



# Al's Story

**CAIL Trustee who initially set up the  
Voices4Choices Project**



## AI's Story

### Interview: Robby

**AI:** I think my opinions about self-budget support have probably changed since I put the bid in for the Voices4Choices project. When I put the bid in, it was all about supporting people to get the best possible outcome from their social care assessment and how that social care assessment is paid for by Direct Payments. I had the opinion then, that self-funding was a good thing. You just had to make sure that you crafted it right and you got the outcomes you wanted. There were a lot of people and there were a lot of stories at that time. All sorts of stories then, about their assessment and the issue around creating support groups. It's was all about helping people get the best out of the assessment they could.

**Robby:** Obviously, this is a project that followed on from The Voice Network Project.

**AI:** And we identified the issues in that project that we brought forward to the Voices4Choices project. However, talking to other disabled people, I found that the biggest problem isn't what can you pay for with your money but actually the personnel issues around not being able to get anybody even if you have the money.

**Robby:** Yeah, I've been talking to people and that's a big issue for a lot of people.

**AI:** And also, things like whether PA's get holiday pay or what do you do if you want to fire somebody? The personnel issues, to people who are running their community support themselves I think is a huge problem which I really didn't identify at the time of the project bid.

I am more and more convinced that Direct Payments are just a cop-out. I've come to think Cambridgeshire County Council or any County Council, they have such problems putting in social care and making it work themselves that they've just said, "Alright well you do it then." And, with that money comes a huge amount of administration and just finding the personnel.

There seems to be a massive problem finding PAs and there's also this greyer market. I've known incidences where people have put adverts in the post office desperate to find anybody and end up getting people quite unsuitable just because they couldn't find anybody else. There's a lady I know who needs 24-hour care but she can only get it during the week, she can't get it weekends, so at weekends, her neighbours have to come in and feed her. She's at risk during the weekends. If she had a fall or she got sick or

something, she couldn't even make a telephone call. So, finding PAs I think is the issue.

**Robby:** A lot of people tell me about struggling to find PAs. Chatting to people in the council, they find that there's an underspend in people using Direct Payments because people are given the money but they can only spend it on what they've agreed with Social Services. That means that at the end of the year if they haven't spent the money i.e. they haven't found the PAs, they get it all taken back.

**AI:** There's also an issue around actually managing the money. Some people, due to the illness, haven't got the cognitive ability to actually transfer money into the right bank account and send the worksheets into Purple. I have heard incidences of money being clawed back just because they did the paperwork wrong. I think this is an issue nationwide.

**Robby:** Rather than just Cambridgeshire?

**AI:** Yeah. All the disabled people's organisations that I've spoken to, the availability of good PAs is always an issue. And as I say, you'll probably get this kind of grey market off the books, aunts and uncles, people that are on the dole in fact, working as PAs. I hear horrible stories. One lady said to me, "I don't know what to do because my carer comes in and she smells of drink." However, the consequence of her firing that PA means she's got nobody.

**Robby:** It's a choice between having somebody bad or having nobody at all.

**AI:** Right, right. So, I think there is work to be done somehow to create a PA register. I know the people before Purple had one, but I know it wasn't any good.

**Robby:** No, they're doing something a bit different. They're trying to do this match dating website but with PAs and people looking for PAs.

**AI:** What they have to do is take the PAs off once they've got the job, because what the other people were doing were leaving the PAs on there. So, you would contact these people saying, "Can you help me?" And, they'd say, "Actually no. I found work myself a month ago or six weeks ago."

I think it's also an issue of how much they're paid because Direct Payments don't allow people to pay very much. I know another lady who is quite heavy and really, she should have two people to turn her and move her because she can't get out of bed. When I approached Social Services about her funding because she needed two people, they said that they weren't prepared to pay any more for her care. We contacted a care agency, but the care agency charges X pounds an hour. So, I think what's happening is, the care agencies

are scooping up PAs and paying them more than somebody who's on their own.

**Robby:** I've said this to a lot of people but with the best will in the world you can get into this sort of work to try and support, help and care for people but you also want and need to be paid at a competitive rate.

**AI:** Good rates, yes. That's important. Social care I think gives £8.50 to £9 an hour. Then they have to pay holidays.

