



Julie and Loran's Story

“Don't be afraid to speak up if you think they've got something wrong because although you might be paranoid, at the end of the day you know yourself best”



Julie & Loran's Story

Interviewer: Robby

Robby: As this all about Direct Payments, can we go back to the start of your story and ask how did you hear about Direct Payments and what was it about Direct Payments that drew you to them?

Julie: It must go back to Matt. Yeah, 'cos he had Direct Payments before Loran. Do you know Matt, her brother?

Robby: Yeah, the name rings a bell.

Julie: Anyway, he went to a special school and then when he was leaving school, Social Services started getting involved to find out what the plan was and how to support him. It was through him that we heard about Direct Payments. It was suggested he move to supported living accommodation, which is the same place where Loran now lives. And Matt was to move there to learn about independent living because he was desperate to leave home and become independent like everyone else. So, that's where we heard about Direct Payments.

Robby: Was that through Social Services?

Julie: Yes.

Robby: Okay. So, what first got you involved in Social Services?

Julie: Well they picked him up because he was at a special school and he was about to leave.

Robby: It was through Transitions?

Julie: That's it, I was trying to think of the word. Transitions, yes that's where he was picked up. So, it was through him I knew about it. In the meantime, Loran wasn't really known to Social Services because she went into mainstream school but she was known to education services because she had a statement and she had a lot of support at school.

Then she went to university straight from school and she had a lot of support there. That was nothing to do with Social Services, it was part of Disabled Students' Allowance. We learnt a lot about Loran when she was away, a lot of issues came up. Some of it was a good time, some of it wasn't such a good time. She had support on campus but then when she left campus, at

weekends and evenings, looking after herself, even though she was in very nice catered halls of residence, it was a struggle.

So, then she left university. She graduated. Life was a bit of a struggle and because we knew about Direct Payments we asked Social Services to come and assess her.

Loran: And I proceeded to make an interesting impression by crying and then leaving to make a sandwich because I was hungry.

Robby: Well if you're hungry, you're hungry. You've got to eat when you're hungry, very important.

Loran: Yeah it turns out the person assessing me was known to go without lunch quite regularly and that's why I hadn't left before that point.

Julie: It ended up quite a long assessment.

Loran: Yeah. It was something like three hours long.

Julie: Yeah, see that's what I always find funny when people are like, "Oh this assessment will only take like, half an hour." It never takes just half an hour with me.

Robby: No, I can't think of anybody who's Direct Payments assessment would take just half an hour.

Julie: No way.

Robby: How did you find the whole assessment generally?

Loran: If I had a desk I would head bang it right now.

Robby: Oh no.

Julie: Do you want the detail?

Robby: Yeah please.

Julie: Yeah, okay, how much do you remember?

Loran: Oh, I remember getting very annoyed with everyone.

Julie: The person who came to do the assessment; we knew of him because he had done some work with Matt years earlier in a different role and he knows an awful lot about Asperger's. So, he got the picture of what was going

on but then it was another social worker who picked it up and wrote it up. He met us once or twice but he clearly didn't understand and wasn't that particularly interested in Asperger's. And so, he suggested some ludicrously small amount of money. So, that was just outrageous. We decided what we would do is we would have to write up what daily life is like for Loran.

Loran: That was hard. You don't like confronting those parts of yourself.

Julie: So, we had to write up this document that was several pages long to explain it all, trying to emulate the way they write up social care assessments, the different categories, different areas. And eventually it was agreed that... just trying to remember, we've been through so many social workers. She was given a different social worker and I can't remember which one it was at that time.

Loran: Was that the nice one we had for a year?

Julie: It might have been her. Anyway we were given a much better personal budget in the end.

Robby: Was that due to the write up that you'd done?

Julie: Yes and they decided to re-investigate informally. They didn't have to go through any formal routes or anything. But I knew it wasn't right, so eventually it was agreed that she would have a PA. I'd worked out what we wanted to happen, how the support should work and they sat down with us and agreed it with us on a one-to-one basis. The person involved was interested and so that was alright. That went on for a while, for a few years. Then the whole thing had to be reviewed again.

Loran: So I got shifted to the Adult Autism Team.

