# Paul Written Reflection and Interview Transcript

*This document contains a written reflection (submitted by the participant before the interview) and the transcript of a semi-structured interview conducted online on 6 July 2020. Paul was a Welfare Benefits Adviser at UK-wide Advice Charity in Southwest England. The transcript and written reflection have been anonymised, with identifying names and places removed, or replaced with pseudonyms.*

## Written Reflection

Case Study – EB

EB was ‘reassessed’ for PIP and given only 2 points for Daily Living and no award.

‘Reassessments’ are when a claimant (C) is migrated from Disability Living Allowance.

As a consequence, therefore, his DLA claim came to an end.

EB had a number of conditions health conditions. His GP reported that EB had paranoia; EB denies this.

EB was upset at various points by comments about his views and whether or not he had paranoia when dealing with us (as opposed to DWP or Tribunals). This made him feel as if he could not express his feelings. He said more than one time that “if only you knew what I have been through, you would understand why I feel this way.”

EB carries all his possessions with him, including medication, food and documents which he says prove how his life has been maligned by entities outside his control. He told me about how his home had been intruded upon by malign entities.

When he met with the health professional (Atos) they noted in their report that he brought his possessions with him. However, they commented that he showed ‘no concern at leaving them with a stranger’ when visiting the loo during the assessment.

I provided a submission pointing to the GP’s evidence and the comments of the ATOS health professional. We submitted that EB had been discriminated against by the health professional, who must have known that he was showing signs of mental distress and was simply making excuses for failing to recommend an award of benefit.

I attended the hearing with EB and his sister joined the hearing part way through. I do not always go to hearings, but I felt there was a strong possibility that EB would misunderstand proceedings and be upset by what he heard, so I went to ensure that he would not be.

During the hearing I was concerned at the questions asked by the panel, and by the responses EB was giving. EB is well educated and can appear to engage well with people, however in reality there is no quality of engagement due to his condition.

My concerns were allayed when the Tribunal awarded EB 8 points for being unable to engage with people face to face.

In retrospect their questioning was excellent, ensuring that they got the right information without angering or upsetting EB.

The medical member referred at the start of the hearing to the GP’s comments about EB’s paranoia, but emphasised that “what comes across is that you have a mistrust of people.” EB could readily agree to this and nodded his head.

When his sister attended she wanted to express concerns about what she saw as social isolation and inability to self-care. This irritated EB, who became visibly agitated. The judge intervened to stop his sister from commenting any further. This in turn upset his sister, but fortunately EB remained relatively calm.

I also intervened by telling her that we could discuss that after the hearing was over.

When we left the hearing during deliberations (before the decision was given) EB commented that he felt the medical member was sceptical and didn’t believe him. I agreed that was the way it may have appeared, but we should wait to hear the decision first.

When the decision came we were all very pleased with it. I told his sister that I would discuss community options re his isolation with him, but that it was ultimately his choice if he wished to go ahead with that. In the end, he did not.

## AR9 Interview Transcript

I= Interviewer P= Participant

I Hello.

P Hello.

I Hello. Good. Can you hear me okay?

P Yes.

I Yes? Brilliant. I only just saw your email. Thank you for sending that to me. It looks really interesting.

P Okay, no problem. I might have some other things to tell you about but, yes, I thought that was like an obvious... There doesn’t seem to be an email address or anything for him but if you email [name] you can probably get his contact details.

I I’ll have a look. I think I recognise like the bureaucratic model may be from something else that I’ve read before. But it’s one of those things that reading more only helps you understand it better rather than getting more confused.

P Yes, I think it’s one of two talks that they gave where, okay, that’s the theory but I mean [laughs] is it actually true? Yes, you know, general experiences that the tribunal sit in system is much more satisfactory than the assessments.

I Yes, I think it can give it a bit of a… It’s a difficult perspective when one side of it is so bad as well. So, I think the assessment’s such a low bar to get over. Yes, that can skew it sometimes. All right. I’ll just get started. Are you comfortable and quite happy where you are?

P I am, yes. Um, just before we get going. I read through your profile, and it sounds like we’ve got quite a lot of things in common which I didn’t realise because it wasn’t in the document that you sent but I read the thing on the website… when I was doing my photography degree and I was looking at probably more… Sort of related but after that… when I was doing that work about things like dramaturgy and stuff which you could get rid of. Yes, so I was interested in the idea of people performing those disabilities and so what I did was I recorded conversations with people. Some of them were friends, some of them were in mental health groups, some of them were students, some of them were teachers. And the way that they would talk mainly in that context about their work, which in the art world is all about self-flagellating, suffering in order to achieve greatness or whatever. And in the context of mental health as well. And there were actually a couple of people in there who were talking about their assessment ESA, I think.

I Oh, really?

P It shouldn’t be long ago that it wouldn’t have been PIP probably. And I commented to one of them that, yes, perhaps this can feel like an opportunity to address your health needs. And, so it would have to be a positive conversation when in fact you then find out the plot is to stop your benefit at the next opportunity and so you better not open up, better keep your mouth shut.

I Well, I think it’s those kinds of experiences that, yes, puts people off because I think even if that’s not been your personal experience you’ve heard of that happening to other people. So, that’s going to change how you engage with people… um because of course it would. Yes. But that’s really cool. I only have heard of dramaturgy because I had a friend who was doing that, so we would… performativity nerds together. Because I think it’s one of those things that a lot of people don’t… haven’t heard of or it sounds a bit weird. So, it’s always exciting when there’s someone else that knows a bit about it.

P I can’t remember which bit of the dramaturgy is separate. But the whole idea of being onstage and offstage and who you engage with and how in terms of institutions as well. It was Enoch Powell who wrote the Water Tower speech as well. Which is something else that… Have you heard of that?

I No.

P So, he was the one that got rid of the mental asylums. Before he made the Rivers of Blood speech, he was the health minister responsible for getting rid of the asylums. Which in one way you think is really good and you think, oh, wow, how and why did he do that? That it was a reform much like welfare reform whereby… um, there was very little thought about, well, how people can transition from one system to the other. And people then ending up in the community without any support and basically being turfed out and then having become institutionalised and therefore not being able to fend for themselves.

I Yes, it’s really interesting. So, when I worked in the charity sector for a while and Winterbourne, the scandal about that, was a huge deal into moving people into supported living and in the community. And it kind of just meant… it’s like a kneejerk reaction to something that happens rather than making sure the quality is right on either side. And, yes, it just always seems like quite a shame that it is that kneejerk reaction rather than people thinking about what you actually need or would want and how that should look.

P The um… the government is you know, just terrible at converting from one benefit to another. So, you know, it’s not just Universal Credit, I think the problem with Universal Credit is that it’s so wide ranging and it covers so many different benefits that it’s replacing. And so many different problems that can arise and so much of it’s down to the claimant to argue their case or point out something to the completely ignorant bureaucracy that doesn’t have any idea about most it. but you know, have you seen the thing about income related to ESA?

I What bit about it?

P When they introduced ESA it was the first time that incapacity benefit, which had been contribution based, also had an income related… so, you could get income related or a contribution-based income. And then they’ve recently discovered that they didn’t, shouldn’t really need to discover it this late in the game, but they haven’t bothered to assess what their income was. And so many people ended up not receiving any income related benefit that potentially they would’ve got quite a lot, or they would’ve got free prescriptions as well. Um, and so there are, allegedly, 70,000 cases like that and there are probably a lot more than that, it could be twice the number I think now. And my colleague [Leanne], who sent me your email originally, remembers talking to them in 2010, 2011, 2012 when this reform was starting and telling them that they should be income related to ESA. And being told by the helpline, no they don’t and that’s a separate benefit, they can’t get it. And it’s the same thing every time they introduce a new benefit, I think. It’s just that they then don’t know what they’re doing and misadvise people left, right and centre.

I Yes, and it’s just such a vulnerable group to be testing stuff out on as well. So, with the PIP in particular, so I know a lot of people it’s the Motability component in particular, that means that’s taking away your car, that’s taking away, potentially, your job, your ability to go out and do other things. And, yes, even if you look at the overturn rate, and I know the DWP side to it is, oh, it’s a very small percentage of the whole decisions. You’re still looking at a lot of people. A lot of people.

P They always say it’s a small amount. Their guess is always about 1% of the reality.

I [laughs] Yes, goodness. Right. So, quickly, just to let you know, I’ve got a notebook here. So, if my head is down, it’s because I’m just taking some notes. I think you’ve got quite a good understanding of what this is about from having read my page on the OU website. But if you’ve got any questions before I properly get into it, please feel free. And just if you need to get a glass of water or just stand up or whatever, it’s completely fine as well. And could you just quickly confirm for me that you’ve had the consent form and the information sheet.

P I have. I haven’t looked through it today but, yes, I’ve seen it before [laughs].

I And you’re voluntarily participating in the research.

P Yes.

I Brilliant, thank you. Have you been at [mental health charity], isn’t it?

P Uh, so, I started volunteering for [UK-wide Advice charity] in 2012. I’m now employed by the [mental health charity], and I work for them fulltime, whereas at various times I’ve worked for [UK-wide Advice charity] to a very limited extent on a paid basis, mostly as a volunteer over the years. But, yes, I’ve been doing this project for three years now and I’ve kind of been working paid since 2015, I think, at one level or another [laughs]

I So, how is that funded? Is that a local government thing or?

P So, my particular project, if you like, over at [mental health charity] is, or has been until Thursday of last week, funded by a local charity [name removed] and they’ve got very deep pockets. So, it’s one of the benefits and perks of working in [local location], really. I don’t imagine there are many other places where you’d get virtually a whole salary from one charity. But on the other hand, the disadvantage is that it’s a relatively rural area and it’s a very small backwater in terms of benefits. But also, I really would like to know more about the other local [organisations] that give benefits advice because I suspect that those bigger ones are either getting their money to pay for someone to do their role through um… local authority at the council, or from health service funding, like CCGs. Which we don’t have anything like that to fall back on, so I think it’s going to be quite challenging for us to go forward. Although, allegedly, having already said ‘no’ once, they’re now coming back and saying, [name removed], that they might see if there’s something they can do. Which I’m a bit pessimistic about but let’s see. Uh… because the other bit of funding that we’ve got is from [a mental health charity]. That, like… there’s a national structure and then there’s a local charity and the local charity actually helps people, but they don’t have any money. And the big charities have some money, but they don’t necessarily want to pay for someone to do… but they have started to fund local [organisations] and that’s just in two phases now. One was the local role which we got, which was for anything to do with benefits, really. And the other was a more targeted bit of money for a small number to trial services related to Universal Credit. And I think we put in a pretty good bid actually. We put a better bid in for that one, the first one but we didn’t get it because, I think, because we were on Universal Credit long before anyone else, so we’ve already had all the problems. We’ve been through that, and everyone suffered but we didn’t get any help with it. uh, and… and secondly, because we’re a bit of a backwater, it’s not a very interesting area in terms of demographics uh, and so I think they probably wanted somewhere that was new to Universal Credit in a particularly… Well, they did say it was about strategic location really. Um… so, they might give us some… they have given us some more money but it’s to do with COVID rather than to do with this specific project. So, basically, I think its… I can’t really see it coming from anywhere else than those two pots and it might be that we’ve been… so… um, but we’ve managed to extend my contract until the end of March [laughs].

I So, it’s often by the seat of your pants a bit in terms of funding and what services you’ve got there?

P Yeah. Five years is the most that you’re going to get from a grant and that’s a lottery, generally. But often it’s three years, sometimes it’s not even that much. And the grant that we’ve been relying on really was only ever supposed to be a one-off and then, you know… ‘find yourself some sustainable funding’. Well, that wasn’t fitting for benefits advice. Those that survive really are ones that have some kind of statutory funding to fall back on I think, like Citizens Advice does.

I Do you have any benefits advice services from your local councils or is it all charity run?

P Yes. It’s just [charity]. That’s it, full stop. Um… there are other things that go on and I sometimes wonder whether I’m less aware of these because I think that [there] is quite a closed mind-set and quite inward focussed locally. But the housing association, have a couple of different advice projects. They’re not really advice we don’t think, we’re very sceptical about it, we think they’re a bunch of shysters. But they’ve got Universal Credit advisors, they call them, uh, and they’ve got a Passport to Housing in accompaniment with one other thing that’s sort of similar which is to do with affordability moving through housing. But, you know, these people are partial because they work for the housing association where all they’re interested in is paying the rent. Um and Citizens Advice used to run one of the projects for them and that was their experience, all they were interested in is paying the rent. One case worker told me one of the people, they got a big grant from [name removed] actually and all they were interested in using that money to pay off and not actually worrying about whether it was sustainable. And I’ve also had one or two clients which have been… you know, have problems with the housing association. Some of the people who work there are good, but the new types are not so good. They did do a report actually, the National Housing Federation, and they did the questionnaire, did the questionnaire. So, there’s that. I’ve met people, a couple of people who work for Unite Community Union, Community whatever it is... Like you’re into basically the volunteers who’ve probably got disabilities themselves who… To help people with benefits but they don’t any advice knowledge or… So, there may be more. There’s Age UK as well but they’re only for people over 55.

