison: The money has to be specifically used for whatever you've agreed to use it for with you and Social Services. You should have what's called a personal budget, which should outline what the money has to be used for.

Michelle: Yes, it does.

Addison: And when going back to Social Services, they will come and chat to you, you have to say, "Well yes, I have spent the money on these things and here's the receipts."

Michelle: Yeah, I'm writing everything down. I need to speak to Social Services over the summer try and put something else in place. Maybe another club, like the Sports Works Club, if there's another option we could look at for over the summer. I could just pay for that out of the Direct Payment for the summer because I haven't got the PA sorted.

Addison: I think that's probably a good thing. Do you feel comfortable getting social service to come over and do that?

Michelle: Yeah. I'll ring Helen and see.

Addison: Is she quite receptive?

Michelle: I've not actually spoken to Helen on the phone. Angela used to be very good, she was very approachable, very friendly but I've not really spoken to Helen on the phone, it's been through emails.

Addison: There's quite a high staff turnover in Social Services teams, so often you're dealing with someone that you haven't dealt with before. So, I suppose its early days.

Michelle: Yeah, it is probably a little early to say how that relationship going but fingers crossed, I'm remaining positive.

Addison: Fingers crossed! Have you had any problems so far with Direct Payments?

Michelle: Only the not being paid bit.

Addison: Oh yeah.

Michelle: I got notice that I think it should have gone through towards the end of the month but nothing appeared in my account. I thought “Oh well I’ll leave it another seven days, maybe something’ll come through,” no nothing came through. Then I emailed them and said that the money doesn’t appear to have gone into the account? Thought maybe I’d given them the wrong account number or the wrong digit had gone in, do you know what I mean? It might have been an entering error. But they said, “No that the payment had bounced back the first time.”

Addison: Oh that’s a bit strange, did they say why?

Michelle: That was a bit strange. They didn’t say why but they were chasing it. Then, I heard nothing from them for a few more days so I chased them again and they said, “Oh no, no, no, sorry. We’re just on it. It’s now been entered manually and the payment has gone through. It should be in your account within three working days.” Right fine. So, on the third working day, no money! I thought I’ll give it another 24 hours. If it’s not in there tomorrow, back on the phone and sort it out.

Addison: So a lot of chasing then?

Michelle: Yeah, quite a bit of chasing but actually it was there the next day. So, whether the account hadn’t just quite caught up and it was in there but hadn’t shown, I don’t know. It was in there on the fourth day after that. So, I had to chase them a couple of times and as I say that was only a week or so ago so.

Addison: Okay and then Purple’s lost something?

Michelle: Now Purple has lost the Direct Debit mandate to take the money out of the account.

Addison: It sounds like one thing after, chasing one set of people and now chasing another set of people.

Michelle: Yeah. Purple did say they had the Direct Debit mandate but it obviously has been a few weeks since they had it so whether it’s got lost in the meantime I don’t know. But again, I shall be trying to chase them up this afternoon to find out what we can do. Whether I can just give them the details over the phone and they can then fill out a mandate I don’t know. But, then they won’t have my signature so I don’t know. We’ll go forwards one way or another.

Addison: Just try to do things as best you can.

Michelle: Yes, exactly. Unfortunately, I don’t have a printer at home so I can’t print stuff so I’ll have to wait until I go back to work tomorrow to print off

what is needed. So, it's going to delay the process again. We're staying positive, we're staying positive. Amy's oblivious to all of this. She just thinks, "Oh I'm going out with Olivia, it's great, fantastic," which is good. But yeah, I do feel it's a little bit of work for me at the other end.

Addison: So do you feel like it's adding too much work for you to you?