**Robby:** Holidays, sick pay, pensions.

**AI:** And then there's this whole issue of sleepovers now. There was an issue in the courts recently where it was decided that PAs should be paid for sleepovers. Normally they were not paid when they sleepover, in case the person wants them. However, the judgement said you have to actually pay people to sleep over. Well, I'm sure that's not going to be reflected in the amount of money that the County Council gives to people.

**Robby:** I tend to agree, PAs should be paid for sleeping over but then people need that extra bit of money to afford to pay for them to sleep over.

**AI:** Absolutely. So, all in all I think it's a bit of a cop out from Cambridgeshire County Council, to be honest. I think they should be held accountable for all those people who cannot find care agencies. I think they should go back to County Council saying "Right, it's your job now, you have a duty of care!"

**Robby:** There is defiantly one we're going back to the County Council on. We run five events all across Cambridgeshire that were designed to get people who needed support to find out a little bit more about Direct Payments. Jo Public, that's who we were targeting. We did get a few of members of the general public but the interesting thing I found was that it was predominantly professionals coming to the events.

**AI:** Always. It's so frustrating because I remember putting on events in the beginning with Cambridgeshire Alliance and offering Direct Payment advice, as well as lots of other things, on the day. The people who came to the Direct Payment advice were actually professionals.

**Robby:** You think, "Why don't professionals know more about it this than they do?" Professionals seem very interested in learning more about it.

**AI:** But, the problem is you're only reaching the people who want to be involved. It's people who don't wanna be involved that have actually got the need.

**Robby:** My thought is, professionals are the front-line people. They're the people that need to be taking the information about Direct Payments out to people, making it an option. "Oh, we're having such and such a problem." And, then the professionals can go, "Oh have you heard about Direct Payments?" But, if the professionals don't know about Direct Payments, then they themselves can't suggest it as an option.

**AI:** Cambridgeshire has a target to reach of people with Direct Payments and I know that they haven't reached it yet. So, there is a push for the County Council to get more people on Direct Payments. I definitely know there are books about employing people and HR issues. I really think that if you put on training about policies you would get people. How to fire the PA, how to make sure they're the right ones. I know people that have got PAs that aren't DBS checked. What are the dangers of not doing a DBS check? Again, faced with a choice of not having somebody or having somebody that's not DBS checked, you'll have somebody who's not DBS checked because you're relying totally on this person to get you out of bed, to cook your meals and feed you.

**Robby:** It's not actually a legal requirement that they have to be DBS checked.

**AI:** Which I think is dreadful but on the other hand if they did, they'd probably get even less PAs. So, my opinion has changed greatly from "We should help people get the best deal they possibly could at their social care assessment", to, "We should help people manage these personnel issues." So, what have you found that the issues are?

**Robby:** Well, as we've said a big issue is finding PAs, that's a huge one for people. Although, Direct Payments aren't just about PAs. So, the reason why I was here is that I had an interview before I came and saw you. I was chatting to a lady who had a PA for a couple of hours a week and then she used the rest of her Direct Payment for swimming classes for her daughter. She was very happy with that. Her issues were more administrative. So, when you take PAs out of the equation what's the rest of the time used for?

**AI:** Yes. So, she's a carer and she's giving her time for nothing in a way. You know that, if that person needed the care that was provided by her mother, if her mother's not there, that probably would be an issue.

**Robby:** It would be interesting when her daughter gets older, when she becomes an adult and needs to find more PAs then.

So, I thought you would be a really good person to talk to because obviously you put in the bids for the Voices4Choices project but you don't use Direct Payments yourself.

**AI:** Myself, no. And the issue there is I have a husband who does my care for me. He cooks for me, he helps me if I need help getting dressed and he drives me places. So, that's the issue. I do have a sort of PA but it's a family matter. He's a carer, a family carer and they doesn't get recognition for how important they are to the Direct Payment issue. If I had to go and get money to pay for somebody then that would be another drain on their resources. I think unpaid carers should factor into this kind of conversation about Direct Payment because if it wasn't for unpaid carers the whole thing would be an utter disaster. The real PAs that we get are husbands and mothers and wives.

**Robby:** It's a legal requirement that you can't pay a close relative if they live with you. In fact, I was recently told by someone from the County Council that you shouldn't really pay relatives at all. It was against County Council policy but they would sometimes look the other ways in exceptional circumstances.

**AI:** They have to. They have to.

**Robby:** Well, I've interviewed quite a few people who do employ relatives as their carers. I think, like you said, they have to, there's no other option.