I Yes, I think it’s similar in quite a few places. It’s disability specific or demographic or charity specific.

P Yeah. Um there is [charity] degenerative disease project. That’s just for degenerative conditions where people are likely to die. But in terms of general, into which you would put mental health, there’s no other… It’s just [charity] basically.

I So, your role and what you do, is it just you?

P It’s just me pretty much, yes. I work on my own, largely. We’re looking at changing things but it’s a bit under wraps at the moment as to how that’s going to work, but for the last three years I’ve virtually just done appeals. And those have been referred to me by [local charity] because they have an appeals project, but it’s run by a volunteer and it’s staffed by two other volunteers as well and just… The volunteer cannot provide the same service as a paid member of staff who’s there fulltime because they’re only in two days of the week and then they’re off on holidays half the time and they may not have the same interests. One of them does but two of them just aren’t interested in social policy at all. I ran a report last week because I was interested to see if there was any difference between us, if there was any added value. And one area that I did identify was that in the last tax year I managed to get £90,000 in benefits that weren’t related just to the appeal. Um whereas theirs was negligible, I think one of them might have had about £10,000 or £15,000 or something.

I So, is that in like add on?

P In the other areas it’s… Yes, so I had it… I don’t know exactly what that was composed of, I haven’t looked at it in that much detail. But I now have a couple of clients in particular who we managed to claim severe disability. Um because they… Have you heard about this? Basically, people on legacy benefits like ESA can get to the severe disability premium. The government stopped those people from moving across, but a lot of our clients, because we’ve been on Universal Credit for five plus years, have already moved across and already lost out. So, they can apply for probation but only if, in these two cases, we first went back to ESA or back to JSA and say can we have the backdating for 2016 and then did it with that. So, I managed to get about £7,000 for each person or the two people from that. But the client would never have been able to do that because if they ring up and say to universal credit they would just go, no, because you weren’t getting it at the time. So, that kind of thing may have been… was certainly a part of it. But I don’t know how much.

I It sounds like quite a bit of your role is being there to navigate that bureaucratic tangle, so they all play…

P Yeah, I help clients who are doing PIP appeal, so they can get limited capability for work… without doing it for them but by helping them to fill in the forms, advising them what happens at the assessment. By, I can’t remember what else, but you know, just basically empowering them to do that. Whereas the voluntary service [charity] gives I think is a bit paternalistic and not very effective. And so…uh I know some research that shows that might be the case, I should say. But what I’m trying to do, I do quality over quantity, so trying to maximise their income. Obviously, that should always be the point, really, of the benefits advice. I always do a benefit check before and afterwards, the volunteers don’t…um from what I can see. And that’s the area where you can get the added value because you’re then ensuring… And what I want to do is to then you can sort those out, you give a platform to the person that then they can look at what they want to do with their lives afterwards.

So, one of my first clients on the project was a 22-year-old, I think, mother of one, who was only a toddler. And she was very, very distressed, very upset. Every stage we went from the beginning of the process, filling in the PIP form, all the way through to tribunal. It took nine months which is a pretty truncated process by most people… because we, because I was helping her, we put in every form, we challenged every decision almost immediately. Whereas normally it takes one to two years…uh because many clients waylay, they don’t put in the claim, they don’t put in the reconsideration, or they don’t bother to go ahead with the appeal in time. Normally, it’s accepted by tribunals but nevertheless they then end up waiting a lot longer. They do so only in cases where they’ve got support because otherwise, they wouldn’t feel encouraged to do it, I think. Very small numbers of people challenge decisions, that’s a national …you know, statistic but also locally we’ve seen that in the research we’ve been doing. Uh, you know, so, it’s a tiny, tiny number. Out of 170 people, like six or ten went ahead with challenging it and only a couple of those made it through to appeal or something like that.

I So is that because people don’t want to appeal or aren’t sure?

P I think that’s something that we would need to do some more research about because it’s just really… I mean, there were conversations that happened with it, but we haven’t necessarily got a record of that. It’s more of a, what happened you know, and dates and things like that. But I think, probably, to make that difference you don’t really need… Because at [the charity] you have to ring in every time you have a problem, sort of thing, if you want that support and people could come along at any point during that process. But these were people who’d started with filling in a form… I think, you know, even if you’ve got a telephone number that you can ring, that may not be enough. You might need someone to ring you and remind you and we did do that with the research. But I think it’s about them having trust in the person that’s advising them, who really knows what they’re talking about, so that there’s no uncertainty in what their rights are or what the merits of their going ahead is. And them then knowing that there’s going to be support in that process throughout. Um… whereas it very much relies on the claimant, the client, to be sort of self-advocating I guess in that sense. So, I think you really have to have something that you can fall back… You have to have something to fall back on. Um… there was something else I wanted to say but I can’t remember it now[laughs]

I [Laughs] It’s all right. I’m sure it will come back. Probably after this but… So, do you normally see people from, say like, the PIP form right through or is it at different times?

P Not normally. But in that sense, I was talking about my client MG, the first one, and this was about the platform that we’re trying to build for them, like a life raft here…uh, because she had no benefits, I think. I think she had housing benefit or something. She had her own property and unfortunately, she was sexually assaulted, so she had to move, and this is not the first time in her life. I worked on the young people’s project before that. And it opens your eyes to thinking, okay, actually if this is your first time experiencing something, whatever it is, the benefit system, then it’s going to be more challenging for you to go through that process. So, I worried a lot about her at the time, over those nine months, um but eventually did manage to get her through all of those stages. She was ringing up quite often in tears, not every week but often enough to be a bit of a worry. I had to do basically everything for her because she didn’t do anything, she couldn’t even ring them let alone fill in a form or write a letter. We got the tribunal; I was quite worried about that as well. She went with her mum, I think. And she got enhanced on both, which is 145 quid a week. That’s a huge change. She was on Universal Credit, so then we looked at what we could do about the limited capability for work and I, with some support advice from a colleague, gathered a letter from her GP which is incredibly detailed, like two, three pages about each of the activities in the limited capability for work. And… included safeguarding forms, sort of warning them that this is a vulnerable person and one or two other bits and bobs and filled in the form for her and sent that in. And it was a completely different picture that appeared, we got the decision, she had limited capability to work from work related activity and there was no assessment let alone an appeal. So, [laughs] it was just an amazing difference. But you have to have quite a lot of experienced knowledge to be able to do that for someone plus time… plus time to do it.

So, she’s gone from a situation where she had limited capability for work, sorry, where she had standard allowance 317… No, she didn’t get 317 because she was under 25, so she got £250 a month or something. Rent was probably covered but separately. To going, to then having £336 a month in limited capability to work and work rate activity, £145 a week in PIP. Uh and she… all she wanted to do with the money was to get psychotherapy. And you think, well, here you’ve got an example of someone who’s written onto their PIP form this is what they want to do with it and you’re not giving them the money when they’re going to do something positive with it. And we know that most of our clients have no concept of what they would do with the money, and they just use it to cover their general expenses. Who’s young, who has the potential to heal and to be able to go out and work and you’re not even prepared to give them a dime basically. And she had personality disorders, I think OCD and more than one personality disorder, and she might have had bipolar disorder as well although we kind of wondered whether all of those conditions could reasonably be diagnosed in one person but it… that wasn’t important really. The point was she was distressed and that should be what PIP is about, it should be about that they’re distressed and then you do prompting. What does it matter what their condition is? And clients tend to write really weird things on their PIP forms [laughs] like they use bin bags to sit on to go to the loo and list their mental health problems.

I Ok, do you think it’s a bit… I mean, the forms are very long and quite difficult to manage anyway, aren’t they?

P Yes. I think that with mental health there’s a temptation to write all sorts of bizarre things and I’ve done that as well in the past sometimes. Having said that, I was quite often successful, more often than not when I did those without doing anything else. So, I know there’s something to that, giving a lot of information in the form. Um, also, it’s very complex legal territory and there are all sorts of things that just don’t count. Like, with activity one, preparing a meal and cooking a meal, you don’t get any points for needing help to get to the supermarket and back and clients find that incomprehensible. Which is fair enough.

I And also unless they’re talking with you, they’re not going to know that either.

P No. And also, you know, the… the form, what’s written in the form plus what the health professionals and how they deal with it in DWP. In some areas, not very many, the guidance is more favourable than the law. Um, so, this whole thing about public transport, well, it doesn’t really help you very much with the planning of a journey. If you can’t get on a bus because you’re distressed, it’s not really going to help you very much. It’s part of the picture but it’s not going to get you across the line. So, even a disability rights handbook, I did write to them and say, why does this give so much emphasis to it… it says, you must say about public transport and, yes, you should but it’s not going to be the thing. And if you drive, you’re basically fucked because… [laughs] The other thing is I think, some attitudes of mental health that I would like to see addressed through tribunals as well about that… If you work and if you drive, you’re probably not going to do so well unless you’ve got a very… if you’ve got, I think if you’ve got autism you could probably get away with working but if you don’t have autism and you’re just depressed and you’re working you probably won’t get any points. Or you won’t get more than prompting, I should say, in engaging.

I Why do you think that is?

P Why?

I Yes.

P I think it’s prejudice. I think its jealousy, um to be honest [laughs]. Because some… you know, I mean, I haven’t… It’s difficult, even if you do… when you think… the one example that I sent you I think it was an exceptionally good tribunal as it turned out, although I was quite worried as it was going on as to which way it was going to go. Because they were asking a lot of questions, and I’m thinking, God, he’s not scoring any points here and… um you know, or I know that or I know that I can see, you know, you can see in the tribunal he’s able to come across quite well, you know he’s very polite, he’s probably very well educated, um he’s very articulate. Like, when they’re saying to him, you know, it comes across that you don’t trust people and he just says, ‘well, yes, but um if you’d gone through what I’d gone through, you’d know exactly why’. So, if you just take a tick box approach, which the health professionals tend to, yes, he’s making eye contact. Yes, he’s saying relevant answers to questions. Therefore, he obviously doesn’t have a problem, um whilst ignoring the fact that he’s got these huge bundles of bags that he drags everywhere with him because he’s got stuff in there for his diabetes and all these documents that he wanted to show me. I told him to leave them in the waiting area [laughs], which according to them, if he leaves the room and doesn’t quibble about it, he probably doesn’t have a real problem with that. He just, it’s just a lifestyle choice that he drags all this stuff around with him [laughs]. Um but in yeah, you know I’ve had conversations with colleagues, I think there’s one of the volunteers… because I work in the [charity] at the moment, which I should say for context, um… and that’s… I’m taking a mental health view on a service that isn’t designed for mental health clients, really. So, that’s important to note for context. But one of the volunteers I think used to be on tribunals and was a disability member and I’ve also heard anecdotes, probably most of these from many years ago, not current about, you know, the kind of, there can be amongst disability members and maybe some GPs or even legal members that if they’ve got a disability, it’s like you haven’t got a real problem. ‘This kind of benefit is for people like me, you know, not for you, not for the likes of you, back off’. Uh and um… I don’t know how true that is but that may be an element of it. And I think then that there’s obviously been some significant legal changes, like PIP has now got an activity about engaging with people. I’ve got no idea where it came from, but it wasn’t part of DLA. Um because I’ve looked at the consultation and I can’t see any public discussion, unless you have, about why they decided to have use certain activities and not others. Like, why… where’s getting out of bed gone [laughs]?

I Yes, there’s a lot of them… I think there was some back and forth on the consultation and it’s like we’ve decided to do this and that was it.

P I read the consultation but there didn’t seem to be a discussion about the activities as such, apart from saying to people do you think this is a good idea or not. And then people saying yes or no and then them deciding to do what they liked or splitting the communication activity into two and changing some of the descriptors, it just seems to be pretty much born whole. So, there’s been that change, there’s been the recent change to the Blue Badge, uh, in terms of mental health. There was the whole ruckus about psychological distress, and they tried to change the regs and then… they’re basically a bunch of liars in terms of how they handled that. Uh… and I also did a lot of looking at the statistics because I was on furlough, so I spent a time comparing DLA in August of 2013, just before PIP came in, and PIP today. Completely failed to cut the budget, there are more people claiming, they’ve got higher rates than they did before [laughs]. They’ve gone and fucked it up and they probably should’ve just left it well enough alone [laughs]. If it’s not broke, don’t fix it I think is probably the lesson there. And within that, particularly with mobility, you know, I think it was pretty difficult and nay impossible, and it’s reflected in the statistics, to get the enhanced rate mobility for mental health. Whereas now it’s at least theoretically possible, though I would say it’s probably about a one in ten or one in 20 who find that they actually qualify under descriptor F and more likely that they’ll get it because they’ve got… but then there’s also a levelling because you’ve got the combination of points with walking around and also the mental side, um, and sensory problems. So, it’s levelled the playing field. So, it may be that perhaps some tribunals’ decisions makers, health professionals, whatever, think this is a benefit for people with real problems, like having broken legs and such forth and so forth and not people with mental health problems. You know, failing to comprehend or even acknowledge the fact that the law is changed significantly.

