



Kimberly and Brian's Story

“You took me out of a home, you put me in a flat and now you've left me to die!”



Kimberly & Brian's Story

Interviewer: Addison

Addison: Okay so, as this is all about Direct Payments, let's start off by asking how did you actually find out about Direct Payments?

Kimberly: Oh, I knew about 'em years ago but haven't been using 'em for a long, long time 'cos Social Services, they kind of push it on you.

Addison: So was it Social Services who told you about them years ago?

Kimberly: Yeah.

Addison: And they've been pushing it on you now?

Kimberly: They do. They push and push and push but for many years I refused. I didn't wanna know because I was always afraid of getting in debt because there's always hidden charged with care or at least there used to be. I remember, many, many years ago, before I was getting all the care from Social Services I needed, I had to use my DLA to pay for some. I got in debt and ended up in court and had a CCJ and everything on me because I couldn't afford to pay it. There were hidden charges, like the hidden petrol change from PA's getting from one client to the next but you didn't know about that until you got the bill.

They don't do it anymore but back then, I mean you're talking ten, fifteen years ago. But, because of that I refused point blank, I didn't want Direct Payments at all I was so afraid of getting in debt.

Addison: Yeah, that's a big thing with people; you're responsible for a lot with Direct Payments.

Kimberly: Well at the moment we don't deal with this. The money goes into the Trust and they deal with it. They pay the companies; we don't know anything about money or anything like that because it's too complicated to understand. I know for a fact that Social Services don't give enough money to pay agencies properly and then they know that my agency is such and such per hour. They've just reassessed me and they've basically said we have to ask the agency to bring their prices down to meet the same prices as the ones Social Services have on their books. But they're not going to do that. So, what's the point of Direct Payments then?

Addison: Yeah, that's very true. What was it that finally convinced you to go for Direct Payments?

Kimberly: Nothing convinced me, I didn't want it. I never wanted it and I don't want it now. I had no choice in the end because all the care agencies on Social Service's books... There were so few because most care agencies won't help Social Services anymore because they won't pay 'em enough, so they can't afford to survive. So, a lot of agencies won't work with Social Services any more. The only way we could get an agency to help me was to go Direct Payments.

Addison: How have you found getting agencies to help you now you're on Direct Payments?

Kimberly: There's plenty of agencies that are willing to help you but there's not enough in the Direct Payment to pay 'em.

Addison: I think agencies pay quite competitive rates and PAs want those rates. Whilst it is a caring profession, it is also a still a profession and they need to be paid accordingly. A lot of people have said this to me, that Direct Payments don't pay enough to cover PA's fees.

Kimberly: Yeah well, we don't do have a Personal Assistant. We get care agencies because of the times I need care, I wouldn't be able to get a Personal Assistant. I don't need it all day 'cos Brian is my main carer. So, the carers only come in to help me in the morning. We have one carer in the morning to help Brian help me and then three days a week another carer comes in to help me when Brian goes and does some work. He works for 8 hours a week, so they come in to help me when he's at work. They also come in once a week for half hour, so Brian can have a half hour break. He gets a whole half hour break! A week!

Addison: I guess that must get quite tiring.

Brian: Before it used to be me working full-time and being a full-time carer. And that was even more tiring than it is now. It's still a lot of work but before it was impossible to try and keep up with it. The flat became a mess because I couldn't keep up with both at the same time.

Kimberly: I think it's all a con because you've got all these trusted people and they take the money happily from Social Services. Social Services are paying them extra money to handle the money but then they don't do anything.

So, we had a care agency where the carers weren't turning up. We tried complaining and there was even safeguards put in. But, when we asked the Trust to help us they didn't do anything. It was like, what are they being paid for? I ended up having to get my social worker involved again. So, why are

Social Services paying these people to help us when they don't do nothing?
It's a con and it's a waste of money.

Addison: You're paying them and they're not providing the service you're paying them for?

Kimberly: Yeah.

Addison: And it's not as though you can stop paying them 'cos you need the care at some point.

Kimberly: Yeah. You get a certain amount of money that goes into the budget which is for the care. Then there's another amount of money that pays for the Trust to manage the money for the care but they're also supposed to help you find care agencies and help you learn how to manage your own budget so you can be independent without their help. They're supposed to help you if there's any problem with the agency. They don't do nothing, absolutely nothing.