**AI:** My lady who needs help at weekends, she has no-one except her carer that lives in during the week. We have tried everything to try and find her something. Nobody wants to work weekends and nobody wants to sleep over weekends. And, even if you get a team of three in total, the paperwork that that involves with keeping those team of three paid and scheduled is huge.

**Robby:** Would that be something that would put you off then?

**AI:** Not, paperwork. No, not really but I do know that it does put people off. I know one lady whose son who doesn't live with her has set up a WhatsApp group of her carers so he can keep an eye on when people aren't turning up. Because, if somebody phones up and says they're not coming in today, that means this lady gets to spend all day in bed.

**Robby:** Which is obviously not good.

**AI:** Not good. I mean, that's bed sores waiting to happen. Bed sores kill you. It's what Christopher Reeve died of, it's sepsis. So, it's quite an issue about getting people out of bed.

**Robby:** Yes, it's a big thing, it's important.

**AI:** I think the first line of bid I wrote, said, "One of the problems about County Council supplying care was that 15 minutes could happen any time between 9 and midday to get you out of bed. The same during the evenings

getting you into bed. And, anything's better than that..." Except no, if you haven't got anybody to do it at all then the old system's better than nothing.

**Robby:** I think I heard most PAs won't do anything less than an hour.

**AI:** Quite right too!

**Robby:** 'Cos otherwise it's just not worth it for them. It might sound callous but the PAs have to look after themselves as well.

**AI:** It's a job, it's not a vocation, these people need money. They've gotta feed their kids and then pay rent. The issue keeps coming back to personnel, wages, management, hiring and firing. It's all to do with administration. When I spoke to the guy in Norfolk Coalition, they had a 7 days a week advice line for social care, for Direct Payment and every single enquiry came back as personnel issues.

**Robby:** So, huge issue for people. One person I spoke to uses Facebook to advertise for her PAs.

**AI:** When I advertised for a cleaner I advertised on Facebook group and I got a lot of responses but I didn't have any idea who these people were.

**Robby:** Yes, how do you vet people?

**AI:** Right. Well luckily one of the ladies that applied was the daughter of a lady in the shoe shop that I go to. I went to her mother and asked if she was alright to hire but then I thought afterwards, "Why would her mother say no?" Ha-ha!

**Robby:** So, what are some of the benefits you think of Direct Payments? From people you've spoken to, from the outside looking in.

**AI:** Well, the one main benefit is you can have care when you need it and not have to sit in bed for three hours waiting for somebody to come for 15 minutes. The other benefit is carers can be used to run the house. In both instances, my ladies live on their own and running the house becomes part of the PA's chore. Whereas you wouldn't get that within a 15-minute social care slot. You would then have to go out and hire a cleaner or an administrator. I think it stops social isolation 'cos these people are in their house 24/7 unless somebody takes them out and even if they don't go out, they've got people coming in that they can talk to. If there's a problem with the computer or those kind of things, there's somebody who can help. One of my lady's is hard of hearing and can't make phone calls, so her PAs makes phone calls for her. Well, there's a whole social isolation issue of combatting loneliness.

**Robby:** That's very important.

**AI:** Oh god, I would just go crazy if I had to sit in a house all day every day and watch daytime television, it would kill me! So, certainly combatting loneliness and the ability to do other things other than care.

I know a lady who had care supplied by the County Council who got her up, who got her dressed, then came back and fed her and finally came back and put her back to bed. That woman was alone in her chair for the rest of the day, looking out the window. So, the aspect of taking them out is important. One of my ladies uses her social care money to hire a driver to take her out places. She does Sailability and they take her out on a boat. So, it is quite flexible. It's not entirely flexible, but it is quite flexible.

There are things you can do which you wouldn't get from the council. So, those are the benefits really and that's why we wanted to do the project, to make sure that people knew what the benefits were. The whole idea is to get people who are using the social care assessment talking to other people who are disheartened. I think the problem is that not a lot of people are using it successfully.

**Robby:** I think that is probably true. Trying to link people in with one another is challenging. Although hopefully, once we get this Library of Experiences up and running that might make a difference.

**AI:** People might look at that as a way to ask, "What are Direct Payments? What can they pay for? What are the things I can say I need?"

**Robby:** It covers a lot. Certainly, people that I've spoken to do use it for PAs but obviously it covers a lot more than just PAs, which is an important point to know. So, are Direct Payments something you would consider looking into for yourself at a future?