I I was going to say because um… I know there was lots of noises about it being treated on a par with physical disabilities and how that was meant to be part of PIP as well. That was kind of undermined with them trying to change the regulations on mental distress. But practically, have you noticed any difference with it maybe being a bit better than DLA in comparison or…?

P Um, I should qualify my comments by saying because of when I started working, although I have filled in the odd DLA form, I’m not really very expert with that. In fact, actually, if anything, I counted more attendance allowance forms. Because I worked on an outreach project which was funded by social services, so I would go into people’s homes, generally older people. I did also do one guy who I thought might score, genuinely score over 50 points with him because he had a missing leg, missing arm, couldn’t sit upright and, you know, literally he did… spoon feeding with every aspect of his daily living. But I think in theory it should level the playing field. Um, I mean, if you look at the statistics that the DWP produces it’s hard to really to know how to interpret those. Because I looked at, um, conditions and subcategories from StatXplore and it shows that those with mental health it’s about 50/50… in terms of you getting an award or not, see you might think, oh well, that’s quite good but then if you look at all the other condition categories, um, all the ones that are above it are all the sorts of things you think, well, yeah they should definitely get PIP so that’s, you know. And all the things that are below you think, well, can you get PIP for that? I’m not really sure about a skin condition… maybe a bit of washing, medication, therapy?

I Well, it’s hard to know what counts as a skin condition, isn’t it? So, psoriasis, technically, would that come under a skin condition or an autoimmune?

P So, on StatXplore you can go in… I can show you my bar charts if you like but you go in StatXplore, you can report, you can find the data with condition and there’s an overall condition category. Now, I don’t know how they did it in terms of primary condition because it’s only one, I presume, per claimant, I think.

I Primary?

P Yes. So, I presume that the condition that’s been lodged is the one that seems to be presenting issue. So, there’s psychiatric, which includes Down’s syndrome which you may not think of as being a mental health condition. And also, autism, which perhaps you wouldn’t either, um, which it could have a high level of need probably under PIP. And then skin category, you can go underneath skin category and see what’s in there, a friend of mine’s got Ehlers-Danlos syndrome and that one is actually quite good for skin conditions but the other ones that are under there would be much worse, which is why it’s down at the bottom of the league table. And at the top of the list, as you would expect, is cancer and…and things like that. And also, weirdly, the whole thing about uh…um musculoskeletal conditions and…and uh, psychiatric. So, they say that psychiatric is the biggest condition category group but then they put it ahead of the two other categories which have been split in half for general musculoskeletal versus specific musculoskeletal and I really thought, well, actually if you look at it then really musculoskeletal is way out there in front and mental health is way behind but it’s bigger than some of the other… you know it depends how you put those together as to what is considered normal or not.

And I think that one big change that a colleague of mine commented on, who has been a welfare rights appeals worker much longer than I have and I think she was working there at least in 2002, so went through the whole DLA system. That, you know, there was this… it’s true, there was no positive concept of aids or adaptions. So, with DLA, because I’ve actually done a couple of child cases recently, to have aid or adaptions is, in a sense, a negative thing because if you can do it with it then you won’t get any points whereas with many of the daily living you get two points for needing an aid or adaption. And my advice to my friend who has Ehlers-Danlos is, do not emphasise your mental health, emphasise the fact that you need aids and adaptions, um, because I also have a client who went through um, all stages of PIP, went to tribunal, wasn’t expecting her to win, didn’t think she’d qualify, was honestly a bit sceptical about her health needs in that respect… myself, which is pretty unusual, I normally agree with the client. She was rejected. We did try asking… Did we ask? We asked for reasons, we told her we don’t think there’s a case here. She then got the mental health team to try and dispute the tribunal’s decision, because she lost. She put in another claim, she’s refused again, she got zero points and then she did an MR and she suddenly got eight points for aids and adaptions [laughs]. She went through seven stages before finally getting an award only because of the aids and adaptions and not for the mental health. Which is probably her primary issue.

I That’s a hell of a lot of work as well, isn’t it?

P Yes. But if someone’s… I think if someone’s very belligerent and won’t take no for an answer… with PIP they may win it eventually but they need to present a lot of evidence, independent evidence and they need to get like carers letters and things like that if they can. And I think if you game the system like that, you probably will get an award. I’ve got a couple of friends as well who have been through it, and one of them, I asked her to show me her award notice because I was surprised that she got enhanced, and I looked at it and she told me what it was like. And I thought, oh, right, because you’ve never really told me how bad your… the mental health is, I never really got that aspect of it. And the other one basically admitted to me that she’d kind of gamed it and exaggerated it, must of convinced the tribunal though, but she got the letters from carers. She told her relatives to ‘just really emphasise how useless I am, how I can’t do things’.

I Did she… Was there other evidence as well or was it carers and her own account?

P She wrote descriptions, she got relatives to write letters. I think…my, I’m looking at maybe starting to do a project around assessments but my advice would be… like I think in the advice, in the [charity] where I work in particular, but I think it’s true, more widespread, there’s this real hesitancy about evidence, about submitting evidence and really an inclination to say to the client, if anything just get a letter from your GP stating their opinion about your health needs. But that doesn’t work for mental health anyway. Um… so, you’re not very likely to get that. A lot of GPs want to charge for it about half the time, 140 quid I’ve been quoted, which I find improbable.

I I think they’ve recently changed it so that they can’t charge but that’s very recent, I think.

P Let my clarify, they can still charge for reports, but they can’t charge for health records unless I am mistaken. So, I’ve had that inclination based on the culture in which I work. But I was advising one of my clients who I’d spent a lot of time helping, assisting her… uh, because of her needs, because of the unusual nature of her situation with regards to benefits. But in terms of the PIP decision which we were appealing, which is why she got in touch in the first place, I was looking through her bundle of paperwork and you’re supposed to get the education history, everything that’s happened with every claim all the way through, all the claim forms, all the assessment reports, all the decisions. Of course, many times they don’t produce that, they usually… They’re starting to produce DLA evidence now, even if the claimant doesn’t ask for it, which is good, that’s a positive change because that can be really key, it’s been said to be key. But anyway, I was talking to her on the phone, and I said, well, you know, what I would say to you is, why have you submitted all of this evidence? And then you’ve submitted all of these reports from over the years and it seems to have just been… It was also annoying to look through because it was like 300 pages or over 100. And it takes, and sometimes people submit things twice and then you end up with two copies and you’re not sure if it’s new or not. But then I said, well, actually I suppose you did get assessed successfully the first or even the second time before you got this, so maybe that is the best approach. So, I think the best approach is probably just to submit as much independent information that’s not your story, your version of events. There’s generally very low credibility put on what claimants say about things in the health professional advice, in the decision maker’s decision. I’ve spoken to the disability minister at the time, which was Sarah Newton, and I’ve told her that, alongside other people in the room, you know, you just need to… to believe people when they tell you that they’ve got an issue with something. And that is, you know, the truth, that is what they should be doing, that’s how DLA work, there were no assessments, it was on paper, generally what the person said, um, and it was done on a kind of big dictionary of health problems that they used. So, generally that would be best. But it’s quicker to, as someone said at CPAG when I went to training once, it’s quicker to jump through their hoops than it is to try and get them to change where the hoops are, sort of thing. So, yes, that would be the morally right thing to do but they’re not doing that, so, we might as well change our way of working, our advice to our client to try and get them through those hoops so that we can get as good an outcome as we can as soon as we can rather than just sticking belligerently to the line, you need to believe the client and we’ll just go through various stages of appeal and spend a year and a half trying to get you through that process.

I I guess, practically you’ve got to work with what is there, haven’t you? So…

P Yes. So, generally, just request health records for two to three years and shove that in and then get any letters from any party. And a lot of claimants don’t realise, again inaccuracies in the advice given of the forms that they sent out with the information, assume that when they’ve been given the three boxes for health professionals in the form, that they’re going to contact them. And I have seen just a handful of factual reports from GPs. The odd one from other people, like a carer I think did one, a support worker did one, but it’s far from the norm. And I think it’s something to do with the way that it’s contracted or arranged, statutory speaking. Whereas with Employment Support Allowance or Universal Credit is integrated, that’s very common that every time that you do one of those, you’ll expect to see some kind of reports. Problem is, they’re bloody useless anyway because the GP doesn’t write anything on them. But even when the GP has written something on them, and they’ve sent in a supporting letter and they’re very clearly supporting, and they actually explain something relevant, which is very infrequent because the GP doesn’t have any direct understanding of what the PIP criteria are or any willingness to help their patient in so many cases. Um, you know, even when they’ve done that, even when they’ve got all the evidence, even when the claimant’s given a consistent story it doesn’t make any difference. And the health professional will note the various things that they observe or that they think are important like level of medication, which is said to be a low dose, therefore you don’t have a problem. High dose, therefore, it should be effective, you shouldn’t have a problem or even an intermediate dose. It doesn’t matter what dose of medication you’re on, apparently, it’s a reason to stop your benefit [laughs]. And they’re just, they’re trying to estimate these, and I think the other thing I probably need to adjust is that… I’m trying to get my head around, particularly how tribunals do it, as to how they assess someone. You know, I’ve got a case that’s recently been completed unfavourably, unfortunately, 97% of my appeals have been successful in the last three years, so it’s very unusual to lose. But there have been one or two, less than five. And even those where we do lose in tribunal, normally we can get it set aside and get it reheard but there’s been… I think four or five cases where we couldn’t do that.

And, um yes so, it’s this young lady and she’s got mental health needs, I can’t remember what her diagnoses are now… I want to say autism but I’m not sure, um was it OCD? I can’t remember, anyway, don’t worry about that. So, uh, so she had an interleaving ESA issue in that she was a student, and her ESA should’ve stopped or been reduced because of the PIP decision and because of her status, student or otherwise. So, that was really the cause of her asking for advice. But we appealed the PIP decision eventually. She needed a lot of encouragement to do that because she’d discussed it with her mother and thought that it probably wasn’t worth it, and I encouraged her to go ahead. And I think it was, in my point of view, it was worth doing and there was a lot at stake because it had this £10,000 overpayment that also needed to be addressed through this. Um, and … um so eventually managed to get it in, we got a tribunal hearing. When I interviewed her before we had the hearing, she’d… There’d been certain things said in the evidence I guess and the case that I put forward, based on interviewing her, was that her needs were much greater than had been stated and that there were some misinterpretation going on of what she said or what she understood the law to be. Um so, we appealed that, and she found that the hearing to be humiliating, I think, or upsetting or she described the guy as ‘gnarly’. And her mother said that they were kind of saying to her, ‘come on, you can do this, can’t you?’ And unfortunately, in this case we didn’t have a recording of the hearing, which they started doing in the last two years, but they don’t always record it. So, I couldn’t hear it for myself. Um, we got the ruling through. Yes, there was a sense that they were laughing at her, or they were laughing during the hearing, the panel members. We got the decision through and their reasons include… So, the key issues were could she prepare and cook a meal, cos I think she got four points. She needed to pick up… Or maybe even two points. She needed to pick up, I think, six points, four to six points. I think she had prompting, so she needed to pick up two more points. So, social engagement, social support, plus two more from preparing a meal. She got zero for preparing meal. And uh… so… anyway, the reasons were from the tribunal that heard the appeal, from the judge that writes the reasons. Firstly, they said that I should’ve submitted a statement from the client, signed by her, for those things that had changed. Which I kind of can see and take on board, however I’ve also spoken to tribunal doctors who’ve said that they don’t like signed statements. So, you know, you can’t really win either way and it’s all very subjective. But I think if I had… If I knew… The other thing is a lot of tribunals will accept what you’ve written as observations that they’ve heard in the interview, which is what the law says. So, maybe if I can… But trying to work out which ones, you know, where that’s relevant is difficult. You might only get one in 100, that’s like that. Anyway, fair enough. And then they said that she was preparing a meal in the presence of other students with whom she lived. And that I’d also sent in a letter from the student support from the course, who said in their own words, I didn’t coach them as to what to say. I gave them, I gave the evidence to the tribunal to see what I’d asked, and you can see what the response was. Where they said they were giving her effectively social support because they were her mentor, they don’t know what the definition of social support is. And their comments and the reasons from the tribunal were, um… ‘we considered that it wasn’t likely that they would be offering that kind of support’.