Addison: What did your social worker say when you brought this up to them?

Kimberly: My social worker had to step in and actually help us in the end because the Trust wasn't doing anything. So we've changed Trust but I don't know if this new Trust is going to be any different. I think it might probably be the same because they've come out and seen us to sign the paperwork to take over our Direct Payment but we've heard nothing since.

Addison: How long ago was that?

Kimberly: Couple of weeks ago now

Addison: Okay. That's, frustrating. I think they do take a little bit of time though.

Kimberly: But, they can communicate in the meantime and say what they're actually doing rather than leaving you there wondering.

Addison: Yeah, you shouldn't be the ones having to chase them; they should be coming back to you. That's quite important. Have you thought about finding your own Personal Assistants? Personal Assistants don't come in all day; they'll just come in for like an hour, two hours, whatever you need. That would be something Purple might be able to advise you on?

Brian: The thing is can PA's do everything that needs to be done, like your medication?

Kimberly: They can. I don't think it we've ever had a Personal Assistant. The difference between a Personal Assistant and care agency is just a name. The difference between it is, whereas a care agency can send lots of different carers here there and everywhere, a Personal Assistant is the same person.

Brian: Okay.

Kimberly: So, you can have a group of Personal Assistants. The problem I had was, Social Services put in things like, you had to have somebody else if someone went off sick or this or that. I don't have enough work for them to do so nobody's interested. Back before Brian moved in I was having 24-hour care, that was different. So, that live-in carer, that was a Personal Assistant.

Brian: Okay.

Kimberly: But, yeah it's not it's nice the fact that a Personal Assistant gets to know you better but you haven't got that security that a carer agency can give you. If one goes off sick or one goes on holiday you've got guarantees that somebody else will come in.

Addison: One of the things another gentleman that I interviewed said to me was that he has Personal Assistants but he's always on the books of a care agency. So, if any of his Personal Assistants do go off sick or take a holiday and there's no other PA's to cover him he can go to that agency and say "I need someone to come in today to provide my care for me." That is a potential option. I don't know if that's perhaps something you'd be interested in exploring?

Kimberly: I don't know because it's really hard with my medications, isn't it? With a care agency, no carer is allowed to come in here without shadowing first. They have to be taught how to use my nebuliser, my breathing machine. They have to be taught how to do my medications because they have to be drawn up in syringes. So, there's complications with my medications and my medical review that means that a new person walking through the door wouldn't know how to help me.

Addison: Yeah, that sounds a lot to manage.

Kimberly: Ha-ha! Yeah.

Addison: Okay. I mean, it sounds like you might be struggling. It might be something to go back to Purple and mention to them. They'll be able to give you some solid advice if you want some. I'm just thinking off the top of my head that might be a potential option.

Kimberly: Well we're new to Purple anyway. We were with Penderels Trust and they're the ones that did nothing but I'm not convinced at the moment that Purple are any better. I'll have to wait and see.

Addison: Well Purple has just won the contract so no new people are going to Penderels Trust at all. Purple have a got a lot to prove, so I think they want to be showing that they are competent otherwise when the contract comes round again the Country Council will just award it to someone else. So it's very important to them that they're doing the right things.

Anyway I suppose you've already answered this one a little bit but do you feel you've had enough help and support through the Direct Payment process? So support from Penderels, from your social worker, from Purple?

Kimberly: I don't know. I was always afraid of getting in debt because of the hidden charges. There's no information out there that really explains Direct Payments properly. It just says, "Oh you can have your money and you can have more independence to choose who does your care." Okay, but how do you handle the money? How do you deal with the money? How do you do all the things you're supposed to do, the paperwork, this, that and the other? We were told that Penderels Trust would help us with interviewing agencies, interviewing carers, doing this, doing that. They didn't do any of it.

We rung 'em up and said, "So, we need to interview a new care agency, are you gonna help us?" "Oh no, you just write down some questions and ask them." And, we were left to it all alone. They're being paid god knows how much a month to help you but most months they didn't have to do anything but pay the agency, which is just a Direct Payment so they're doing nothing anyway. The odd time when you did need help, they still couldn't be bothered to help.