Michelle: Well, on top of my work, which is quite stressful, I basically have ignored it, which is maybe why things have taken quite so long. I've just sort of let it roll because I've been too busy with my work. Now it's the summer holidays, I'll have time to maybe focus on it a bit more but during term time it's just crazy so I haven't really had much of a chance to deal with it. The email pops up in your inbox and I think it's just spending a bit of time on it. I need to spend some time on it to plan it and manage it. Its simple things like finding bus timetables so I know what buses that are available and then plan an activity around the times that are on the bus timetable. Or trying to match up the bus timetables with swimming pool timetables and its things like, yes you can get the bus but you can't swim because there's no lanes. You know, its things like that

At the moment I haven't got a stock of things that work yet. When I've got a few activities that work and timings that work, I think life will become easier. It's like, well which one do you want to do this weekend?

Addison: It sounds like you have a plan in place though, which is good.

Michelle: I have got a plan. I haven't actioned the plan, but I have got a plan.

Addison: Okay. Well you've kind of probably answered my next question a bit already. What are some of the benefits of Direct Payments that you've found?

Michelle: Well I know the benefit is it does give me flexibility to allow Amy to do things. For example, we're trying to get her to be a bit more independence, so going on a bus is quite a big thing. Otherwise we walk out the door, we get in the car and we drive. The likelihood is that she will never drive so she's going to have to be reliant on public transport so she's got to be happy to get on a bus and pay.

Addison: Yeah, independence is important. That's what Direct Payments is all about, trying to increase independence.

Michelle: Yeah. And, obviously again, going to the swimming pool. If she goes with me then obviously I do what I need to do but if she goes with somebody else she's going to have to take herself into a changing room, get herself sorted. They might just check that her clothes are on the right way

round, that she's picked everything up as she leaves and that kind of thing. But, they're not going to go in there and help her. Little things, like if we go out for something to eat and she won't go to the toilet on her own. Well if you go out with somebody else you're going to have to go off to the toilet on your own, wash your hands, come back. She's used to mummy being there she's not as independent.

Addison: PAs can help her do that.

Michelle: I think that's fine and I'm happy for them to help her but equally because it's not a member of the family she has to think a bit more for herself, which is a good thing.

Addison: Has she already started doing that with Olivia?

Michelle: I don't know at the moment. I think it's quite early days 'cos obviously they've only been out a couple of times. Olivia's not said that they've had any issues. I've set her a little shopping task to do and given her the right amount of money to go for that shopping. I said, "Right, this is your shopping money. This is what you need to buy. If you spend it you won't have your bus fare to come home," and things like that. So, she is having the purse for the bus fare and the purse for the spending money. I took her out shopping last weekend and she wanted to pay for things, which was a good thing. But, she's still completely oblivious to how much money's she's got and what it's going to pay for.

Addison: Is it useful to have the separate purses then?

Michelle: Yeah, definitely for Amy, yeah. Definitely at this stage because I think otherwise she would just pay for stuff and she wouldn't realise she wouldn't have the money to come home again on the bus. I write it down for her as well. So it's like, "Right you're going to buy a birthday card so, birthday card is £2. You've got £2 to buy a nice birthday card." It was things like that. We'd get on the internet before she goes and we checked. I said, "Right we'll go on Asda's website. We'll see how much is a birthday card, how much was strawberry laces, how much was this," all the things that were on her list so I knew she had the right amount of money with a little bit extra to go with her. But again, that takes time and planning.

Addison: Do you think at some point you can get her involved in this planning?

Michelle: Yeah, I think as she gets a bit older you would hope that she'd be able to do it but I think as she becomes a little bit more independent then she might then find the items and say, "Right I need £2." So, the aim is to get her a lot more aware of money.

Her school are very good. They take her out, do little shopping trips to the post office and get her to buy a stamp for the office, so she's becoming more aware of using money and what coins mean and how much she needs and the fact that she needs to wait for change.

Addison: It sounds all very positive, moving towards independence.

Michelle: Yeah we're moving towards independence. It's going to be a very slow process with Amy but she is moving in the right direction.

Addison: That's good. Is there anything else about Direct Payments that you want to talk to me about today?