Well, that’s what the evidence says. So, what… Anyway, so we put this together. I put in a request for permission to appeal to the first tier, then to Upper tribunal. In terms of cooking and social support we said, she’s doing these things, yes, but she’s doing them with the required support. So, which is it, chicken or egg? Which comes first, independence or support? How do you determine these? And unfortunately, both refused it. The Upper tribunal, they did not see that there is an issue in terms of the chicken or egg. Because I thought that was going to be a significant legal issue. I don’t know really, I mean I think that, I guess what they’re saying is, and I would accept, that in terms of tribunals the balance of probabilities they have, in the First tier, quite a lot of leeway to make a decision based on the evidence. They said they’re allowed to come to form an opinion about something, but I don’t really understand how you do form that opinion based on that evidence, uh, and how… So, I was hoping I guess, in terms of preparing… I felt that the engagement with social support was blatantly wrong. I thought that was obvious. But in terms of the preparing a meal, some guidance to the First tier tribunals tell them how to question or query or work out… there is case law like that and you know, it is… I can see an argument for the fact that maybe she could do it either or both of those things with the level of support that they said. But it’s so subjective and so many First tier tribunal’s decision makers would have given her the benefit, the benefit of the doubt you might say. So, yes, it would be useful to understand how they’re interpreting.

Because when you go to a tribunal you don’t really know where they’re going with it. Like I described with the case that I sent you, I didn’t really know which way it was going. I left the hearing with him, and his sister and I said normally I’ve got a pretty good idea of what’s going on. I’ve got no idea of what we’re going to do. And they just went down the line and giving him eight points for social, uh, social engagement, which is quite straightforward, um, and decided that even though I did think he had some issues with the other activities, he didn’t score any points anywhere else. So, if he hadn’t got eight points in that activity, he wouldn’t have got any award at all, which is the difficulty. Sometimes you’re between those pillars and posts. And indeed, you know, most of the people who have lost their appeals and where we’ve been unsuccessful or we’re still appealing it, it’s not that they have no needs, they always say that they accept that. And usually, they do get four to six points, two to six points and they just need a little bit more and it’s just potentially falling between those stools as to what they think is eligible care needs.

I What’s your experience with the judges and the panel members, um, sort of the sense you get from them? I know you were just saying in that particular one it was really hard to see which way they were going but…

P Yes. We don’t go to the majority of our appeals, so it’s based on those few that I’ve gone to. So, we’re probably talking about ten in the last few years that I’ve been to. And I think that going forward I want to go to assessments; I want to go to appeals because I think that’s where I’m going to gain the knowledge to be able to answer some of the questions I have in my own mind. And therefore, to advise the clients better as to what the best approach is with those. I think there are problems with going to tribunal hearings. Again, it could be partial but the law centre have slightly lower outcomes than we do and they go to all their hearings and tribunals don’t want to hear it from us, they want to hear it from the claimant. So, actually if you are quite active in the hearing you might be shooting yourself in the foot [laughs] by being irritating. But you are entitled to obviously, you know, put your case across. But when I went with that client and I gave the case study about… I basically had very nervous two to five minutes… I basically just said, I submit this. I didn’t… Wasn’t… Didn’t feel I would be able… I would’ve been shut down. I’ve been shut down by… Tribunals have tried to shut me down when I’m trying to ask a client a question. I’ve been shut down when I’m trying to give them information that will explain what’s going on. So, I went to this hearing with this hearing with this lady, uh… who is, initials are RSE, and, um, she’s now waiting whether she’ll get permission from the Upper tribunal. She went to one tribunal, and they gave her four points. I can’t remember whether they gave her some for mobility as well, if she did get four points. She got no award. She had chronic fatigue I think, or it might have been fibro, because quite a lot of my clients have got one or the other or a comorbid with their mental health problems or some kind of physical, you know, joint pain, back pain, that kind of thing. But, anyway, so she had chronic fatigue, I think. Uh, she’s in a somewhat comfortable position because she’s got a spare house that she rents out… And she also works a bit. She’s claiming work because it’s easy to claim when you’ve got means and when you’re working. But that, as I say, if they’re working then they’re likely to not go very well in a tribunal. And there is some evidence obviously from going to work about whether you engage with people and obviously that needs to be interrogated but I think it’s… you know, they tend to ipso facto, and obviously when you’re looking at the decision you’re basing it on what their reasons given are and directly preceding because sometimes it’s not the same as what they’ve reasoned. And they might go away and think about it for a couple of months and in between it might get distorted as to what actually happened.

Um anyway, going back to her, so she went… By the way I haven’t got a time limit on this, so…

I&P [overtalking].

I Oh ok good.

P But she went to one tribunal, and she got four points. I think it was washing and dressing or washing and preparing a meal or something. Um, and then she… then we didn’t like that obviously because we got no award, so we asked for it to be set aside. They lost our fax requesting this. We then got a decision effectively saying, sorry, we’ve lost this, we’ve lost the recording, we can’t do a record of proceedings or our written statement of reasons. Therefore, there’s obviously an error in law here, you can get it set aside. So, then I thought at the last minute, right, I really should get some health records here because she’s obviously a bit dubious and I’d rather put in more evidence now we’ve got the chance to do that. I sent this to them ahead of time, I sent it by email, I chased it up, yet they did not present the evidence to the tribunals. I went into the tribunal hearing room and said to them, before they shut me or… as they were… Or they probably didn’t even listen to what I said, because they were so keen to shut me down. I was saying to them, I’m sorry that this is coming late, I did email it to you on Monday, but it appears that it has not made its way across from your distribution centre to your hearing centre,, um, but we did think that we needed to do this. And then we had a discussion and the client accepted that we would get an adjournment so that they could, they couldn’t look at these 200 pages of records at the last minute. Because what you need to do is you need to get it there before the morning of the hearing, when they’re going to look at it. So, we spoke to the client, we talked about whether, um, I would be able to come… Yes, I could come but we’d need to limit it down to times when I’m available and it may be a problem, or I may not be available when it happens. The client preferred to go ahead, if necessary, without me in order to get another hearing. So, this is what happened. So, then she had a third hearing, this time with the evidence in front of them, and she lost again. And she got four points for… She got two points the same, two different points which suggests that there’s some subjectiveness going on here because if you added the two together you might get six points which is still not an award but it’s closer to the line. And now it’s gone to Upper tribunal having been refused permission and I asked them to set out the reasons, because she’d been so uncertain of the reasons during that period when she had a hearing that I didn’t get the reasons from, um, so, we still don’t know really whether we’re going to get an award at the end of the day. We just keep pushing along and every time it gets set aside just keep pushing [laughs]. This is an issue from 2018 and just keep pushing away at the thing and she’s happy for me to do that. Um, but you know, but then with the judge, the comments they made in their decision notice about the one that got adjourned with the health round at the last minute, ‘we had to adjourn at the last minute because we got these documents at the last minute’. You know, and it may have even said ‘it’s the representative’s fault’. Mmmm, not my fucking fault, it’s because he can’t bloody forward an email from A to B [laughs].

I I guess that is not going to help with the relationship between advisors or anyone going there.

P You know, we try our best to get stuff in, um, and I guess the tribunal was irritated because it wanted to get on with it but sometimes… I think more often they won’t do that. They will adjourn, they will think about it if ... But sometimes they’ll… They’re so keen to get through it that they’ll just make a decision and then usually when they do that, we can get it set aside. There was a guy who I’m quite pleased with his case because I never met him, and it went on for 18 months and we had to get it set aside at least once. And it was about whether he failed to turn up to an ESA assessment. Um, and there was a tribunal that went ahead without him even though I’d asked them to adjourn in that circumstance, they refused and carried on, set it aside. Then there was another hearing at which another judge was present, and she then adjourned for further records, that was good. And then it got another hearing and then that one, with us having done all of that, and having written to them several times saying, no, I have not spoken to the claimant, I do not know where he is or what the situation is [laughs], therefore we’ve given you what information we have, and we want you to go ahead now. You should think about what, you know, what you think is right to do when he doesn’t show up again um [laughs].

I Is that something that’s often quite challenging, is I guess the engagement of your clients as much as the other side of the process?

P Most of the time I’m dealing with my clients… um, there’s been a lot of problems, not a lot of problems but a minority of cases there’s still a lot of problems for me and, or colleagues with regards to the appeal forms. So, uh, you get your MR notice, and you have to fill in a form and tick certain boxes and put down the name of your representative. The… that part of the process is done by even less well-trained volunteers. Uh, I mean, you know, so, the appeal team are pretty good, they have a very high success rate, 95%, so should be seen in that context. It’s just that they, so, their specialist benefit advisors like me, so they’ve got the experience and knowledge but… I mean, they still have problems with training, but you know… it’s about the extra stuff that I can do because I’ve got the time and inclination to look at those things. Which includes gathering evidence, they don’t gather evidence at all really. I did a records of access request book that took four months and was a complete pain in the arse, but it was the difference between winning and losing. Um, anyway, but going back to, yes, engagement with… Yes, so the volunteers are generalist advisors or some of them are not even that much who fill in the appeal form. So, I’ve had situations where they’ve written…

So, I had one lady in particular, same, it happened exactly the same time as the other one I just described. Same people with their contemporaneous appeals. They put… she had domestic violence, as it turned out. So, they put down the name of the homelessness charity that now has responsibility for such things. Not even a name. I think… I don’t even know if there was a name for the person who worked for the organisation. So, there were no contact details for the client. I couldn’t get hold of the client, so I was… I’m always quite active in saying, you know, is there some way that we can work around the consent here because this is ridiculous. I can’t help my client. She’s obviously in a difficult situation because of what’s been put on there and I can’t represent her without speaking to her. So, eventually it was agreed that I could contact the organisation because they were the ones that were written on the form and simply say to them, we’re trying to assist this lady with this appeal, can you put them in touch? Then I was told that… Because I spoke to a male who worked there and he said he was a manager, that was the… go to the manager was the suggestion. He said, first of all, that support worker doesn’t work here anymore, so that creates a problem. Second of all, I’m not allowed to have access to their details because I’m a man, so I need to get hold of a woman who’s in the right department area, responsibility to do that. And then even when they got through that they couldn’t obtain the person. And then luckily about… I think we had a hearing date at this point, so it was like two weeks before her hearing. Suddenly I got an email from a female colleague of his saying, as it happens the claimant has just been in contact with another domestic violence service and so, yes, we can put you in touch. So, I interviewed her right at the last minute, put the submission in and, uh, she won her appeal.

But we have had a lot of problems and I actually had some other issue. And in fact, the domestic violence worker that she was with thought that the issue was about this other thing which was due to tax related to Universal Credit and not about limited capability to work. And the client, completely focussed on this problem which was a significant issue but was a small amount of money compared to £330, £340 a month. Uh so, you know, the client basically had completely lost interest in it, like no knowledge or understanding of it. Might well, probably wouldn’t have got the hearing notice because it would’ve been posted to the wrong address. Likewise, basically the appeals team, as I say, lack a certain amount of interest and motivation around certain things and its advice is quite inward looking. So, I have said it and there has been some improvement, so I guess that’s good. But it’s quite a big service, to get them to change anything is quite difficult. Um, but when you are in contact with them you should update their contact details as well as putting them on the form, you should put consent to discuss with somebody else. I’ve had two clients who died whilst they were dealing with their appeal and in one, in the latter case, because I’d made some of these changes, I had consent to discuss with his dad, so I could give advice. Whereas with the first case they were totally fucked off because I wouldn’t talk to them because we didn’t have any consent. So, that was obviously very upsetting, and you know, obviously for them mainly. So, update their contact details, take consent for someone that you can discuss it with, take a second phone number, second email address, take an address so that you can write to them. Um…and a lot of that stuff doesn’t just fall through the net, and they don’t bother. That has improved. Get their authority so we can actually act for them with other people other than the tribunal. And if we’ve got all of that stuff in place then we’re actually able to do quite a lot of things even if we never speak to the client. We’ve obviously to be a bit careful because we don’t want to do something the client wouldn’t… So, we’ve got to be sure that what we’re doing is not going to make it worse off. If we ended up with a worse off, what we call a downside risk, of what we’re doing we probably would leave it alone. But if we know that they’ve got no benefit in the first place then there’s no harm in their absence.

Clients don’t… A lot don’t have phones at all, let alone internet or email and this is mainly based on my colleague, who manages one of the drop-in services, but they just don’t have a phone. All they can do is walk in. Some of them are having to walk very long distances to get to anywhere they can get advice. They have to walk to the job centre which is like ten miles away in some cases. And perhaps there’s been an even greater increase of people just dropping off the radar entirely in the last few years for whatever reason… um, and they don’t have someone to support them, which I think is why… So, I think I want to move more towards assessments because I think that the evidence that we’ve got shows that the people who go through to appeals have better education levels, have got someone supporting them and therefore even though they do submit their appeal almost a year late [laughs], they do it because someone’s prompted them into doing it or they’ve got a support worker. And many people just don’t have that, they’re living alone.

 I’m aware I’ve splurged a lot of information and I don’t know what your question was [Laughs].

I [Laughs] That’s fine.

P Well, if you want to tell me what they are and...

I It’s meant to be semi structured and guided by your experience anyway, so it’s absolutely fine. I can’t think of anything else that I would be particularly asking you. So, it’s just if there’s things that come up for you.