Julie: She got shifted from the LDP to the Adult Autism Team. They put her in the LDP initially because they didn't know what to do with Asperger's. Then they put her in the Adult Autism Team and so she had to have a different social worker. This social worker, we think, was fairly new and inexperienced. She approached it all wrong and she decided before she'd even met us that Loran's personal budget was going to be slashed. We knew they were cutting down, but...

Loran: To quote one of my PAs at the time, for all the social worker could have known, I could have been talked down off the roof the night before. That's how little she knew about the situation coming into it.

Julie: I think at the end of the day what it boils down to is they got someone inexperienced involved with Loran. Loran is not straightforward, she's quite

complex. It's just one of these things. She's quite complex but this social worker was saying, "Why should I believe what you're saying? And why should I believe what the PAs are saying?" She discredited the PAs. So, I had a year of supporting the PAs because they were so upset by what they were being told, "No, no, no, you're spoiling her and giving her too much support." And, the PAs, well there was only one who really understood what was going on, so anyway...

Loran: One of which is absolutely terrifying when she's angry at someone.

Robby: Oh really?

Julie: Yeah she's a teacher.

Loran: It was never directed at me, but when it was directed at someone else it was like, "Ooh."

Julie: So, we eventually made a formal complaint because the write up that this social worker produced ignored Red2Green's recommendations, slashed her budget by 80% and completely ignored what the PAs had been saying. It was just a nonsense.

Loran: I'd be the first person to admit that cuts are going to be needed somewhere but to cut it by 80%.

Julie: So we made a formal complaint.

Robby: How did you find that? That's a lot of paperwork as well isn't it?

Julie: It wasn't too bad. I think it was more paperwork for Social Services than us.

Loran: Also, we were partially fuelled by anger at this point.

Julie: We did try to challenge the decision that had been made on her social care assessment by writing another ten-page document detailing our complaints for each point. So yes, that did involve a lot of paperwork but because no-one was listening to us we then made a formal complaint. Then we were being told, such and such a person would be involved with this we were given deadlines. We were told when they'd get back to us. That had never happened before and we'd been waiting such a long time for this assessment to happen.

Loran: I think the fact that our complaint got upheld speaks volumes about what happened.

Julie: It was all taken seriously, well it always was taken seriously but a different social worker looked at it and it was only resolved a few months ago. There were some cuts but they were done in an informed way with there being regular reviews and it was acknowledged Loran is complex. The lady who reassessed everything was a very experienced social worker.

Loran: She's great.

Julie: And, she's doing what a social worker's meant to do. She's stuck with us and she has done the regular reviews she said she would do. She's not scary; we now welcome a chat with her.

Loran: Yeah. She was also quite surprised when I was so pleased that she actually read the paperwork!

Julie: And she remembered the detail. And that was great; it was so refreshing to at last find a social worker who would give us the time of the day. But, it was just this one social worker caused a lot of damage and everything was delayed by a year so over that.

Robby: A year's a long time.

Julie: Over that time, the PAs got very disturbed and upset because this was being challenged all the time. There was a lot of confusion between them and the support staff where Loran now lives. Because no-one knew who was doing what hours when and what was still authorised.

Loran: I just got really angry with everyone because everyone was asking me questions and I think I said at some point something along the lines of, "Would you seriously expect the average service user to know their entire care plan?"

Julie: So, we were fighting on Loran's behalf. Loran was involved, she would read everything and sign but it's very painful if you're the service user and you're being challenged.

Loran: I really wanted alcohol afterwards.

Julie: She was challenged with everything because she's got a degree.

Loran: "You have a degree, why do you need help? Obviously you're intelligent enough."

Julie: We did find out one of the problems when they were doing the assessment with Social Services was social workers and their managers knew of Loran because she works for a disability organisation. Because

they've seen her in meetings and she looks well-prepared in the meetings we had to address that. We said, "That's correct but what you need to understand is the type of role she has within that organisation comes with a lot of support."

Loran: I'm supported at all times and that meeting was a meeting that I'd been to before so I knew what to expect. In fact, the social worker now says that she knows that I put on a good mask during the meetings. I mean it's actually quite funny how they think an autistic person can't hide their emotions when really we can, it's just a lot harder to maintain.