**AI:** Well, it's something we're talking about, 'cos my husbands just had back surgery.

**Robby:** Oh really?

**AI:** And, I've become the carer! That's alright for two or three weeks, I can cope but any longer than that and we're gonna have to get somebody. I don't know about going down the Direct Payment route or whether we would just pay for it ourselves. However, I was thinking even four hours a week, you'd pay £50 a week and that's a lot of money yearly. If it's down to your quality of life then it's difficult. I need a cook, ha-ha! My chef has gone, out, disabled. I need somebody to come in and just do bits. I have a cleaner and I actually

have the in-laws to do some bits for me but I think it will become an issue if he doesn't recover fully from this operation.

**Robby:** I suppose potentially, you could ask your cleaner to do those extra bits for you with Direct Payments because you already know them?

**AI:** Yeah, that's right. There are ways and ways of doing it.

**Robby:** So, are you in contact with Social Services?

**AI:** Not at all. I had to go through the process years ago when I first got poorly, before they even talked to you about care, they'd do a financial assessment. The financial assessment came back and I had to pay such and such amount a week!

**Robby:** I don't know about years ago but I think the needs assessment is done first now and then they do the financial assessment. Anyone who has a need, even a multi-millionaire, would be entitled to a needs assessment.

**AI:** I've asked because I live in a house, which isn't good for me in a wheelchair and it's not good for my husband now either. However, I don't want to move so I've asked for help to put in a through-floor lift. The OT came and then the financial assessment came before anything. I know because I have had my bathroom adapted and they did their financial assessment then and the home improvement agency wouldn't pay for it. Instead they lent me the money on no interest, which was very handy. I'm hoping they'll do the same again 'cos the answer to staying in the house is getting a through-floor lift.

The other issue, which isn't anything to do with this, is bungalows are extraordinarily expensive. Even though we own our own house, if we sold the house it wouldn't give us enough capital to buy a bungalow. There are ways of doing it through the governments 'Help to Buy' system that I've found but then you have to buy a new place and I just don't even want to think about getting what I've got in a three-storey house into a bungalow, ha-ha! There's all sorts of things going on but it always comes down to how much can you pay.

**Robby:** That's unfortunate. That is always the case, how much money do you have? How much money can you pay?

**AI:** I have a university pension and I always put in double what I was supposed to pay. The plan was, that when I retired, my husband and I would travel and we would have money to do that. Unfortunately, God decided that wasn't gonna be the case! Because I've got a comprehensive pension I'm not really eligible for any financial help. If I'd just spent all that money for all those

years, I'd be fine. Ha-ha! So, that's fine and there are people who deserve it more than I do, I understand that.

**Robby:** This is what you're always told, you should put money aside for your future but instead it's backfired on you.

**AI:** Yeah, although we have a good standard of life. However, there are things that we could do with in the accommodation. Accommodation is an issue, it's not an issue of social care but I've come across several people who own their own property who are stuck in their own property because they cannot afford to buy accessible property. And of course, because they own their own property they can't even go on the housing register.

**Robby:** How frustrating. So, what advice would you give to anybody looking to get on to Direct Payments?

**AI:** I think, although it costs, I would take advantage of Purple's services. More than just paying them, because they can administer it as well.

**Robby:** Purple are very good.

**AI:** Yes, but people don't do it because they think, "Oh it'll cost too much," but actually it costs too much in time and effort to do it yourself.

**Robby:** Well actually, Purple's budget should be factored in to someone's Direct Payments.

**AI:** Well yeah. I can't advise people on how to get PAs. I honestly don't know that answer. But, certainly don't try and do it yourself. I've heard horror stories when people try and do it themselves. They are perfectly capable when they start, but due to their health issues, it makes it very difficult as they go along.

**Robby:** Okay, is there anything else about Direct Payments that you want to tell me?

**AI:** No, I think you're fine. I think it's a really good project and I think it's changed from what I envisaged but I think actually what you're doing now is better.

**Robby:** Collecting stories.

**AI:** Yes, because this Library of Lived Experiences can be very useful. I also think it's a really useful resource for teaching professionals at places like Anglia Ruskin or where ever.

**Robby:** Yeah. Every week I get through the county council's training list for professionals and I really think something about Direct Payments needs to go on there.

**AI:** Well CAIL can put it on an extraordinarily good Direct Payment training session using your Library of Lived Experiences!