P Is it more about appeals then but then comparing to assessments?

I Yes, so I think from my perspective there’s been quite a lot of work about the assessments. So, the DWP and IPSOS Mori have done quite a lot of claimant research that’s asked them about the assessment process. So, we know what the issues are with that, whereas there’s a lot less on the tribunal side. So, it’s just trying to dig into that.

P I think there’s a significant issue, I think it comes down to the way that I guess PIP has been constrained to those. My colleague describes it as ‘this is disability in reality and this is PIP here’ [gestures] and same with the working capability assessment, they’ve just closed it down. And the good thing is that most people do quite well, and you can get enhanced rates easily where once you might have even been on a lower rate and you can get enhanced mobility where before you couldn’t. But the difficulty is getting through all of those processes, having to go through the multiple stages of rejection. I think for a lot of people, they don’t want to go to a tribunal, thank you very much. If I was a benefit claimant, I wouldn’t touch one with a bargepole, thank you very much. So, even though my colleagues are, ‘oh, well, you need to go to a tribunal, you need to go, you need to speak to them face-to-face’. Well, actually, if you were in that position, would you want to do that? I wouldn’t, I fucking wouldn’t. So… my friend with Ehlers-Danlos is making a claim after we’ve talked about it for many years, she’s talked about it, I’ve advised her on what to do. And she’s point blank said I’m not going to tribunal; I’m not getting the tribunal if it happens, you know. And she might need to because it’s not clear that she’ll get an award because she’s working, which doesn’t help, and fulltime actually in that case. So, I think that can be the issue.

So, do people want to be actually observed by a tribunal? They think it’s like a court, they don’t understand what it’s about. I think that’s become more blurred because they used to have a hearing centre […] and I’ve been there. There’s a very friendly security guard, you just go straight in, and you can… there’s multiple waiting areas. You can have a private room very easily. When you go into the hearing you would have a level table with the panel on the other side, comfortable chairs. Just a much friendlier environment and now they’ve consolidated courts and tribunals, so they’ve got a hearing centre which is very plush and kind of institutionalised… where it’s very plush, there’s white walls, wood everywhere. It’s now part of the court system in that it looks like a courtroom, the panel has been raised above you, so they’re now three, four feet above you or in some cases just slightly above you depending on which room it is. It’s very difficult to work out where on earth you’re supposed to go in this airport like room, the very fort like building you’ve been sent into. There’s no-one and hardly any desks. So, I’ve gone into the secondary hearing centre, called the Civil Justice Centre where they do things like housing and employment cases there and it’s just a couple of social security that go there. And you go in and one of my clients ended up using the support service, so effectively went in with representation which we hadn’t intended because she was a bit distressed and didn’t know where to go and they’d offered to help her, and she said that she wasn’t represented even though we’d done that just not with her.

Um and there’s big security, so the guy with the bags, you had to go through security which took about 15, 20 minutes. I did tell him, I told him, you know, you must turn up early because I know you’re going to take those bags with you [laughs] and you’re going to set off all their buzzers and everything. It was quite funny just watching him, he left some of the bags at the front but luckily, they were able to do that and keep them out of the hearing room. Um, but anyway, in this building, uh, uh… the Justice Centre, you could go up the steps and pass various desks and one time, I guess one of the first times I’d been there, I was less certain as to what there would be, no clerk, no-one on the desk on that floor. If I can’t work out where I’m supposed to go how on earth is a client supposed to work it out? But eventually, because I knew which courtroom it was in, I just hung around long enough and then he showed his face after about half an hour and the thing went on and the client didn’t show up and they were trying to get hold of the client and she’d gone to the wrong hearing centre. They’d gone to the magistrates’ court instead which is where you might expect it to be or maybe she’d been there once before because it got adjourned. So, that’s quite difficult.

I think the DWP, for assessments, I don’t see why they can’t, with some kind of informed consent, as is happening now, interview people by telephone or just let them choose what they want to do. So, when clients deal with appeals, and they don’t want to do that, and we get 95% of them to a hearing. Telephone if we have to but, you know, we really must answer their questions is our advice. And I mean, those that don’t have them have won, but we want to put them in the best positions so… um, well yeah, so people don’t necessarily want to… yeah. They might find that very stressful, having to show their faces. Tribunals are the same, anyone can see your face because they can only deal with them on the phone at the moment. Yes, so you never really have to… I’m trying to remember what I was getting at. But, yes, I can’t see why a client has to go to an assessment. And a client of mine was saying, we were talking about doing a telephone hearing. And they were like, ‘oh, all right, well, it might take me a while to get a letter from my doctor’. I was like, you don’t need to do that, this is the tribunal and they’re perfectly reasonable. They’re not the DWP, you can do what you like. So, it’s just a tick box. Why is it different for assessments? And what good does it do to call someone to an assessment centre when it doesn’t matter what they’re actually doing? You’re going to note down that they were making perfectly good eye contact even if that’s not the case. You’re going to measure their medication. Well, you could do that just as well over the phone. You’re going to carry… you might even bother to carry out a physical assessment on someone that has no physical needs. Well, what’s the point in that? That’s a complete waste of time. You know, and think, I can’t really see what the need is.

I think for my clients it is really useful to see them on WhatsApp or whatever, like have a video there if they’re not coming in because it means they don’t have to ask them, .are you making eye contact?’, ‘Do you normally make eye contact?’ And I think that one of the problems with PIP which I’ve been looking at with the consultation and there was that Demos report about it, which you’ve probably come across. And with the Demos report, they said actually what this is, how you count that cost, its much you know, medical needs costs are one aspect of that, only one part of it actually. The housing sectors, for example, might well influence your actual real-life costs. PIP is you know, and DLA probably too, is hugely unfair, really. And if I look at two clients and they, I might even think that one’s worse than the other, but they get a lower rate of benefit and that might be the right decision in terms of the criteria, indeed it may just be subjectivity, but I don’t think that’s necessarily fair. I think a lot of people are ending up with money that they’re not necessarily using to meet their costs. They don’t actually have the costs and other people who are suffering have costs, but they don’t fit into the boxes that they’ve assessed them as. And they said in the Demos report that we really suggest that you use this as mains because it would be far too complicated. Well, actually, is it? I mean it’s factually… they either live in rented accommodation or they don’t. Whereas asking someone, can you go walking outside or are you walking outside? Okay, but you’re doing it but is anyone grabbing hold of you, is anyone helping you get up after you fall over? You know, it’s all these questions and you’re having to ask people and, in many cases, where they’ve never been anywhere. So, to try and establish whether they get distressed when they go to somewhere they don’t know is very difficult.

So, I think that something along those lines would be, I would say with great hesitancy because obviously whenever they reform these things lots of people lose out, but I would’ve thought that we could do something that was more factual. Which is what they said they wanted to do with PIP and an objective medical assessment, I don’t know about the medical part, but an objective assessment… by reference to what’s actually… you know, asking people questions that they can actually answer rather than asking them questions they can’t answer. With it being so woolly as to what counts and what doesn’t and giving the wrong confused responses to these questions or the prompts they put on the form. I don’t know why they can’t have more tick boxes on the form which they used to have with DLA.

I Um, when you talk about particular people that were missing out under this, is there a group of people that you have in mind, or is it different sorts of people?

P As I said, I think working and driving is a problem if you do it. So, with that, the one I’ve got in mind with work, and I think no… could she drive? I’m not sure. But what she can do is get about to work but she’s always chaperoned. She works for the government; she works as a civil servant. Or she can perhaps sometimes work out, but she says a lot of people… She used to work for the DWP as well, she says. And she said they’re very prejudiced and very judgmental type of people that she’s worked with. And you know, so, for her, because she was working fulltime as a project manager, so she didn’t have any problem with income, it was all about principle. I think you had access to work as well. And she had ADHD and, what was the other thing… it might have been chronic fatigue. Um… no, PTSD. And there wasn’t any particular visible physical disability there as well. Just make a note of that, um. So, in her case she ended up with the mobility standard rate from the tribunal but not daily living. She got six points, no seven points. She got seven points. And we argued about dressing, which I’ll come onto in a second, because you’ve already had washing. But in terms of preparing a meal, what happened was, we disputed it to the Upper tribunals. The only one I’ve ever been given permission to appeal. They set it aside without reasons. The DWP, as apparently is common by that point once it had gone to that level, if it gets to the DWP legal advisors and if the permission has been granted then you can see which way it’s going. So, they basically just fall in.

So, the DWP agreed with this, they submitted a piece of case law they thought was relevant and then we got the decision set aside. And we were like, okay, that’s great but, oh, God, what’s going to happen now? Because it was going to be reheard and she could end up worse off not better off and she might not… you know, after all this and we’ve got to a year down the line. And then all of a sudden, the DWP just reversed the decision and gave her two more points saying that, they I think… I can’t remember whether she needed prompting or whether she needed assistance with cooking. Um, because in the hearing she’d been asked all sorts of questions, it was on the record, and she talked about making spaghetti bolognaise I think, but, you know, the question is not what would you, could you, should you, but do you? And that’s the big problem with tribunals is they tend to ask the question, yes, but could you? Could you do this? And in her case, with her ADHD and her mind being all over the place, she says, ‘well, I suppose I could make…’ and talk at great length about how she might be able to make a meal, but the reality is she hasn’t done it for about two or three years. Um, and so I think, I think they finally agreed that she needed assistance to do it and that prompting wasn’t sufficient, but it might have been that she needed prompting or the use of the microwave. I think it was assistance.

And then in dressing, this was preposterous. This is potentially where you get into this weird murky territory with mental health, um, and it’s partly my doing, I guess, because you’re trying to interpret what an aid or adaption is, for example. Or what a reasonable need for prompting is. So, she dresses and washes in the pitch black because she’s worried, as is more than one of my clients, about cancer. So, even though she doesn’t have cancer she thinks she might have cancer, so if she sees herself naked, she might end up, you know, misinterpreting what she’s seeing. So, it’s safer to do it in the dark so she doesn’t completely schitz out whenever she… I mean, when she was in the interview, she was a complete mess, and she was in tears and sweat eventually. She was a complete picture of distress, you know, I rarely see someone quite so extreme. And, so, the tribunal ruled that, yes, she needed prompting with… or something, supervision in the bathroom. She had a sliver of light through the door in which she would wash, um, but she didn’t need it with dressing for some reason, even though she put her clothes on back to front. They said, ‘yes, okay, she puts her clothes on back to front sometimes but that’s not unusual for someone who’s dressing in the dark’ [laughs]. Which my issue was, well, why is she dressing in the dark? Is it not reasonable for someone to have prompting and encouragement in that situation? If the client agrees that if someone was there, if she doesn’t have someone there, if someone was there to encourage her, maybe she’d stop doing it at some point.

I Do you think that’s where there’s just… It’s trying to put so many different things into one set of questions and one benefit, it’s hard to capture the massive diversity of experience and disabilities with one form?

P I think that’s one way of looking at it, yes. I don’t know if it’s something that I would say but it sounds like you might think that [laughs], to answer your question. And uh, you know, Universal Credit is obviously, is hideously much more complicated, it’s horrendous. There are many things lying in the regs that haven’t even come into effect yet, uh, like surplus income, which we think has been happening because of the income support scheme and everyone gets that £7,000 payment in one lump at one time. Uh, anyway, but obviously PIP has developed more and there’s been a lot of case law about the interpretation of things. I describe to my clients of there being a need to go through the front door. Right, if we think about PIP as a house, go through the front door, tell them you need prompting. Don’t try and go round the back and through the windows or under the floorboards. You need to go through their front door, just stick to the stuff that matters. You need prompting, you need encouragement, you need reminding, you need it on the majority of days. Stop worrying about whether you need paper bags or whatever to sit on the loo. Yes, it might be an aid or adaption but, come on we’re stretching it, we’re groping around here [laughs].

You know, and I guess there’s an argument there that perhaps it was reasonable that she dresses in the dark. She was doing it, she was doing it effectively perhaps. And I think they were saying she can quickly take the clothes off and put them back on again. My point was, and I guess this is where there may be a disjuncture with cases I’ve described as well as the student I’ve talked about, where someone is doing it and so is that sufficient, is that... My point of view, and it would be, well, if someone needs encouragement or reminding for distress that should count. Even if they are actually, at the end of the day dressing or washing or cooking or whatever, if they need someone there reminding them then in my book that should count. I think they should be, someone needs reminding, encouraging, prompting on the majority days of the year. Not, although I think that’s a problem as well the majority of days rule, but as far as we accept that. That it’s about the needs they have, not about whether they can do the activity as such. The question is do they need that level of encouragement from someone on a day-to-day basis. Because I think what was lost with DLA… And the other thing is people will say I needed prompting and encouragement to get up. Well, that’s not part of the criteria. And you might be able to go under the floorboards and try and pull out some old DLA case law that says that… To have things like toilet needs, of washing laundry in the night and particularly around children who wet their bed and that those might be DLA cases. You know, you could argue those with PIP but fuck me it’s going to be difficult. It’s going to be difficult to argue that one. So, just stick to the stuff that’s obvious. They don’t know what that is obviously, they might have had some advice or might need more experience in dealing with it. But just try and, and just remember what we’re aiming at here which is the really obvious things about… try and… So, generally, with mental health, anxiety, yes, but actually that is still lack of motivation. If they lack motivation, they’re probably not doing it, whereas if it is anxiety, they might be doing it anyway. And some of the activities, psychological distress when it’s overwhelming counts and in others not.