Julie: It all became very complex, very stressful but we're now in a good place with your Direct Payments, aren't we?

Loran: Yeah.

Julie: Yay! But, what about all those other poor sods who don't have family who are willing and able to fight for them?

Robby: Some people I've seen don't want to make complaints and they find making complaints quite daunting. So, that's good that you actually felt able to take that step.

Julie: Yeah, but there's so many who can't do it and they all shouldn't be put in that position.

Robby: How did you find things like paying for PAs while that you were struggling in that year?

Julie: Well there was money still coming in, so we were okay for paying them but it took a few months before it was confirmed that everything was staying as it was. They were not cutting until we'd resolved the issue. But, it took them a while to tell me so it was just kind of one month at a time, hoping that they were going to give us notice before they cut because if they had cut we would have lost the PAs we had.

Loran: If you can't guarantee stable employment then...

Julie: Then you can't guarantee you can pay them.

Robby: Yeah, it's a caring profession but with the best will in the world it's still a profession. Everyone's got bills they need to pay.

Julie: Yeah, absolutely. It was rough for the PAs because they didn't know. We lost one of them very early on because she couldn't cope with the uncertainty. The one that we've got, who we managed to hold onto, we only

just managed to hold onto her because she lives on the breadline. So, that was hard on her not really knowing from one month to the next. I was hoping they wouldn't just suddenly cut without notice but we did say to her that we are in the position that if they suddenly did cut, "We do have a bit of money, we can make sure you have a bit of notice you know, out of our own pocket."

Robby: Sure. But, that's still not a good position for you to be in and not a good position for them to have to be in either.

Julie: Not at all.

Loran: No. She was also the PA who was terrifying when she was angry. I got the impression over the years, she'd been getting very annoyed with Social Services and how they'd treated her clients.

Julie: She's very, very, very bright and she's got a psychology degree. She's just very good.

Robby: So, you've probably already answered this a bit, but do you feel you had enough help and support through the Direct Payment process?

Julie: I think, actually no because we had to challenge. We were challenging essentially all of Social Services, there was no-one there on our side.

Loran: The Red2Green people were on our side.

Julie: Yeah. The lady who knows Loran well at Red2Green, she had a whole pile of concrete evidence to back up what's wrong with Loran. So she was very good but she wasn't Social Services. We were offered support from the Cambridgeshire branch of the NAS. What was the service manager called...? Anyway, he did offer to help but I said it's alright because we felt able. It's good that he does the work he does and his colleague who's name I've forgotten. It's really, really important that they do that work and they are there and that they're still there in whatever form. But, I don't think that everyone knows about them.

I think when I said to Social Services we wanted to make a formal complaint, I was expecting a few forms to explain how the process worked and who to go to but there was nothing really. They did give us some dates about when they'd get back to us.

Robby: Did they meet those dates?

Julie: Yes they did. But, there was there was nothing about where to go for support. They should have been forthcoming with information. "You can go to these people for support to help you challenge."

Loran: Do you think that might have been that social worker's fault?

Julie: I don't know. She wasn't involved with the formal complaint. So, I was surprised how little information there was. There was no help was offered when we formally complained.

Loran: Which is worrying isn't it? Because when you get to that point then you kind of need the help.

Robby: The Head of Social Services is really pushing for more complaints at the moment. Well I mean, instead of bringing things to her through unofficial channels, she's pushing for things to go official channels.

Julie: Yes but, if people are not happy they need support to complain, whether they're formally complaining or whatever. They need to know that there's someone they can go to who can support them. When the care assessment is written up, if people not happy with it there should maybe be a leaflet that says, "You can go to these people who will help you."

Loran: "Or here is a copy of our complaints procedure."

Julie: I think that it was mentioned somewhere about formal complaints but that scares people. People should know before they even get to that stage that you can go to such and such people if you're really not happy and you're not sure what you want to do next, and then they can talk to you and help you. People need to know that about support earlier.

Robby: What about Voiceability? They're the regional advocacy service for Cambridgeshire.