Michelle: No, I think we've covered most things. Was it things like, do you pay for the PAs bus fare and do you pay for expenses with the PAs? Because one of the activities the social worker suggested was get the bus and then go and have a milkshake and then get the bus back. So a very simple activity but then I'm thinking, "That's fine but am I buying the drink for the PA?" Do you know what I mean? I'm thinking, it's going to end up costing me a fortune you know.

Addison: Yeah it's a lot to think about. Are you comfortable asking Social Services about that or asking Purple about that? Saying what can Direct Payments actually pay for?

Michelle: Yeah, well I did mention it to Purple and he said it really does depend on the PA. So, if it was an agency PA I don't think I would think much about it. I would just think "Well no, you're employed, you do it." But, I suppose the pitfall of using a PA that you know is that you feel a little bit responsible for them. I feel like, well why shouldn't Olivia have a drink? You know if she came out with us I'd buy her a drink so why shouldn't she have one? But then equally I wouldn't expect her to buy her own. When she took them to the fair I tried to time it so it wasn't around the lunchtime or afternoon.

Addison: On the other side of that though it's a job and in a job you are expected to pay for your own lunch and your own drinks. You've got to be making sure she gets paid, making sure she has sick pay, holiday pay, pension, all the rest of it. I suppose you've got a set of responsibilities and she also has a set of responsibilities.

Michelle: Yeah but I think because you're obviously encouraged to use somebody that you know or that you know of that breaks down that barrier a little bit. It makes it a slightly less formal arrangement, you know. It has its positives but it also has its negatives as well. I suppose, that is something I'm struggling to get my head around.

Addison: You're really not the only one. I think literally everyone I have spoken to who has PAs has said something like that. They say "Oh this PA's lovely and such and such," then "Here's like a list of problems with them." But, it's because it's quite a personal thing. They're coming in and doing a very personal job so it is going to be a lot less formal. It is going to be a lot more personable and in any personal relationship everybody has their good points and their bad points.

Michelle: I suppose it's a bit more like a child-minder arrangement in a way. So, I'm just thinking when she was younger and at the child-minders they would take them out for the day and do things. If it was an activity so, say she took them to the cinema or something, then I would obviously pay extra for the cinema but then if she chose to take them for drinks and things, then she covered all of that. So, she obviously covered her own costs of going to the cinema and all the rest of it so maybe I should think of it a bit more like that.

Addison: Maybe, something worth thinking about anyway. I suppose it's a continuous process, continuing to think about it in certain ways.

Michelle: Yeah it is a process that I think at the moment I am struggling to get into a settled pattern.

Addison: I suppose if things don't work out, like with Olivia coming back from Uni, you may end up having to hire a PA that you don't necessarily know straight away.

Michelle: Yeah. But I think I'm definitely going to talk to Purple about Purple Match because I think that's a cracking idea. Love that idea.

I think the other problem is also times because obviously agency workers only work during the week, which for Amy, she's at school all day, then she goes to after school club and I pick her, then she has her tea. So actually, there's no time in the week you know. So the weekends actually work very well for us. Amy goes out on a Saturday afternoon or a Sunday morning or whatever. That actually has worked very well for us but obviously a lot of professional PAs might not want to do that 'cos it's obviously unsocial hours a isn't it?

Addison: I'm not sure. I think some definitely do like weekends. Then I think there's also some issues around public holidays, Easter, Christmas that sort of time. Some are really okay with it, they realise that that's sort of the territory that comes with the job, then there's others like kind of get very frustrated with it.

Michelle: What not wanting to work?

Addison: Not wanting to work over those holiday periods.

Michelle: Yeah, I hadn't even thought about those. I suppose because we've not had those yet but certainly something to consider later on. Cross that bridge when I come to it.

Addison: Oh well, fantastic. Thank you for chatting with me.

Michelle: Okay. No worries.