We rang up and said we had a carer who was going shopping instead of coming in to help me, refusing to come in and just going off shopping. So, I had one carer instead of two, and at that point I was supposed to have two because Brian was out working full time. So, he'd have to leave work to come and help me 'cos the other carer that was here couldn't do anything without the second carer who'd gone shopping. When we reported it to the Trust to say we'd spoken to the care agency but we're getting nowhere, the Trust did nothing.

Addison: It seems like a lot of trying to get things moving forward but a lot of getting beat backwards.

Kimberly: Yeah.

Addison: That sounds very frustrating. Do you feel able to go to your social worker about this?

Kimberly: The social worker was the only one that did help us. That was something I said to her, "What's the damn point in paying somebody else to help us? You're wasting money."

Addison: It's good that at least your social worker has been able to help you. Do you feel that you can go back to your social worker now?

Kimberly: Always. Our social worker's good, we have direct email with her so we can contact her whenever we need to.

Addison: That's good. I've heard there's quite a lot of turnover with social workers, new social workers coming in all the time. Have you had much experience with that?

Kimberly: The first one I had, she went on maternity leave and the one that took over from her I've had ever since. I think Social Services know with me that it's better to keep me with somebody I know because I get confused and then I get panicky and then I don't understand things. But, once a social worker gets to know me they know how to reassure me and make me feel safe so that I'm not panicking and freaking out. So they've worked out that it's just better to keep the same person with me.

Addison: Um, you've definitely answered this question but we'll see if there's any more. What are some of the problems that you've found with Direct Payments and how have you gone about solving them?

Kimberly: Ha-ha! Well I don't think I've found any good things about it yet.

Brian: You should flip it, what are the good things? Nothing! Ha-ha!

Kimberly: I don't think I've found anything good yet, I think it's a waste of money. You're paying Trusts to do nothing, which Social Services were doing beforehand. They have a separate team still doing it now for people who can't do Direct Payments. Whether it's just because I've had a bad experience I don't know but I haven't had a good experience yet to be able to say. So, I personally think it's a whole waste of money.

Addison: Oh dear. I suppose you haven't really found any resolution to your issues. It sounds like you keep going to these agencies and it's almost like you're hitting your head against a brick wall.

Kimberly: Yep.

Addison: Um so, how easy do you find it to do the things you want to do using Direct Payments?

Kimberly: It's a hard one to answer. How do you answer it politely? Ha-ha!

Addison: You can answer it however you like.

Kimberly: You don't have a right to a life when you're disabled. You're lucky if your basic needs get met. I get no social care help any more. I don't get help to go out anymore. I am lucky if I get the help just to have my basic needs met and we had to fight for that too. We had to get a lawyer involved and everything.

Addison: What was that about then?

Kimberly: Just so I could have a shower. I got left at one point for, what was it, four months?

Brian: Yeah I think so, or more even.

Kimberly: I had no care. I couldn't shower, I couldn't use the toilet, I was throwing myself around trying to survive. I was in and out of hospital all the time because I'd fallen and because I'd got ill. I had no help except for neighbours trying desperately to help me where they could.

The problem is the whole system's collapsed and Social Services don't have enough money to pay for the care. The care agencies can't afford to take the lower rate of money from Social Services because they're collapsing all around at the moment. Care agencies are just going bust. Then care agencies can't find carers that will stay in the job because they can't afford to pay 'em a decent wage. The whole system is collapsing.

Brian: And, that directly affects the NHS because people can't come out of the hospitals because there's not care for 'em and so it's like everything's connecting in this great big mess. But, if you think of breaking out of the cycle then what circle do you join?

Addison: So, what did your social worker say when you were having this period of no care?

Kimberly: They felt trapped because they knew I needed help. It was before Brian moved in. Brian moved over from another country so he felt trapped 'cos he was over there and couldn't do anything to help me. What had happened before I had the live-in carer, I had lots and lots of calls throughout the day so it was cheaper to put a live-in carer in. However, the live-in carer that came through the door was abusive. So, they got lots of reports from other carers

that were coming in to support me and from my mum and from neighbours about safeguardings. My social worker did an unannounced visit. She was pretending to be my friend not my social worker, to see what was going on. She saw it for herself and she left with the carer, took her to the train station. The carer was being abusive but I got left with no care. It took months to find any care to replace her. That's the system now, it's awful.