Um… something around budgeting and mental health or preparing a meal. This whole thing about, you know, one is psychological distress or… huh…you know, about whether you can qualify, whether you can ensure that someone qualifies. Because I think also in terms of the points system, I just think that they could with some extra activities, like getting up. I think it’s quite good that there’s an even number of points or you can get a good number of points across activities for prompting. But I just think that there’s maybe some areas where people are needing help and it just isn’t part of this assessment. Because if someone’s prompted to get up and then they go, and they wash, and they dress it’s difficult to show the causal link between the prompting and those two activities that count rather than the one that doesn’t. And I think there was something in the PIP.

So, we provided evidence, that is I and [charity], for [a] case I think it was, when it went up to the Supreme Court about what social support is. So, we basically did interviews with clients and asked them what they needed and how it helped. And some of them… you know, I had a record because we’d done a tribunal, about whether they got B or C or A in that descriptor allocation previously from the tribunal. And in the Upper tribunal they said that there needed to be a necessary and causal link between the social support and the resultant ability to engage or needs or whatever. Uh, whereas the Supreme Court changed that and said, no, you don’t need a temporal, causal link, you just need to be experienced and it can be a family member that you need to be experienced. But crucially it’s not what the DWP was saying, which is that it needs to be more than prompting, it can be any of those things. And I think that was key with the student I described. Is that with the social support, it’s unfortunate that she didn’t have six or seven points because if she had I feel like that was a possibility with the Upper tribunal. You are saying that that’s not social support and yet the social supporter is telling you that’s social support. And what is… who is a social supporter? I think that’s a real problem and I think people are going to continue to not get points for this from tribunals and DWP despite the Supreme Court’s ruling because there isn’t any… [laugh] And I think it’s… With mental health it’s quite difficult to describe to a client, okay, someone who has training and or experience in helping people to engage face-to-face. They won’t know what that is, they’ve probably never met one, but I think that a university mentor probably could be one of the rare exceptions. I think a therapist probably is. Of course, it’s hard to find a client who’s seeing a therapist. So, it’s all very well having these legal definitions and obviously it is helpful some of the time but actually, in practice, even with tribunals that’s… They’re not going to be interested in someone who’s seeing a therapist, who’s seeing a psychiatrist who’s... I think they have in mind, I think they will continue to have in mind someone who’s contemporaneous with the engagement. They choose to think of support worker or mother perhaps, maybe not… because they’re not experienced or qualified, um, meeting together with the health assessor or whatever. Or they’re thinking about, okay, does this person panic? Do they have panic symptoms? Do they have severe mental health problems, and do they have evidence that this has been going on a long time?

I have a young lady as well where I felt that she was, potentially, being discriminated against in terms of her youth. We went to a hearing and the judge was very condescending, quite patronising. Uh, and like I say, we went into the hearing, she brought her friend with her, I went there because I didn’t think she’d show up if I didn’t, ended up with three of us. Um, I can’t remember if there was a PO [Presenting Officer] there or not at DWP. But the judge said at the beginning, you know, we’re seeing that the representative has raised quite a lot of areas of dispute, so it’s quite a high-level award compared to what the DWP has done. Which is zero. Um, and so we need to see more evidence and so, we’re just asking some questions now to see whether we can really get enough information from you or whether we want to see some more evidence. So, they basically saying we’re going to adjourn for health records, probably, but we’re going to spend 20 minutes now just asking you some questions to try to figure out how… Which is fair enough. But her attitude was quite hoity-toity and quite sort of patronising, and I think that can affect younger people when they’re going into a tribunal. It’s like, why aren’t you working? That was basically the question. She said, the judge said, ‘nemagostorian’ [talking fast and unintelligibly]. And I said, sorry, what? ‘Not a good historian’. And I said, no, sorry, I didn’t get it. She said, ‘she’s not a very good historian’ [laughs]. What she wanted to get was a chronological account from the claimant as to her situation, where she went to school, why she isn’t working, what job she’s trying to do, perhaps what mental health services she’s accessed. Because if you’re a young person, effectively there’s a bit of a bias, a prejudice that you ought to be working. And the whole attitudes, surveys about benefits is that, you know, if you’re older, give them the soft touch, let them have the benefit basically. And a lot of my clients are older, but I do have significant numbers that are less than 35, less than 25, less than 18. Um, uh, you know, and those people need a lot more encouragement to access advice and see what the point of it is to try and claim the benefit. They’re more likely to be fobbed off. Um, and the older clients are more likely to have worked perhaps but are more likely to have been seen in the round as having, um, done their bit for society and, uh, so having made the contribution. I base that really on the Ben Baumberg Geiger report that he did about the work capability assessment. I think you should read that if you haven’t already because it’s really interesting about looking at international comparisons as well as about assessments. And obviously PIP is not the same but it’s a similar process to go through. Um, and you know, and they looked also at public attitude surveys about benefits and that was sort of what I’m basing it on. And I think that’s really super advice, so I have started saying to my clients to try and look at statistics and see what’s going on and say… You know, I mean, I think if you were older, I could be saying you’re pretty home and safe here, but you have to remember that this is an attitude thing.

Most of my young people have succeeded in the end or at the first time of asking for the tribunal but we do submit a lot of that extra evidence and many of those have been changed by the DWP. And in the case with the young lady with the historian problem, um, she was adjourned, we then had the health records. Is that what happened? And then when we went into the hearing, because the client was quite worried, she was worried about having to start all over again with a new tribunal because obviously you have to get rid of the people who’ve heard it before… with her anxiety. The DWP PO was there this time and he said… In fact, what I’d said my position was, there is loads of evidence in here. She’s submitted several community health team reports, the health professional notes that she is, has no problems engaging appropriately with people. And yet she’s submitted reports that show there’s evidence that she’s been arrested by the police. So, it’s [laughs] obviously not right. I think there was plenty of evidence but what the PO said at this point, after the health records had gone in, was ‘so what the department’s position on this is that we’ve seen the evidence that has been submitted and had we seen this evidence at an earlier stage we most likely would’ve changed the decision at an earlier stage. So, what we would like to suggest is that we would score you one B…’ and basically it will give us all the descriptions. Basically, what it amounted to was ten points on one, I think she got the mobility as well. I think she got standard and standard; I think was what happened. And luckily, I’m glad I went there because I think she would’ve been completely confused as to what to do. If I hadn’t been there to tell her this is how much it is… you know, and I did think that there was potential that she might get enhanced, to be honest, but having said that do you want to go through a hearing. She obviously made her own choice and said, ‘no, thank you very much, I’ll take that’. Which I think was probably the right decision and perhaps even the right outcome but um... So, that was a quite interesting episode.

I Is there a reluctance, as you said, if you’ve got an award going through all of that to get more of an award…

P Yes, I think so. Having said that, quite a lot of our appeals are people who’ve already got something, but they’ve not got what they wanted. I think people are more likely to dispute a decision if they’re used to it. What I mean is if they’ve been getting DLA for 15 years then they’re much more likely to appeal it. Or if they’ve been on PIP before and they’ve gotten an award they’re more likely to appeal it. Or if they’ve been in a support group and they’ve been moved to work related activity group or are now fit for work they’re more likely to appeal it. Um… I feel a real problem around Universal Credit which I know isn’t so relevant, um, because now it’s not an invalidity benefit. So, how are people supposed to know that they can get help money wise and in terms of increased limited capability for work, if they’re not even necessarily required to hand in a fit note? Whereas at least with PIP, you know, I think perhaps the large numbers of claims that have happened since it’s been introduced is evidence that if you blow up a shit storm of media you’re probably making a mistake especially when there are no barriers to entry, uh, you can claim it as many times as you like, um, you know, you can be reassessed as many times as you like which doesn’t happen with UC. Um, you don’t have to submit a fit note, you don’t have to submit any evidence. Every Tom, Dick and Harry is telling you to make a claim. Housing associations, you know, support agencies, Citizens Advice, with no understanding of whether this person qualifies or not. Um, and it’s like free money because it’s not affected by income or work. You know, it’s so obvious that if you introduce PIP and UC alongside each other then people are going to move towards PIP and people are going to avoid UC wherever possible with all the conditionality that comes along with that. Thankfully they didn’t do that with… though they thought about it. Or something along those lines anyway. I can’t remember why I was saying this, but [laughs]… We were talking about PIP in some fashion. What was the question?

I [Laughs] Do you know what, I can’t remember either. Let’s assume you answered it. Oh, no, it was about if people were more reluctant to contest a decision if they already had something. But I think you covered that quite well.

P I think clients are…I have quite a few clients… You have to respect it because it is very difficult when you’ve got an award and someone is advising you, I try to be more encouraging. I try to give full context. Whereas I think… So, I’ve managed to get numerous… like a good handful of people, I advised at least 20 people at tribunal. And I’ve managed to get people to keep going. So, the first one, the one where I disputed the tribunal’s decision nearly, well two years ago, say, which was she got the standard daily living but no mobility, even though that seemed to be the primary problem because she had fibromyalgia I think and mental distress. Got through, set aside by the First tier, reheard, got it. And it was all about the fact that they ignored the GPs letter saying she needed that help. So, they set it aside because that was obviously wrong because the GP had said so. Even if she did use the phrase, ‘she tells me this’, it should still be legally significant evidence because they’re still expressing their opinion on that basis when they say that. And her quote at the end of it was, ‘it’s not always a good idea to give up’. But I had to tell her and remind her and encourage her to go through this. She needed a lot of encouragement. Her partner I think was… There was a dispute then when we got it set aside as to whether she should go to the hearing. I hadn’t really dealt with this situation before, so I was a bit unsure which probably also fed into her uncertainty. But there’s a record of proceedings, so she’d already answered all these questions, so why put yourself through it when you’ve already answered all these questions a dozen times. Let’s just go with it and when they’ve already set it aside, they’re much more likely, especially where there’s strong evidence, where she’s already got four points, to then give the award. And she got enhanced. So, I think she got Motability or she certainly got the enhanced rate. But she would’ve given up if I hadn’t kept pushing her to do that. That’s with the tribunals, obviously.

And then I think that with the, say with the 170 clients, so we tracked 170 people who got help with the form and but nothing else really. For 18 months across assessments for limited capability to work, ESA, UC and PIP. I think most of them were PIP but only just. And, as I say, only a handful. Even though they were being run by this volunteer and he wasn’t an advisor but… although, actually she is quite a highly qualified legal professional, so she probably could’ve if we wanted her to and she did at certain points. Even though they were being rung frequently, very, very few of them ever went ahead with MR and even fewer of those went ahead with an appeal. And this includes people who didn’t win, who didn’t get any award. So, it’s quite difficult to get people to go through that process. So, I think you have to have… I mean, obviously what we’d want, we’d like… We don’t want to have this mirror bureaucracy where you’ve not only got to employ all these useless people at DWP and the tribunal service (who aren’t so useless) but sometimes they are, but in a very qualified, very expensive, public purse and then charities and council as welfare rights or whatever. So, then you have to mirror that and obviously this whole thing is mad but people, in the way that they’ve chosen to do it, need, you know, I think someone they can trust and feel confident in that’s giving them good quality advice, who’s there when they ring or gets back to them very quickly. And unfortunately, that’s not hardly the case anywhere. So, people are likely to give up.

Um, it’s been frustrating sometimes when you think that someone’s got a case here and you should keep pushing… um, but at the same time you have to respect it. I mean, I had one guy… There was a lady who… We looked at the tribunal reasons, it was appalling. And by the way, some of these we could possibly remove details about without giving them… when you look at the reasons as to how they interpreted. So, we could, I might not be able to do it when you’re doing research, but we could potentially redact and show you bits of what their reasons are. Which seem controversial to me, my advisor described it as a hostage to fortune as to how they’ve described this woman’s ability to mobilise. She was able to drive, so I think she must actually drive even though she only ever went to familiar places. Um, but she didn’t want to, but then she got the award. I think she got it before or it was similar to what she’d had before and then she got the premium, so she was a lot better off. I had a client who… Then it can be really weird in the other direction because I had a guy… This is… Oh, sorry if I talk about limited capability to work. But he um, was on Universal Credit, had limited capability for work and was volunteering. The job centre had told him he didn’t need to do anything else because they were happy thus far… to carry on doing what he’s doing. Long term substance abuse issues, previous homelessness. Basically, I think good job centres like I think ours probably ism will think let’s just leave this person alone. We can see they’ve got an issue, you know, there’s not much point prodding him. And he decided but it was really difficult to do with the job… with the work coach, the work coach was saying, ‘oh, well, no, I would advise him to carry on’ and oh, God, you know, because he’s got this far in the process. I’m like, he’s got more money than he’s ever had in his life before because he’s just got PIP as well and he’s got premiums. Your conditionality requirements are doing what he’s doing now. Why would he go ahead with an appeal? And all we want to know is, are you likely to change that? Well, I can’t guarantee that we won’t. I said, are you going to change it? He said, ‘probably not’. Thank you very much, we’ll just take the money and run thank you [laughs].