Loran: I did end up engaged in the services of an advocate because of the bad social worker. The bad social worker felt crowded at the previous care assessment because it was me, my PAs, my parents and supported accommodation. So, she wanted to have a meeting with me and possibly an advocate but generally just me. I'm pretty sure the only reason she said an advocate is because you're required by law to allow a person to have an advocate with them. So, I ended up engaging the services of a Voiceability advocate for that reason. I take a long time to trust people and when a social worker is acting like that I get immensely paranoid. So, I'm going to make sure I have an advocate with me just so that I don't end up yelling, "Screw you," across table.

Julie: In fact, at the end of the day I don't think you needed her because we then went to the formal complaint and that meeting didn't happen. But yeah,

advocacy from Voiceability, absolutely! As long as people know about it early enough it's certainly a good thing to do.

Robby: Well I'd say use as many contacts as you can. So, from my own perspective, if I was having problems I would go to my colleagues.

Julie: Oh yeah absolutely. I remember using someone in an unofficial context. We knew someone in Social Services who could advise us but we had to keep that person's name out of it. But, not everyone's in that position.

Robby: No. It shouldn't be about whom you know, it should be where to go for the information.

Julie: Exactly, yeah.

Robby: Any other problems that you've had with Direct Payments?

Julie: I think that was the main one. Can you think of anything else?

Loran: You're talking to someone whose episodic memory isn't that great, and my bad memories get depressed, so....

Julie: Me too. I think that it was incredibly stressful and I have suffered in the past with serious health problems because of stress, that's an issue. One of the things that stressed me was just knowing there are others out there who don't have their families to support them and just knowing about that has stressed me a lot because that's unfair.

Loran: Mum's trying to mentor another parent carer person.

Julie: It's going well. I love helping other parents who are going through what we've been through. You know, I don't want them to go through what we've been through so I have informally mentored the odd parent. It's frustrating when they're not taking your advice but then eventually you find out they are taking your advice and they've been hugely successful and that's just fantastic.

It would be nice to think in years to come that it will be easier for someone with Asperger's to access the support they need without forever having to justify yourself. If you get a social worker who doesn't 'get it' then you have to go through it all again. Also, with autism and Asperger's you can go to all the seminars you want to but people need to live with people with Asperger's or autism to actually 'get it.' Some teachers at Loran's school just did not 'get it' and that was quite sad. But yeah, I suppose that's the nature of having Asperger's really. But no, I think that was the main thing, just that.

Robby: Sure. Well that was a big enough problem as it was and it's something you don't really want to go through. Okay so, how easy do you find it to do the things you want to do using Direct Payments?

Loran: I'm kind of looking at you for that one. Mum does all of the admin.

Julie: For us it wasn't too bad, but some of it was knowing a lot of people anyway. Like, one of Loran's PAs is married to a social worker. Though she wasn't the first one we employed, it was someone that she knew. They both used to work for Voiceability and Loran's brother knew them.

Loran: Yeah, that was interesting.

Julie: And we heard from the grapevine through the social worker that one of them was looking for work and we interviewed her and it was okay. Penderels at that time were offering support with payroll. So, it sounded okay but actually we got lucky. I don't know what it's like now because I don't think Penderels are contracted to do that anymore.

Loran: It's Purple doing it now.

Julie: Yeah and so I've not had to get in touch with them at all. When it was Penderels, they knocked up a contract for us. Then we had to get different contracts. One was on a casual contract, one was on a permanent contract and Penderels were really helpful and came out. They were very helpful and that was good to have that support there. They were contracted by the County Council. You didn't need to worry about it, they were there. Give them a ring and they'll come round, so that was good.

Robby: You said you lost a PA due to the uncertainty of what was going on. How did you find replacing them?

Julie: Well we didn't replace her in the end because it didn't seem fair to employ someone else whilst we were still going through all that rubbish. But, she stayed in touch with Loran. The one who remained with us, Charlee, nearly forgot her name! Charlee, oh man!

Loran: I'm gonna tell her you did that.

Julie: Charlee did a few extra things with Loran and she's still working with Loran remotely, so it was kind of all right but it could have been much worse.

Loran: I will note that I was in supported accommodation at that point. It wasn't like I was completely without support but other people in that position would have been a lot less lucky.

Robby: Okay, that's good. It sounds like you've like you've had some quite good people.

Julie: Absolutely, yeah.

Loran: Yeah.