Brian: It was so bad I flew S. over to me so I could make her better before our wedding. She was going downhill. I was like "Okay, I need to do something." So I flew her out beforehand so she could get her strength back.

Kimberly: But that's the system now, there's not enough money in the bucket in Social Services to pay for care. That means all the care agencies are going bust and there's no care. Our area, where we live, it's very hard to get care to come to the centre of the town.

Brian: Because of traffic, no carer wants to fight the traffic.

Kimberly: Yeah, they don't like the traffic.

Addison: That's interesting you said that because some of the people in the more rural areas they definitely have trouble finding carers to come out to see them. I'm a bit surprised to hear that people have trouble in the centre of a town like this as well.

Kimberly: Yeah. And, the funny thing is when we talked to Purple about it; even they knew it was hard to get care for people right smack bang in the centre here because it's dealing with all the traffic. The agency we've got at the moment, we have quite a few carers that bike.

Brian: They actually provide an adapted bike for that, so if the carers want to they can bike around and they don't have to worry about trying to drive. They're just biking around; it's a lot faster for the calls.

Kimberly: It is a better idea for this kind of environment and it helps 'em get around easier. But, something's got to change within the system. Unless money is put into the system to pay the care agencies, care agencies are just gonna keep going away because they haven't got the money to continue existing and they haven't got the money to pay carers and then there's no carers.

Addison: So, do you find that you're getting enough care?

Kimberly: I personally don't. We're getting my basics met but I still feel we struggle a lot. I would like to be able to go out and get a present for my husband for his birthday or a present for Christmas without having to take him

with me to help me. I'd like to be able to do some things that, with a little help, I could just be a normal person but I can't do that because I don't have the help. I used to get two four hours days a week and then one two hour day a week. Two hours I used to get to go shopping. I don't mean shopping like to go buy clothes, I mean to go and do my regular food shopping. But now they say, "Well do it online." The two four hours I used to be able to go out and see friends and things like that. I don't get anything like that anymore.

Once upon a time the government did everything to get disabled people out of supported living, out of residential homes and get them into the community. They've done that, they've put us in the community, they've given us these adapted flats so that we can be independent; now they've taken away our care and everything so people who could work now can't work because they haven't got the care. People have become isolated in flats, whereas if they were back in the homes at least they had people to talk to. Now they're more isolated because they're on their own in the flats and are not getting the help they need. Many people going without showers, without food, without medication.

The biggest annoying thing is, most people think it's just the elderly. It's not just the elderly that are disabled and need care. There is thousands of young people, middle-aged people, all different races, colours, religions, everything, that need help. Not just the elderly! With the government right now, all you hear is, "Oh we need to look at the social care for the elderly." And it's like, "Hi, I'm here! You took me out of a home, you put me in a flat and now you've left me to die!"

Addison: That's quite upsetting.

Kimberly: But, that's the way it makes you feel because that's what they have done. They've taken you out of these secure places, promised you a better life, given it to you and then taken it all away and left you in a worse situation. We don't have the funds or even the benefits. They've been cut so much. We've literally had to go to food banks just to feed me and my husband. That's disgusting, that I am expected to go to foodbanks to survive. But, that's the world we live in now.

Everybody out there is thinking disabled people have it good and they get all this money and no, I don't. I'm lucky if I can buy the syringes to take my medication with. I'm lucky if I can put the petrol in the nice van we've been given by Mobility. I'm lucky if I'm well enough to get up because I haven't had the help and support I need. Which is a shame because if I had the support there's so much more I could do to give back to society but I can't do it because I don't have any help, because I don't matter. It's the way the world is now.

Addison: It might be the world is but it is not the way the world should be.
Everybody matters.

Kimberly: Try telling that to the people with the budgets!

Addison: I do know that social workers are very stretched.

Kimberly: I know it's not the social workers' faults because they're not got the money.

Addison: I do think they should be exploring different options to try and get the right support in place for you.

Kimberly: I don't know what other support there is to put in. I asked for a student volunteer at one point so I could get out and that comes and goes. You get a volunteer for a month or two and then they go away again. Then, if you're lucky, might get another one. If not, you just have to wait it out until someone comes along who wants to volunteer.