Um, you know, I think there’s probably been some cases like that with PIP as well but it’s, you know… I think it just varies depending on what… I think, I think we… what I want to do is to look into and address issues where people might not even be aware that they’ve got a benefit problem, where they might be in the long… I don’t think that’s probably so much of a problem with PIP. I did get a couple of cases with, there were three or four because the government reinvestigated cases due to case law. But what I have in mind myself is MH with the psychological distress for mobility but there were other things about epilepsy and stuff but anyway. So, we had three of four of those and two of them had the notification, the MR notice, which is very confusing. I requested MR, guess what, never replied. So, basically, they went through this trawl of tens of thousands, hundreds of thousands of cases, in the vast majority probably decided no… I think the statistics have said that they didn’t change them. I did have one client who ended up with a higher rate of benefits, so that was obviously good, bit of a surprise, one of them out of the three or four did. But with those ones where they didn’t, I wrote a letter, I even rang them in one or two, I think in both cases, to say we’ve done this, we want a response. And they agreed to look at it again once they’d registered the new PIP decision. Never heard back from them. The only way you can actually get them to address the decision that is like that, which is unusual, meaning that you have to get the right person in the DWP to look at it. Even if you did, they probably don’t really know what they’re doing, and they probably wouldn’t be able to deal with it. So, basically, complicated things end up on a pile and are never looked at, full stop. Not a year, not two years, never. And the only way to get them to look at is to do a JR PAP letter and force them to do it in 14 to 21 days, they have to do it. But even if you do that sometimes they get a really garbled response and you can’t use it to appeal, so it’s pretty difficult. Or you can try and ring them and try and dispute it. But I mean, I think that is what, I think that’s what I want to address because there’s some people who are ending up on very small amounts of money because of things. Like those people with the PIP would’ve got, you know, two or three maybe even four years of mobility and they didn’t get it, either on higher rate or on standard rate. But if I can’t… I haven’t got time to keep a case open, to keep going back and ringing up help lines not to get through to anyone who’s actually going to do anything. But that seems really wrong to me. Uh, compared to people who’ve got a pretty good award or even some of them do get enhanced. I’ve had quite a few cases where I think submitting evidence is really good and that sometimes they revise the decision, DWP or the tribunal gives a higher rate. I even had one guy where I, I think, did I submit evidence? But I wrote a submission saying… I mean, sometimes a submission it is evidence, and it can persuade them. The DWP revised it and gave him, offered him the standard rate daily living and I’d written a submission that said, I don’t think he’s entitled to the daily living. I think we might get the mobility, was basically the gist of it. So, we were like, yes, thanks very much, we’ll take that. That’s like double what we thought he was going to get.

I That’s more. Yes, the daily living’s more than the mobility, isn’t it?

P They make some very strange decisions, um… but there has been a small number of cases where with UC and PIP where we’re getting phone calls, they don’t always ring us, which is unhelpful, from the decision maker offering… and I managed to persuade the decision maker to give him the standard rate of mobility as well as standard daily living. She said, go on then, make a case [laughs]. I didn’t even give that strong a case. She said, okay, all right then [laughs].

I Do you get to know particular decision makers or is it someone completely different each time?

P Not really. I think that one I’ve spoken to two or three times. The difficulty is trying to get hold of a decision maker, having the telephone numbers if you can get them, if you can note them down. But the standard approach is help line, ‘no, I won’t let you speak to the decision maker’. ‘No, you can’t speak to the decision maker, that’s not possible’. Um, if they do sort of agree to it, I’ll send them a note or an email or whatever and it never happens, and you never hear back from them. Or if you can get hold of the decision maker, they’re really good. Some of them are really, really good. And like that lady, obviously, I managed to persuade her. Or they know what they’re talking about, or they can see the evidence, or they’ll send you the evidence so you can understand what’s going on. And it might be that it’s good news for the client and things are resolved.

However, uh I’ve also encountered some who are discriminatory, who have a terrible attitude, who are belligerent who are…uh and there’s a rigidity and a want to retain… To fall back on this is the way that it works, and this is the system and you just have to accept it and, ‘no, we’re not going to help you’. So, the lady with the, um… I mentioned it earlier, I can’t remember what I said about it, but a Record of Access Requests is what they call it, ROAR. So, her problem, again, a more needy case I would say. She allegedly failed to return the PIP2, I think it was, which was the questionnaire. [sigh] And I say allegedly because there was evidence in the bundle that suggested that it was wrong. The…so, we got the bundle, spoke to the client. The client has got drug and alcohol issues, other mental health problems probably, no fixed abode. The forms were sent to one of two or three or four different addresses. Now in homeless temporary accommodation, fortunately, virtually next door to the office I work in. So, when I couldn’t get a hold of her, I went and knocked on the door. And when I couldn’t get a hold of her when I knocked on the door, I could speak to the support worker there who was bloody useless. Normally they’re really good but she was bloody useless. So, she allegedly failed to return the form. Submissions said that she’d failed to return it but there was a document in the bundle that showed that the form seemed to suggest, because these letters are not very clear, but they sent the form to an address in Bradford that she no longer lived in. So, of course she didn’t return it from there because she wasn’t living there. The client’s account of it was that she had returned the form.

So, what we did was I wrote a letter, subject to access to request it was headed, to the decision… the maker. Because it got the address of the decision maker in the thing and the law says that you don’t have to make the request for information to any particular party, you just have to send it to the organisation. You have to give them enough information to identify what you’re asking for, their signature, all of those things. We had all of that, we were her representative already. And I spoke to the decision maker, no I didn’t speak to the decision maker, I spoke to someone in the same department as the decision maker, a woman. I got the impression that the decision maker was a man, I’m not sure why, perhaps she said he was. Um and so, I sent this in. So, I said, okay, so what’s going on here then? We’ve sent you this letter three weeks ago, we’re waiting on a response. Can we have it now please? Obviously, in the letter and perhaps on the phone I’m explaining why we need this information because I’m asking for telephone records, for letters that have been sent out. Basically, for just records of correspondence that have come back, to show whether they’ve sent it out and whether it’s been returned, and to which address it was sent and which phone numbers have been registered or phoned. She routinely loses her phone because it gets stolen, plus she can’t remember what’s going on from one minute to the next. So, one way or another her account isn’t very reliable, which is why I’m trying to evidence it. So, I explained, I obviously went through this. I was, I guess I always feel like I’m being aggressive or something but it’s in response to their attitude, I guess. And she says, ‘no, we’re not going to respond to this because it’s gone to the decision maker. Uh and sorry, the decision maker’s given the response, they’ve sent the evidence and that’s what the tribunal will have to decide the matter upon’. And I said, well, they can’t make a decision because they haven’t got the evidence. You haven’t sent in the right evidence. The evidence that you’ve sent in is clearly demonstrating one thing and you’re saying something else, so we need the evidence in order to decide it. And her response was, she was quite irritated about, probably what she saw as an attitude problem on my end about this document [laughs]. And um, so, so she said, ‘well, you need to make a complaint’. Of course, I don’t want to make a complaint because it’s just even more… I’ve already sent you the letter, I just want a response. She says, ‘I’m sorry, is this a subject access request?’, I said, well, it was headed to subject access request, so yes [laughs]. And she said, ‘oh, well, in that case I will forward it on’. Which then took another several weeks. Then we got a response from the relevant department with a letter saying, we need you to fill in this form, record of access request. We need you to fill in these boxes and write in these things and get another signature from the client, who I’m going to have to get a hold of.

So, I reluctantly jump through the hoops, sent in the form, sent in the thing. Then we write into the tribunal service saying, we haven’t got this evidence, I’ve tried to gather it, I’ve done the right thing and they’re not responding, not providing the evidence. And then I actually ended up having to ask for it to be postponed because we hadn’t got it yet. Then I suddenly got it two weeks before the hearing. So, I managed to send all that in and I think it still got adjourned for some reason because they wanted to see one extra page from the documents. I didn’t send them all 200 pages. Four or five pages that proved that she had returned the form. And we won the appeal, this was when she didn’t turn up to the hearing, she went to the wrong hearing centre. Um, and during the process I started doing recorded delivery, one day I rang her and said, did you get the documents I sent to you? She said, ‘no’. I went on and checked the tracking, she’d signed for it ten minutes prior to the call [laughs]. And I don’t think that she’s a liar, I think she just can’t remember, literally, ten minutes after something’s happened. But obviously the DWP or health system has said that she’s a liar.

I Well, that’s just a default position, isn’t it? Rather than it’s maybe indicative of her condition.

P So, when I went to the hearing, I can’t remember what I said and I had to be a bit careful about what I disclosed, about what I knew about her because I didn’t want to give them the whole story of that little incident where she couldn’t sign. I just said, you know, I have rung her, and she’s not remembered that a few minutes earlier that she’d received a document or something. You know, I have tried, I’ve tried really hard to keep in touch with her, I’ve managed to develop something with her and yet, you know, I think it’s evidence of… Although, we don’t have evidence, medical evidence as such, I think this is evidence that she’s not competent, you know, not able to do these things and that’s the problem. And they agreed, thankfully. We were sort of relying on her not to turn up. In a way it was better that she didn’t turn up because she would’ve just said something that wasn’t true. Not because she’s lying but because she doesn’t actually remember. She had a very strong opinion that she sent… She very strongly believed that she’d sent the form back twice. The evidence seems to suggest that she sent it back once and so we were concerned that when asked… She doesn’t look like there’s anything wrong with her. She looks quite healthy, she looks, you know, she’s the vision of a reasonably healthy person. She’s well put together, if I can put it that way. She dresses well, I guess, or puts her make-up on or has her hair okay. Whereas if someone turns up to a tribunal hearing and they stink, and they’ve got bits falling off and whatever then it presents a different picture [laughs]. But I was actually surprised the first time I met her that that’s what she looked like because she was so incoherent over the phone.

I What was her condition?

P I’m not really sure, to be honest, apart from historic drug and alcohol. I think she had epileptic fits or absences or something. Her partner also was in and out of hospital for various things and he was also… And then she had problems with her housing as well and they accused… they tried to boot her out of her temporary accommodation, and she’d actually disputed it and I put her in touch with a law centre. And I don’t know why it changed but it did change because they accused her of him having gone there or something, accessing when he’s not meant to be there for security reasons or whatever and… but then the CCTV showed otherwise. But she felt that what they were trying to do is get her out because they wanted to put someone else in that they considered to have higher needs or something. So, they were just looking for an excuse to boot her out. Anyway, now she’s got her own house in a village, in quite a nice town and even though there continue to be some problems… and initially PIP then said to her, she tells me, ‘oh, well, now we’ve seen what happened we won’t ask you to do another assessment’. Which was great to hear but then 12 months later I heard it all started all over again and it was back at square one so.

I I was going to ask because that hearing was about whether she’d sent the form back or not. So, an assessment hadn’t been done?

P Yes, so that was the problem, is we knew we’d get her through this process and then she might just end up at the beginning again. So, I think what they did was they just said, okay, all right, let’s just forget about all of that. Because it’s pretty difficult to assess someone today on what their health was in 2017 or something. And her feedback to her… Actually, I might in a couple of weeks if you get back to me or in a month because of sensitivity, I might be able to send you some quotes that clients have given about… Because we asked them in feedback, which a lot of services don’t really ask people the right questions I think, or they don’t bother to ask at all. We asked them how does this, what we’ve helped you with, how does it affect your view of the future? And a lot of them commented on the assessment, fear of assessments or how it’s transformed their lives or what they’re going to do with the money and stuff like that which might be interesting.

Um, but in her comments, her comments were, ‘thank you so much for sorting out this, I reckon that it’s… [unclear], you’ve sorted out a problem that had been going on for years’. And I think where you failed to turn up to an assessment or you failed to send in a form those are the kinds of problems, especially with homelessness, that they just never get addressed. So, really, we’re helping the people who are actually a little bit better off because they’ve gone to the assessment and so they might still be getting some benefit or they’re in… Whereas if you’ve not done that and you end up in a two-year appeal about not doing it, at the end of that process then you’re then back in the queue again. And then you’ll just fail that next bit which is then you go to the assessment board you forget to send the form again. Which is what happened to the guy that didn’t… that didn’t, you know, that I never met, he didn’t go to the assessment.