Robby: It's good to network. Do use the Direct Payments for anything else or is it just mostly PAs?

Julie: PAs, Red2Green and we're paying for a bit of extra support from the support workers at Loran's supported accommodation and that's it. There used to be little extras but they're not allowed anymore.

Loran: Didn't you used to be able to pay for petrol or something?

Julie: Yeah but there isn't any petrol anymore because Charlee works remotely.

Loran: Oh yeah.

Julie: Yeah. So, there were some cuts with the new social worker but the cuts were done from when it was very specific what the different sums of money were for. So, X hours for Charlee a week, so many hours extra support a week with the supported accommodation and Red2Green. Though we did negotiate going to Red2Green right through last summer. That was a new thing and that was easy to get actually. We said "They're now meeting in the summer, can she go?" and, I was told, "Well you need to justify it." So, we wrote an email and it went through and I thought, "I've never done anything so easy in my life."

Loran: I get the feeling Charlee may have been helping.

Julie: I think that your social worker had already agreed it. She just needed us to put something in writing, so that was good. It's very specific the type of support. Having said that and maybe I shouldn't say this but Loran has a lot of medical appointments that come and go, different types of medical issues and she need support with them. Strictly speaking, Social Services will not provide support for medical appointments.

Loran: So despite the EHIC things that they're putting in now, health still isn't quite meshing with everything else.

Julie: It's not strictly speaking part of Direct Payments.

Loran: Which doesn't make any sense because you know, we're supposed to be integrating health with everything.

Robby: Well yes, I've come across this quite a few times. Social Services aren't talking to healthcare, healthcare aren't talking to Social Services. No-one wants to pick up the budget.

Loran: Yeah. In my experience healthcare wishes it could talk to Social Services.

Julie: And the official line is, "Well talk to the nurse with the speciality of disability."

Loran: Learning Disability Nurse. I'm autistic; I don't actually fall under her remit strictly speaking.

Julie: So, unofficially, when they can make some spare time, the support that is paid for Loran they can support her with the appointments. We had an unofficial conversation and I was told, "Well if they can fit it in." So, it's not written anywhere but she can now use the support workers or PAs.

Loran: Basically, people have to get a little bit creative.

Robby: That sounds like a very roundabout way of doing things.

Julie: The type of appointment she has sometimes she needs to chat to someone afterwards. Some new appointments she went herself, which was amazing. But, she might need someone to come with her and she might need someone to help her work things out afterwards. She might need help managing her appointments and keeping track of what she's doing when is beyond Loran. It's not written into her care assessment and it's not being catered for officially but she needs that support.

Loran: Which is something I've really don't get, because surely Social Services should be interested in health? If health goes wrong, the other problems that Social Services have to deal with also go wrong.

Julie: But, there's no money for it.

Loran: And yet they still make money for other things, hmm?

Robby: Okay, let's move on to some of the positives. What have the benefits of Direct Payments been for you?

Loran: Well, you don't get the council dictating what you can and can't do.

Julie: You've got some choices. We hand-picked her PAs. We said we wanted PAs who were well-informed about Asperger's. Not just through

seminars or whatever but they'd actually worked with people with Asperger's and that they got on well with Loran, so we hand-picked them. We also said we wanted to pay them more than the minimum that would normally be paid to PAs because we were looking for specific experience and we were told what the upper limit would be, so that's what we did. It had been suggested by the social worker that maybe we were paying too much blah, blah, bah. But, it was a deliberate thing and at the time we were told that's okay. If you pay a higher hourly rate though, you get less hours but we had some choices. She got those PAs we wanted and that was marvellous.

Robby: That's what it's all about, choice, putting you in the driver's seat. That is the tagline, putting you in the driver's seat of your care and support needs.

Loran: They actually use that as a tagline? It's so cliché.

Julie: And when we interviewed them it wasn't them that had to get on with me, it's not about me, they had to spend time with Loran and see how that went. That went extremely well. Loran confides in them. It took a long time for Loran to trust them but now that trust is there.

Loran: It takes a long time for me to trust anyone.

Julie: But now that trust is there, she confides in them, she can say anything to them. She's an adult, there's an understanding that nothing comes to me, and so she really can tell them anything. If they think maybe I should know or would want to know, they'll ask Loran, "Can we tell your mum?" And she'll say yes or no. That understanding's there.