Addison: Yeah, I have heard student volunteers. It sounds like a good programme if it works on a regular basis.

Kimberly: But, it's not something I think that should be relied on, it's something that should complement other support that is there. But, unfortunately due to the lack of budgets from Social Services they have to rely on them.

Addison: Okay, so what advice would you have for other people using Direct Payments?

Kimberly: Don't do it. Never ever agree to it.

Addison: Well, as you said, you felt quite pressured into agreeing with.

Kimberly: Yeah. For years and years and years they tried to get me to agree to it. And for years I refused and then this time I just didn't have a choice 'cos there was just no care agencies on the books.

Addison: Have you gone back to Social Services and said, "Look, I don't want this?" Because you are entitled to go back having the Cambridgeshire County Council fund your care at any point that you want.

Kimberly: No, we didn't know that bit, did we?

Brian: No.

Addison: Yeah, that is a thing. You can call your social worker up and say, “Actually, Direct Payments, they’re not working out for me. I want to go back to Cambridgeshire County Council sorting out all my care.”

Kimberly: I think it’s a big con. I think the idea is great and if it was done properly it’d work. Problem is too many people are thinking about their own pockets and not actually what disabled people need and want.

Addison: Well that’s very sad. That’s pretty much all of my questions. The only thing left is if there is anything else that you want to tell me about Direct Payments?

Kimberly: There needs to be a lot more information out there for people. I mean, you can read reviews of people saying, “Oh yeah, it’s given me more independence, it’s done this, it’s done that.” But, it doesn’t say how, why, when. It doesn’t explain how it’s done that or why it’s done that. There’s no information out there that explains properly what you’re expected to do with independence or what companies are expected to do. And, because we don’t have the information, we rely on the social workers telling us, “Well that’s what the Trusts are supposed to help you with.” Then you go back to the Trusts and they don’t help you. So, you go back to the social workers saying they’re not helping you and the social worker has to help you. You’re going back and forth, back and forth.

There needs to be strict lines that we know and the Trusts know to make sure they’re followed, otherwise all that’s happening is Social Services are paying Trusts money to do a job they’re not doing. There needs to be proper leaflets and booklets and videos and things showing people how it can work, how it can be done. They say all the time, “Oh it gives you more independence, it gives you more choices.” How? Even now I don’t see how.

Addison: Yeah, I think, think you’re absolutely right. To some extent that’s what we’re trying to do with building this Library of Experiences. Talking to different people and seeing what they have to tell us. But you are right, there needs to be a lot more information out there and a lot clearer information as well I think. So, anything else you can think of about Direct Payments?

Kimberly: I’m afraid I don’t have any positives for you, I’ve only got negatives and I don’t think that’s what you’re after.

Addison: Negative experiences are just as valid as positive experience, if not more so. Part of what I’m doing is to pick up information from people such as yourself, so people have an idea of what it’s like from someone who’s actually been through the process. However, what I’m also doing is feeding back to the Country Council on things that people have told us. So, I think negative

experiences such as yours would be useful to feed back to the County Council and say, people have told us X, Y and Z.

Kimberly: But, where's it gonna go from the County Council? Because that's the problem, everything gets stuck at the County Council. It needs to go further than there. The people that give the money to the County Council need to hear why the County Council can't cope on the stupid little budget they've been given.

Addison: The organisation I work for facilitates the PDSI Board, which is Physical Disabilities and Sensory Disabilities board. This feeds back into into the Adults and Social Care Forum, which is a forum that governs policy and services within Cambridgeshire. I can take what you've said me, anonymise it and make sure it goes into that forum and hopefully something can get done about it there.

Kimberly: He-he! You're thinking what I'm thinking I can tell.

Brian: It is frustrating 'cos it's like nothing gets done. It's always talked about but nothing happens after they've talked about it.

Kimberly: People are only interested in the positive things; nobody wants to hear the bad. The thing is there's more bad happening and it's getting worse and worse but nobody wants to face it and deal with it. People are dying unnecessarily and it's because the help and care isn't there but all anybody does is turn a blind eye.