And I had another guy living without any Universal Credit. Was that what it was? Sorry, in fact without any ESA for a year and he was stealing sandwiches from corner shops and probably bin diving because he had no benefits to live on. But he refused to go on UC, he said I’m not doing it. So, he had his housing cost, that was all right. And then fortunately got PIP for him for some reason. He was the only one, I did like six or ten applications at that point in time, his was the only one and it was just as well because he was the only one that really needed it. And he got PIP standard rate. And he was… you know, and then when he did get his ESA back… But he basically waited a year, went to a tribunal. His house is full of … waste, if I can put it like that, he’s a hoarder. And I got to know him quite well and he was very, very anxious and I developed quite a good relationship with him. They changed the decision; within minutes he went in the hearing, and they changed it. Went, okay, you’re entitled to ESA again. I guess, then putting him back in the queue for reassessment but then after that I could never contact him again, phone stopped working. For some people they’ll put their head above the parapet to solve some problem and then as soon as it’s resolved they’ll go back underneath out… out of touch. Because what I wanted to do was obviously address or help him perhaps with the next assessment or… um and quite worrying really about the state of his life. Fearful of his housing association kicking him out because of his hoarding but knowing that really the solution to your problems here is you need to deal with that. You need to get some help therapy, or you need to help them… He didn’t want the stuff in his flat, he just didn’t want to tell them that it was there because he thought he’d get kicked out. And I’ve had clients who’ve been... I had that client who had an injunction against her, and she was one of these who put their head and went back under. Why the housing association then put an injunction for her behaviour. And we had evidence for a PIP claim from her GP which was really good but before we could use it, she disappeared again.

I Hm, yes, it’s really tough. Because I think as you’ve said it a couple of times you must just really feel like you’re, more able to help the easy ones. Because you’ve got to be able to send the forms in, write the forms out, have a network around you that’s going to help you.

P Being in [local area], for example, a few operations that are outside of [south west England] or they just don’t live anywhere. They live in an advice desert basically.

I Yes, and I think that’s been getting worse and worse, hasn’t it?

P What I want to do… I think [advice charity] is doing this, but I don’t trust them, to be honest, to do it well. I’ll probably struggle to do it because I think it’s just inevitably a hard thing to do. But it’s to do with the sides of the [charity] that nothing ever gets decided and the other I think never moves forward. Although, they are doing that now, but I question their motives really about it. Um, to sort of, to make sure that we’re in touch with organisations that… there is a refugee charity, locally, for example. And we don’t have very many [here] but there are some and if they’re going to have a problem with the benefits it’s going to be that they’re not allowed to have any at all, you know, which is a much bigger problem. A lot of my clients have autism and there’s an autism specific service which is NHS funded locally. So, I think that’s why I’ve got a lot of clients diagnosed with autism because they can go… you know, I think clients are looking to view it… I always tend to view it favourably from a client’s perspective with their invisible disabilities or whatever. But basically, they just want some help.

I Yeah.

P Why wouldn’t you claim? I know why I wouldn’t, and I can see the problems with the assessment, but I think that the judgmental attitude of assessors, in many cases, is you’re not entitled… ‘Why are bloody feckless unemployed people coming here trying to get free money?’ And some people have real problems. Some people have an intermediate dose of medication, that’s their problem [laughs]. ‘This is for the likes of them not for you, you feckless bastard’. Um, but and… you know, so, PIP is, on the face of it, an opportunity to talk about your health problems, a positive conversation, some free money with no strings attached. So, why wouldn’t you go through that door? I think it’s become very confused, as said in the Demos reports, now as to whether it’s something to do with social care. All the elements of disability or benefits have become very confused. Um… now, the most common denominator you might say… Because PIP is there to pay for the extra costs of disability if they have. And yet numerous of my clients in temporary accommodation have been told by the affordability advisor, if you can put it like that, who works for the housing association or some other godforsaken organisation. That they need to claim PIP because that’s the only way that you’re going to be affordably able to move into your home, into another home. So, in other words, until you claim and succeed with the claim for PIP, we’re not going to move you on, you’re going to have to stay here forever. Or we might, if we can find an excuse, boot you out onto the street so we can move someone else in who we think is the deserving poor, basically. And I think one favourable thing that I will say, that I do say in training, is that it has improved transparency. Because although you can’t get your head, and this is the real question as to why you’ve scored zero points, at least you can see what the activities are called that you might have some idea as to what’s relevant. Whereas with DLA there are certain prescribed areas but really it comes down to a judgment about the number of hours… I mean, maybe we didn’t need this to be improved and the transparency. I think there was a lot more subjectivity to DLA in certain ways. I think a lot of people ended up with a very long-term award, which wasn’t revised, who weren’t entitled to it for many of those years that they were on it. And so, then they might claim PIP and they might be entitled to that and that’d be fine, or they might find, ‘oh, I might not just get PIP at all now’ and everything stops. Um, but at least if you… And the decision maker notes make no sense at all. They’re just a garbled, uninterrupted paragraph with a thousand words quoting some things selectively from the report, um, which confuses everyone. But at least you can look at it and go, oh, okay, I can see where I’ve come up short and if you are only a few points short of an award or you’re near the barrier at least you can see what you need to do to move across that in that area. So, I think that’s a slightly favourable thing about it. Uh, my colleague’s view, and I guess I kind of agree with it but I would… And you know like they talked about combining assessments for limited capability of work and PIP?

I Yes.

P Probably. And the big problem is the clients getting to the fucking assessments. Some of them send them to [local location], which is like a two-hour journey. Probably, three, four, five-hour journey by public transport because there aren’t busses or anything. Or there might be trains, but they can’t get on those, at nine o’clock in the morning. They all say that there used to be a tribunal hearing centre in [city centre], county court I think. But anyway, what was I saying?

I You agreed with your colleague, about something.

P Oh, yes. So, I think that her view is that they should be doing a better assessment of what someone’s needs are so that they can kind of move them on. Or prescribing things to assist them with those problems that they have rather than necessarily giving a cash benefit or giving all of it in cash benefit. Um, you know, so, with Mob A, with mobility allowance, there was a proper medical assessment with… In that through industrial injuries there’s still a proper medical assessment with a properly qualified assessor. I hesitate about those things because I think a lot of people may lose out, but I think that the policy should be to ensure that everyone’s got enough money to live on and that will be to cover their disability costs. And to encourage… Well, I mean, I think, well basically… And I don’t really want to encourage, I don’t want it to be conditionality but like I say the young woman that I helped, she’s saying she wants money for psychotherapy. Then why the hell wouldn’t you give her the benefit? Because she’s got a chance of actually doing that and moving on. Whereas a lot of statutory services, benefits, attitudes of people in the systems that we have to deal with, social care, it’s all about disabling the person and trying to stop them from being able to progress in life.

I had a client who the GP had problems, I won’t go into all the details because we’ll be here for half an hour, but her GP was causing problems, basically, at providing evidence. Uh, and there may have been questions of credibility as I’ve learnt from colleagues about the client. But unfortunately, public services have turned towards, let’s blame the client. Basically, that everything’s the responsibility of the individual even if they’ve got health problems they can’t manage on their own, there’s nowhere to get any help with that. So, they can’t even walk to the [local advice charity] let alone find one. Um, you know, and so, everything’s just kind of turning… And there are some good people out there in those systems, but everything’s become gradually privatised and public service duties are being given to housing associations to administer who can be quite negative. GPs are saying, ‘oh, it’s too much time, I haven’t got time, I haven’t got money, I can’t afford to provide you with health records, and you have to pay us in this way or that way’. Find some way around the about GDPR to do that. Whereas what we should be doing is, at least where people are willing, showing that they want to transform their experience. That we help them to do that by giving them sufficient compensation or access to services. And so, you know, a lot of my clients I do encourage, like I have to think about quite the right way to express it. You’ve got £145 a week in benefit, you’re going to get a premium, you’re going to get ESA of £191. I think you can afford psychotherapy. I think you can probably afford to pay them £25 a week [laughs]. I know that some of them do have costs and things but in reality, that’s a fuck of a lot of money. And a lot of therapists will reduce their costs, so you know, even if you got standard rate PIP that’s still £110 a week in ESA and PIP, a half of which would be enough to pay for one session a week. Do you want to carry on living like this? Do you want to carry on feeling like this or would you rather get some help? And in many cases, it’s fear of the person that they might have trust issues. But there is help, you know, it’s difficult but there are people out there that can help you. And do you really want to go through the NHS system which will never really help you and only give you 15 weeks of therapy or would you rather just…? And that’s what DLA and PIP should be, like they say, is supposed to still be a social model disability that it’s addressing. But it’s just not. It’s a medical model or an attention model, if I can put it like that, in terms of you get a higher award or benefit if you need help or you need aids or adaptions.

I All right, I’m going to stop you there because I think we could go on for like another five hours [laughs].

P Yes [laughs].

I But thank you, it’s been really helpful. I hope you’ve enjoyed it too. So, I think I’ve said to everyone that I would hopefully get a research summary out once I’ve analysed and finished doing the interviews. It might not be until early next year or the end of this year. It’s been a bit delayed because of, you know, that pandemic that’s going on. But, yes, if anything comes up please just feel free to get in touch with me.

P Yes, well, do stay in touch because I’m interested to hear what happens next. But I mean if you had something that you wanted to ask me about, or you wanted us to provide you with client case studies or something that was more niche. Either I or my colleague could do that for you. Or I was saying about the quotes that the client… Whatever, if you have something that you think could be useful.

I Yes, that’d be interesting. There’s one thing that I’ve found quite difficult. So, all the… I’m doing a case analysis as well as part of one chapter and you can get the Upper tier decisions online and that’s fine but finding any of the information for First tier decisions, like it’s just not online at all.

P I think we could provide you with some of those, um, examples quite easily as could any advice provider. You just have to ask for the reason, that’s the only way you’ll know what they’re saying. Quite a lot of the recent ones have actually been scanned because we’re not in the office. So, we’ve actually got them to hand. I suppose it’s just a question of thinking about identifiability and things like that. I think my colleague is quite confident about how to release those things because I’ve seen her send things that even have the person’s first name in them. I don’t know how, you blurt them into Twitter or whatever. Where it’s just like a thank you or something. But I always feel a bit uncomfortable or uncertain about it, like I said with the case study that I sent you. And I’ve sent some of those things to [mental health charity] actually, so I almost have the email on what my thoughts on it were if I dredged it up. So, we could definitely do that, and I think… And there are a lot of clients that I’ve got who would be perfectly comfortable with that. With the case study that I sent you, the really big problem was his paranoia and his denial of his paranoia. Something to do with, I think this is going to come out, what’s happened and you know and all the entities are going to find out. And I said, that wouldn’t happen, that can’t happen, that would be a breach in your GDP rights and if that does happen then I’ll see if you take them to court for thousands of pounds. But he’s just afraid of… I don’t know, you know, he’s described it. But there are… And I think it also is testament to the degree to which I know my clients that there are some people… Whereas I’ve also worked with advisors who are very protective of that, and they don’t want to break confidentiality in any way, shape or form or ask the client’s consent. I am a bit uncertain about it, but I do have some clients where we’ve got reasons where they would be quite happy to share that information and I might even have already done that. Like the student, I think I sent some stuff about that one to [charity] and I also sent the stuff about the other one I described. So, I’ve got they’re statement of reasons, excerpts, or statement of submission excerpts.

I Yes, I think it’s a tough one. So, I having worked in charities, myself, before. You definitely come down on the side of making sure they’re okay with it. I think it’s like it’s what it’s for as well because I think with some of the places it’s used as sort of advertising about what they do. And look at this terrible person and how much we’ve helped them, that sort of thing. And it’s like if they’re not okay with that then it’s kind of just using them.

P Yes, I think there should be informed consent as to how people might see their words in context. I think that that can be the real challenge to help people understand what that is, although I do try. I think in the charities that I work for at this level it’s just a lack of professionalism and a lack of experience and a lack of… So, I suppose if maybe you’re in a PR firm or whatever or whatever you’re in, even in a council, there’s more people around. You can get, hopefully, advice on how to do it right. And if you’re a student, like you get when you’re in a university context, you get guidance to decide what the tick boxes should be. I probably, on my feedback form, I should have said, are you happy for this to be quoted in whatever, which we didn’t. We haven’t published anything anyway so…

I So, with the university stuff it’s like the ethics process there is difficult for a reason. So, it’s to protect the uni and you as much as your participants. But, yes, I think it’s like with everything, it’s a bit of a collaboration. There are some people that I’ve interviewed that would be fine for me to say really specific details about where they work and what their life is like and other people that are not so much. So, it’s just working that out as well, isn’t it? But, yes, anyway, thank you very much.

P I look forward to hearing more.

I Brilliant. Thanks.

P And if you need examples of statement of reasons just send me and email whenever. Today or another time just to say what kind of thing. Or even just saying that, those examples. They are A, D and JL. A, D and JL. What am I doing?

I All right. Well, thank you. I’ll be in touch. And have a nice afternoon.

P Thanks, you too. Bye.

I Bye.

[End of recording]