Loran: I'm beginning to get a similar level of trust with some members of supported accommodation staff.

Julie: It was good because they're her PAs. So, I might be the one who employs them but they're her PAs and they're very professional. I'm chuffed to bits with them.

Robby: Fantastic. Okay, so what advice would you have for other people wanting to get into Direct Payments?

Julie: Document everything. Keep all your records going back. When Loran struggled at university, it was useful to hang onto all those emails and remember what happened because we could say later on, "Well actually, we know if you put Loran in this position this is what will happen because that's what happened before." So keep old records.

Loran: Sometimes being paranoid is a good thing.

Julie: Don't be afraid to speak up if you think they've got something wrong because although you might be paranoid or whatever, at the end of the day you know yourself best or if you're a parent, you know your child best. So, if you think something's been missed, say so.

Loran: Yeah. Sadly the squeaky wheel gets a grease. Kind of wish it didn't have to be like that, but...

Julie: But, I think there is a lot of officialdom and bureaucracy in that big monster called Social Services and that even bigger monster called Cambridgeshire County Council. But, they're all humans in there and it's quite good to talk to people, don't you think?

Loran: Yeah, though sometimes I do wonder about some of their decisions. Remember the financial re-assessment form I got? It was kind of funny. Basically, it was asking me for proof of various things, including housing benefit, which is paid to me by Cambridge City Council. This was a form sent to me by Cambridge County Council, so I was just like, "And, the reason you two can't talk to each other is?"

Julie: We spend a lot of time filling in forms that are very similar but from different people for different reasons. It could be different benefits or like, as Loran said, it could be Social Services or it could be the City Council. Can't they talk to each other? Can't they share information?

Loran: Pretty much most of the government bodies have information about me in triplicate by now the way things are going.

Robby: Yeah, communication is key.

Loran: Also we live in the age of the internet, it's not like it's hard.

Robby: Yeah. I would have thought some of this information would have been digitised so it could be accessed easily.

Loran: It probably is, they just have their own databases.

Julie: Talking about advice, I think social workers have an incredibly hard job to do, really, really hard. They've been squeezed and squeezed and squeezed and they are human. It's no excuse for making mistakes but...

Loran: Especially not to the magnitude of the bad social worker.

Julie: No. But, remember they are human. I think there are a lot of bloody good social workers out there.

Loran: Yeah. We just kind of got unlucky with that one particular social worker. Oh, Charlee got very angry with that social worker.

Julie: But yeah, they're human and I know we've met some cracking social workers who probably work way too hard.

Loran: Yeah.

Robby: Ah that's good to hear. Good to know there are good ones out there.

Julie: I know people are always quick to complain but actually I try my best to say when something's really good as well because people need to hear that don't they?

Loran: I still think the bad social worker should have gone for retraining but that's my opinion.

Julie: Well Charlee we don't know what happened to her. But, we did make a formal complaint that concerned her. It's not our business to know what happened to her.

Loran: I know, I'm just saying my opinion.

Julie: Yeah.

Robby: Well that's it really, unless there is anything else about Direct Payments that you would like to share with me today?

Julie: I can't think of anything else.

Loran: Well sometimes they send those funny documents to me instead of you, which is interesting.

Julie: They send a statement about once a month. The County Council send a statement once a month that details the payment, the actual Direct Payments that have gone into the bank account and Loran's. I keep it because although it's a joint bank account to pay the bills, it's me who administers it and Loran's like, "What am I meant to do with this?" It comes to the house, I recognise where it's from so I open them.

Loran: Yeah it is quite funny though because my mum's already my representative in this.

Julie: Loran have no interest in seeing it but it always comes addressed to her but that's alright. To tell you the truth Loran, I just file them away because I just want to know the lump sum that's hit the account, not the breakdown,

because what sad person's going to spend the time working out that breakdown? As long as it adds up to the amount I'm expecting.

Loran: Dad. Dad would. Dad would though, you know he would.

Julie: That's why he doesn't touch it.

Robby: Oh right. Well thank you very much for this, it is very appreciated.

Julie: Oh thank you.