Brian: People are getting more disabled because they haven't had the help. They've stretched themselves too far to the point where they gain another disability 'cos they overdid it. Now they've damaged themselves even more and they can't go back to where they were. If they had the help in the first place, they wouldn't have overstretched their abilities and then made it worse. And, then it costs more money again for everybody.

Kimberly: Sad. I used to be a carer years ago and I tell you what, I would have been fired on the spot. Caring's not what it used to be, it really isn't because they're so rushed off their feet. They're trying to do so much for nothing. It's not what it used to be. I'm not saying carers are bad. They're not bad, I get a lot of nice carers but they're just so rushed off their feet.

Brian: It's not the carers themselves...

Kimberly: It's the system.

Brian: It what the agencies are forced to do.

Kimberly: For the carers but it all comes from back up at the top, doesn't it? If you follow the chain down it all comes down, whereas if you fix it up there, the good will come down and down and down and it will fix the whole system. Then it takes the pressure off the NHS and the ambulance services and all the other services that disabled people and elderly people have to rely on just to survive. And, in the long run it probably will be cheaper. But who am I? I'm just me sat here in my little flat!

I don't see it as I'm being political. I think political views to me is saying, "Get that party out and put this party in." I'm not saying that, I'm saying the government as a whole, all the parties, all together need to bang their damn heads together and wake up to reality before it's too late. I mean come on, the UN have even said that the government are discriminating against disabled people by the way they're treating them and what have they done? Nothing to change it.

Brian: What needs to happen is every single politician needs to be put in a wheelchair for a day, all at the same time.

Kimberly: Do you know, that would be the most amazing thing you could do. The people who have the power, not just the government but even people in Social Services, the people that have to make these big decisions, put them in our situation. Put them in an adapted flat in a wheelchair and tell 'em you can't get out that chair, not unless people come to the door and help you. See how they cope with what they're provided and see how they like it.

Addison: You're not the first person to suggest that. I had someone else say the exact same thing last week.

Kimberly: I remember when I was at college, which was years ago now, we did a drama performance. I did have a tutor who said, "Well you're in a wheelchair, there's nothing you could do. You're in a wheelchair, you can't act or anything else other than being a grandma." He couldn't look past the wheelchair. We did a performance piece that we had to research first, so I said to my group, "Right, I wanna ask you all a favour. I wouldn't normally ask this but I need to get a point across to this damn teacher so that he opens his eyes and realises I can play more than a damn granny." We went out for the day into town. One pretended they had a speech problem within a wheelchair and they couldn't talk. They used a board to talk with, pointing at the letters. One walked with crutches, one pretended they were deaf and would sign; luckily her mum is actually deaf so she could sign really well. We obviously had me who was just me, 'cos I couldn't be walking or anything.

We went out and we did all these things. They went into shops and cafes to see how people responded to them and how it made them feel. They came back and we all met in a pub afterwards to have a drink and food and talk

about it to work out how we were gonna put it into a performance. They said they felt ignored. Everybody talked to the carer, everybody ignored them and they felt frustrated and all of a sudden, all these other people who had never experienced it before knew how I felt. They helped me put that into a performance to show other people and it did change the attitude of the teacher.

What we were able to do as part of our performance was pick a member of the audience and bring 'em down, sit 'em in a wheelchair and start walking around them in different directions and saying all these names and the things that we had been hearing throughout that day so they got a bit of a feeling too of how it made us all feel.

I'm not saying stick politicians and social workers in a wheelchair to shout names at them. I'm saying they need to live it and see it for themselves. That is very powerful.

Addison: Yeah, I did something like that. Someone who was blind and someone who was deaf came and gave us a presentation. They had us blindfolded and gave us these great big earmuffs that block out all sound. We had to be like that for five minutes. Even just five minutes was very hard-hitting for me. So yes, I can definitely see the value in doing something like that with policymakers to help them understand a bit more.

Kimberly: Yeah. They need to understand that you can't move out of that chair. You can't use that arm, so we're gonna tape it down on the armrest or something 'cos you can't use it. Now, you gotta go make a drink, now you gotta go make your lunch. Oh no, you can't go to the toilet, you gotta wait for the carers to come, and no they're not coming for another six hours! They need to experience all that, because when you talk to them they don't understand because they don't know how it feels.